JMIR Neurotechnology

Volume 1 (2022), Issue 1 ISSN: Editors-in-Chief: Pieter Kubben MD, PhD

Contents

Original Papers

The Potential for Using Extended Reality Technology in Interdisciplinary Case Discussions and Case Planning in Stereotactic Radiosurgery: Proof-of-Concept Usability Study (e36960)
Swathi Chidambaram, Maria Palumbo, Vito Stifano, John McKenna, Alberto Redaelli, Alessandro Olivi, Michael Apuzzo, Susan Pannullo. . . 2

Interrater Agreement on National Institutes of Health Stroke Scale Between Paramedics and Stroke Physicians: Validation Study for the Digital Training Model in the Paramedic Norwegian Acute Stroke Prehospital Project (e39444)
Mona Guterud, Helge Bugge, Jo Røislien, Karianne Larsen, Erik Eriksen, Svein Ingebretsen, Martin Mikkelsen, Jo Kramer-Johansen, Kristi Bache, Else Sandset, Maren Hov. 12

Design Innovation for Engaging and Accessible Digital Aphasia Therapies: Framework Analysis of the iReadMore App Co-Design Process (e39855)
Tom Langford, Victoria Fleming, Emily Upton, Catherine Doogan, Alexander Leff, Daniela Romano. 25

Remote Consultations for People With Parkinson Disease and Cognitive Impairment: Interview Study With Patients, Caregivers, and Health Care Professionals (e39974)
Jennifer Pigott, Megan Armstrong, Elizabeth Chesterman, Joy Read, Danielle Nimmons, Kate Walters, Nathan Davies, Anette Schrag. 39

Editorial

JMIR Neurotechnology: Connecting Clinical Neuroscience and (Information) Technology (e41122)
Pieter Kubben. 22

XSL•FO
RenderX

Original Paper

The Potential for Using Extended Reality Technology in Interdisciplinary Case Discussions and Case Planning in Stereotactic Radiosurgery: Proof-of-Concept Usability Study

Swathi Chidambaram[1], MD, MBA; Maria Chiara Palumbo[2], MS; Vito Stifano[3], MD; John McKenna[4], MS; Alberto Redaelli[2], PhD; Alessandro Olivi[3], MD; Michael Apuzzo[1], MD; Susan Pannullo[1], MD

[1]Department of Neurosurgery, Weill Cornell Medical College, New York, NY, United States

[2]Department of Electronics, Information and Bioengineering, Politecnico di Milano, Milan, Italy

[3]Fondazione Policlinico Universitario Agostino Gemelli, Department of Neurosurgery, Catholic University, Rome, Italy

[4]Department of Radiation Oncology, New York Presbyterian Hospital, New York, NY, United States

Corresponding Author:
Susan Pannullo, MD
Department of Neurosurgery
Weill Cornell Medical College
1305 York Ave 9th Floor
New York, NY, 10021
United States
Phone: 1 2127462438
Email: scp2002@med.cornell.edu

Abstract

Background: Extended reality (XR) is a term that captures a variety of techniques, such as augmented reality (AR) and mixed reality (MR), which allow users to interact with virtual models in real time. This technology has an emerging role in several applications within neurosurgery. XR can be useful in enhancing how radiosurgical cases are planned. Multidisciplinary team (MDT) review is an essential part of the radiosurgery case planning process; during case discussions, patient images are reviewed, usually in 2D or 3D modifications. The current commercially available platforms for this review need improvement.

Objective: We describe a novel visualization application, titled “NeuroVis” by our development team, which uses an XR Microsoft HoloLens headset to provide an interactive 3D visualization of a patient’s neuroanatomy in stereotactic surgery (SRS) case planning discussions.

Methods: We present examples of 6 common radiosurgery indications to demonstrate the utility of NeuroVis to solve common visualization hurdles in MDTs.

Results: The utility of NeuroVis is demonstrated through 6 common brain tumor SRS cases as a proof-of-concept illustration of the utility of NeuroVis to enhance radiosurgery case discussion by improving visualization of the standard neuroimaging used in radiosurgery treatment planning by MDTs.

Conclusions: The NeuroVis application provides several interactive features that produce an enhanced ability to place participating members of an interdisciplinary treatment team on the same visualization plane. This technology, by facilitating team discussions and case review, has the potential to improve the efficiency, efficacy, and safety of radiosurgery treatment planning and, as a result, to optimize patient care.

(JMIR Neurotech 2022;1(1):e36960) doi:10.2196/36960

KEYWORDS

mixed reality; augmented reality; extended reality; HoloLens; interdisciplinary teams; virtual reality; brain tumour; tumor; radiosurgery; surgery

XSL•FO
RenderX

Introduction

Neurosurgery involves complex anatomy, high levels of accuracy, and extreme precision. Image-guided neuronavigational technologies are often used in neurosurgical procedures; these platforms have undergone several developments in recent decades. Extended reality (XR) technologies, such as augmented reality (AR) and mixed reality (MR), which allow the viewer to merge a virtual environment into a real, physical environment, have emerging roles in the future of neurosurgery [1-3]. XR allows for visualization and virtual manipulation of anatomical structures beneath the surface anatomy, thereby aiding in surgical planning and education [4-7]. Furthermore, XR technologies allow surgeons to view 3D holographic reconstructions of anatomical regions of interest, thus improving upon the simple 2D views that are offered by most current neuronavigation systems. XR approaches, including AR and virtual reality, have already been studied in the neurosurgical subspecialties of spine, tumor, vascular, and pediatrics [8-12]. Importantly, however, this technology has not yet been applied to the field of brain stereotactic radiosurgery (SRS).

SRS is a highly interdisciplinary subspecialty in neurosurgery where brain imaging is crucial in treatment planning and delivery. Cases are often reviewed in multidisciplinary team (MDT) conferences, where cases are presented and imaging is reviewed. This MDT approach is an essential part of radiosurgery treatment planning, and its features in brain SRS have been previously described [13]. Relationship of radiosurgery targets among each other and with "critical structures" is key in creating safe treatment plans and in optimizing the efficiency of treatment delivery. These relationships are best appreciated in a 3D space. A particular challenge of MDT discussions in radiosurgery conferences is that communication is limited by participants' varying ability to mentally convert 2D radiological images into 3D anatomical views. "Simulated" 3D projections are often presented as a surrogate for real 3D views in an effort to depict anatomy via rotation of images to mimic 3D space. To address this issue, we created an application called NeuroVis, which can provide an accurate and interactive 3D visualization of a patient's neuroanatomy that can be displayed during SRS case planning discussions through the use of an XR headset. To our knowledge, XR technology has not yet been integrated into the MDT case discussions. In this proof-of-concept technical note, we describe and demonstrate, through selected figures and a video (Multimedia Appendix 1), how NeuroVis could enhance radiosurgery case planning discussions among MDTs for 6 common brain tumor case scenarios.

Methods

Overview

All patient radiographic images were anonymized prior to their use. A commercially available XR headset, Microsoft HoloLens, was used for the visualization and interaction with virtual holograms (Figure 1). The HoloLens is a head-mounted display with video-transparent lenses and has an untethered and wireless design.

Figure 1. Microsoft HoloLens headset.

Patient-Specific Hologram Creation

The NeuroVis application was designed with Unity 3D (version 2019.2.17; Unity Technologies), a game engine software, and used in conjunction with the Mixed Reality Toolkit (MRTK), a Microsoft-driven library that provides a set of components and features used to accelerate cross-platform MR application development in Unity 3D.

Patient-specific 3D models of the brain were created from both anonymized magnetic resonance imaging (MRI) and computed tomography (CT) acquisitions. The segmentation of the different brain structures was accomplished using software developed by Brainlab, integrated in the planning procedure, and 3D Slicer, an open-source software platform for medical image processing, applying different segmentation tools. The exported 3D models were imported into the virtual scene and supplemented with scripts to allow the holograms to be interactable with the user's hands (move, scale, and rotate). Moreover, several tools and interactive features were developed to allow the user to (1) hide the different anatomical structures independently, (2) isolate lesions and planning treatment volumes (PTVs), (3) visualize axial, coronal, and sagittal MRI or CT planes overlaid on the

XSL•FO
RenderX

3D model, (4) manipulate handheld clipping planes that allow one to visualize cross-sections of the model in real time, and (5) change the opacity of each anatomical structures independently within the model. The holographic interface was designed closely with the end user in order to be user-friendly, effective, and useful during the procedural discussion. The application proved to be working for both HoloLens (versions 1 and 2; Microsoft Inc), making minor changes to the MRTK profile settings before the application is built and deployed on the device.

Regarding the visualization of raw MRI or CT images, a volume rendering open-source code implemented for Unity was adapted to work in the HoloLens and specifically adjusted for the application. A 2D projection of a 3D discretely sampled data set (MRI or CT volume) was displayed on 3 orthogonal planes to reproduce the sagittal, coronal, and axial view. All the anatomical planes can be scrolled throughout the imaging volume using hand gestures on virtual sliders. The method used to render 3D data is the raymarching technique. The way in which all the sampled volume values were combined and then displayed on the output-rendered image was determined using a direct volume rendering with a 1D transfer function. As the displayed images are a projection of a 3D volume on a 2D plane and not a preacquired stack of 2D images, the user is able to manipulate and choose every possible spatial orientation of a plane encompassing the imaging volume.

In total, 6 clinical scenarios are presented, demonstrating the use of NeuroVis in SRS case discussions.

Ethical Considerations

The Office of Research Integrity at Weill Cornell Medicine conducted a review of this project and determined that it did not constitute human subjects research and therefore did not require further institutional review board approval or exemption, as identifiable private information was not being obtained or used.

Results

Overview

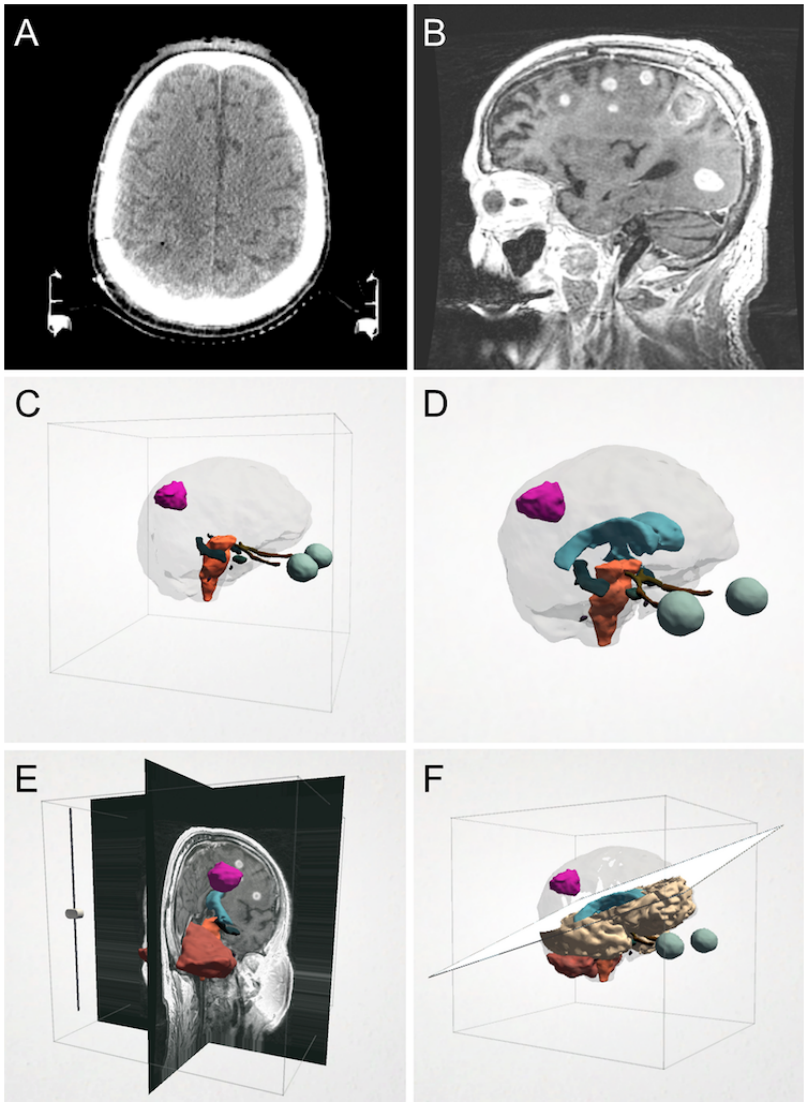
The presented cases represent common applications for radiosurgery; we chose a variety of neuro-oncologic scenarios, as these represent the most usual indications in our practice, and ones in which the value of NeuroVis was most apparent to us in developing this tool. The associated multidisciplinary case discussion process is described for each situation, to allow NeuroVis use to be understood in context.

Case Scenario 1: Postoperative Resection Cavity

Patients are commonly referred for radiosurgery following resection of a brain metastasis, with the goal of minimizing the risk of local recurrence. Postoperative SRS addresses the surgical cavity, minimizing the risks of wider field irradiation [14,15]. The radiosurgical target can be large and in proximity to eloquent structures and organs at risk (OARs) [16]. In our multidisciplinary radiosurgery conferences, the neurosurgeon and radiation oncologist, along with the dosimetry or physics team, develop a plan for postoperative SRS based on pre- and postoperative imaging. The formulation of the treatment plan is typically based on discussions of the MRI and CT scans on a 2D screen (Figures 2A and 2B). Introducing NeuroVis in this step allows each viewer to see and interact with the same 3D hologram when discussing cases, and improves the understanding of the relationships between key structures and the resection cavity. For instance, the hologram viewed and manipulated through the XR device gives a better impression of the size and shape of the resection cavity and allows the neurosurgeon to explain operative approaches to the team. As seen in Figure 2C, the XR technology also allows for better visual approximation of the resection cavity and nearby OARs. Furthermore, the operative corridor can be more clearly imagined when the cerebrum is faded away. NeuroVis can optimize the visualization of volumes in the postoperative setting (Figure 2D). With NeuroVis, the MRI planes can also be integrated with the model to further understand the 2D to 3D transition (Figure 2E). A feature called the clipping plane allows for better understanding of the surface anatomy in relation to the treatment region (Figure 2F). All of these unique features of using NeuroVis in the SRS case discussion setting can help improve our ability to visualize and plan these common SRS cases.

XSL•FO
RenderX

Figure 2. NeuroVis holograms for a patient undergoing stereotactic radiosurgery planning for treatment of a postoperative resection cavity.

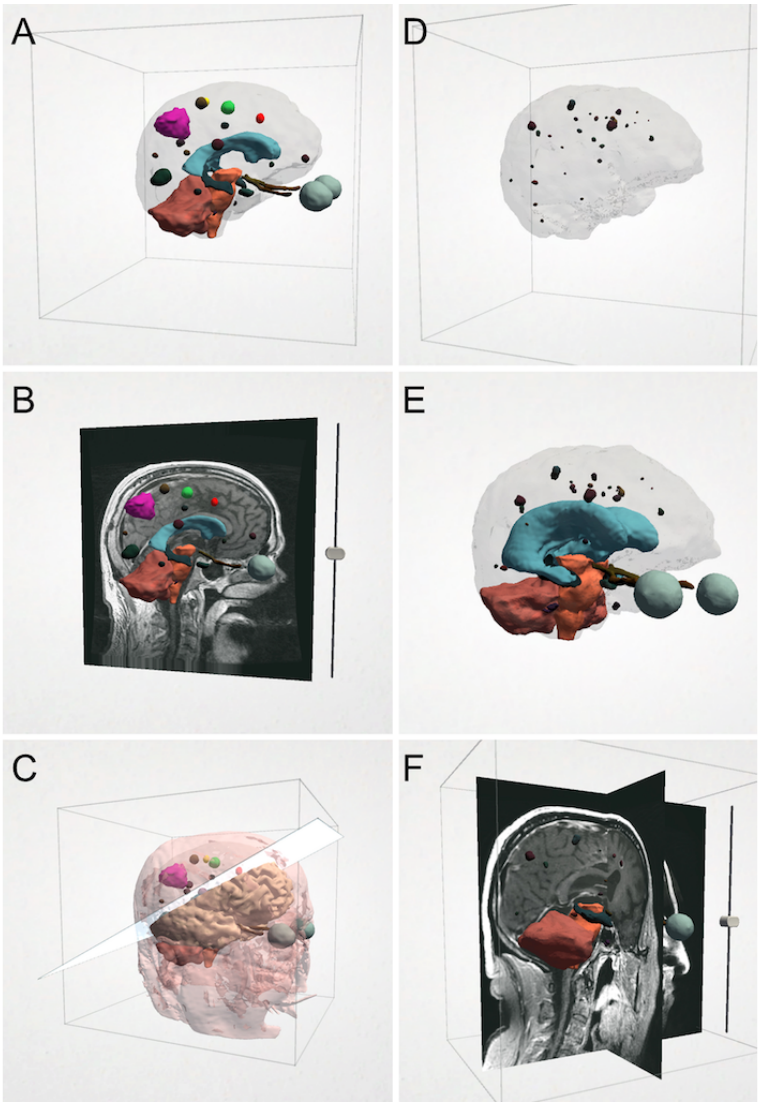


Case Scenario 2: Resection Cavity With Additional Metastasis

In cases in which a patient with multiple brain metastases undergoes resection of 1 or 2 dominant lesions, the patient often undergoes postoperative radiosurgery for the resection cavities and the remaining unresected lesions. In these situations, the maximum dose constraints to OARs are an important consideration given the multiple targets, of which one or more can be large, and the potential for overlapping treatment arcs [17,18]. Using NeuroVis, OARs and radiosurgical targets can be isolated and combined in various ways to help maximize the safety of treatment plans by helping the dosimetrists and physicists see these key relationships in a dynamic way (Figure 3A). Furthermore, incorporating MRI planes with holograms during planning can be helpful in understanding the relationship between the resection cavity and lesions (Figure 3B). This new way of seeing and planning can help determine whether lesions can be clustered for staged treatments as each lesion and resection cavity can be virtually isolated to form groupings [17]. The clipping plane feature allows us to view the relationship with the scalp and helps us create plans that minimize the scalp dose with grouping of lesions and fractionation (Figure 3C) [19].

XSL•FO
RenderX

Figure 3. NeuroVis holograms for a patient undergoing stereotactic radiosurgery planning for treatment of a resection cavity with metastasis (A-C) and for a patient with multiple intracranial metastases (D-F).



Case Scenario 3: Multiple Brain Metastases

Patients with multiple intracranial metastases, previously treated with whole brain irradiation, now commonly undergo SRS [20-23]. Furthermore, radiosurgical treatment for many brain metastases is now feasible [22,24,25]. The main visual challenge in planning cases with several metastases is understanding the topography or spread of the many lesions intracranially. NeuroVis can enhance these discussions by allowing all practitioners on the team to view the patient's tumor burden and topography in 3D holograms (Figure 3D). Visualizing and reviewing cases with NeuroVis provide an appreciation of the clusters of lesions that might be present, especially as some lesions are too small to easily understand purely on 2D MRI evaluation. Moreover, the hologram in a XR headset allows for an interactive view of multiple lesions where MRI planes can be combined to show the transformation from 2D to 3D visualization (Figure 3F). The features in NeuroVis make it possible to more accurately understand the proximity of lesions to OARs (Figure 3E). Furthermore, changing the opacity of certain anatomical structures such as the ventricles and brain stem can be helpful in elucidating their relationships to adjacent subcentimeter lesions.

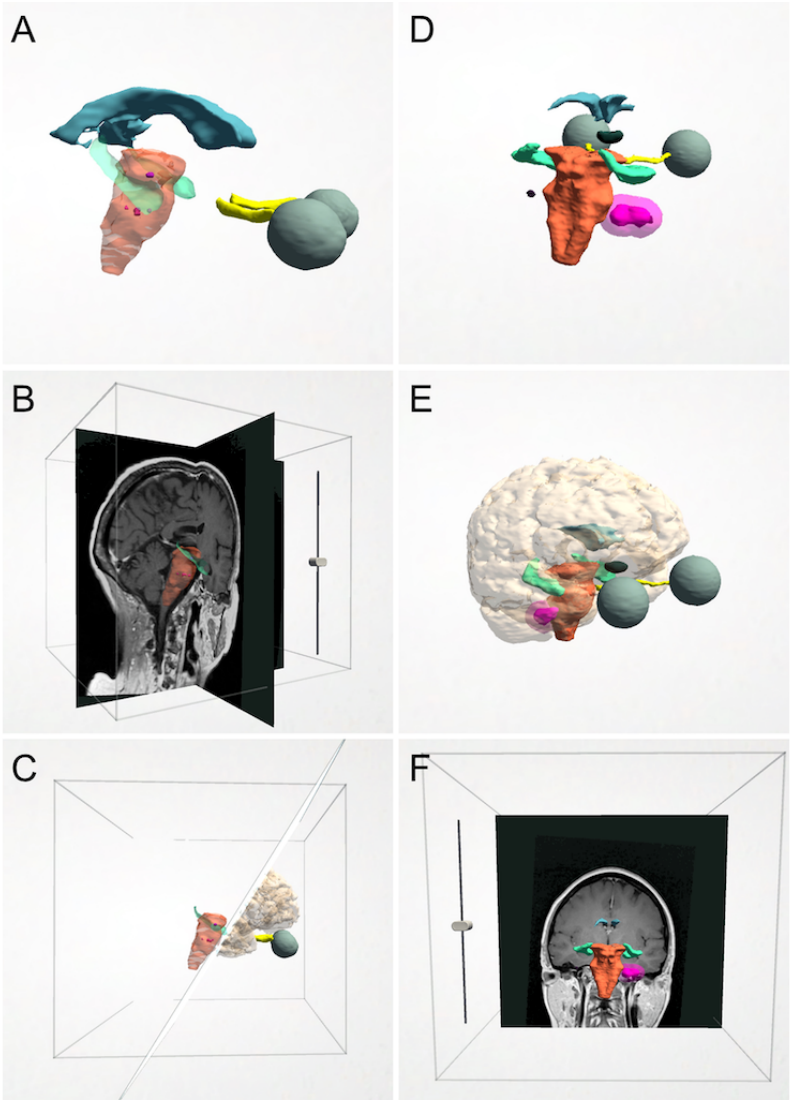
Case Scenario 4: Brain Stem Metastases

A particularly challenging SRS case scenario is that of a patient with single or multiple brain stem metastases. The previously prevalent pessimism regarding the outcomes of patients with brain stem metastases, which resulted in the use of whole brain radiation rather than stereotactic radiosurgery in these patients, has been challenged by the favorable results shown in several single and multi-institutional case series of patients treated with SRS for brain stem metastases [26-29]. Nevertheless, these remain very challenging cases to treat with SRS given the strict dose constraints associated with the brain stem, a key OAR. In planning discussions for brain stem metastases, the 3D orientation, shapes, and clustering of small brain stem lesions are often poorly visualized with traditional imaging modalities on a 2D screen. With NeuroVis, the opacity of the brain stem itself can be altered to allow for a clearer understanding of the relationship of the lesions within the brain stem anatomy (Figure 4A). Similar to the technique used in other clinical cases, the axial, coronal, and sagittal MRI planes can be overlaid with the

XSL•FO
RenderX

hologram to better visualize the relationship between the 3D oriented model and 2D MRI contours (Figure 4B). Here too, the clipping plane feature allows for delineation of the relationship between the contour of the brain stem itself and the lesions within (Figure 4C). In addition, by fading the cerebrum, we can gain a greater appreciation of the depth of the lesions and their relationship to the surface anatomy. These new techniques of manipulating and visualizing these challenging lesions can be used to optimize dosimetry and safety of the treatment plan.

Figure 4. NeuroVis holograms for a patient undergoing stereotactic radiosurgery planning for treatment of a brain stem metastases (A-C) and for a patient with a vestibular schwannoma (D-F).



Case Scenario 5: Vestibular Schwannoma

Vestibular schwannomas (VSs) are often treated with radiosurgery owing to excellent rates of tumor control and safety. Hearing preservation is a key goal; studies suggest a better chance of hearing preservation with radiosurgery than with observation for VS [30]. Limiting the radiation dose to the cochlea during SRS has been shown to be important in hearing preservation [31,32]. NeuroVis shows the VS contours in detail, allowing for a better understanding of the tumor's proximity to the cochlea to facilitate planning. Isolating a holographic depiction of the lesion and PTV allow us to see its proximity to the brain stem and cochlea, the closest OARs (Figure 4D). Similar to the case of the multiple brain stem metastases, the deep-seated location of a VS can be better understood by changing the opacity of the overlying cerebrum to further elucidate the relationship between this lesion and its surrounding structures (Figure 4E). Adding the MRI planes also augments the ability to identify potential surgical corridors (Figure 4F) if surgery is still under consideration for a patient as a potential treatment option.

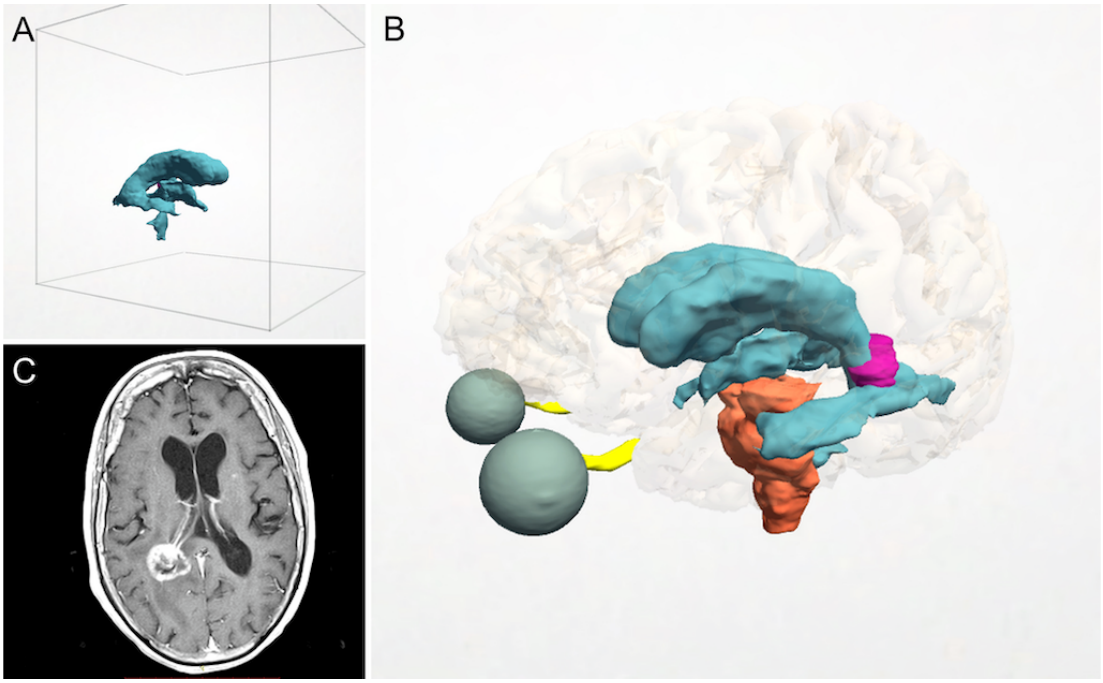
Case Scenario 6: Intraventricular Lesion

In planning radiosurgery for intraventricular lesions, we acknowledge that the lateral ventricles are complex semicircular structures that are often poorly understood on a 2D radiograph. A 3D holographic representation of the ventricles is thus inherently useful in understanding their anatomy (Figure 5A). When combined with various MRI planes, this visualization of the intraventricular pathology can be further enhanced with NeuroVis. Fading the opacity of the ventricles allows for visualization of the target and its voluminal occupancy of the ventricles in 3D space (Figure 5B). Of note, this case demonstrates some new challenges that arise in terms of

XSL•FO
RenderX

segmenting the MRI scans to create a 3D model. Heterogenous enhancement of this intraventricular meningioma complicated the 3D segmentation of the ventricle, which was needed to create an accurate hologram (Figure 5C)—a hurdle that was overcome with use of manual segmentation using tools available on 3D slicer.

Figure 5. NeuroVis holograms for a patient undergoing stereotactic radiosurgery planning for treatment of an intraventricular lesion.



Discussion

Principal Findings

In this proof-of-concept technical note, we have demonstrated that NeuroVis can present imaging data in a better way by placing all users in an MDT on the same visualization plane when discussing cases. It also helps us understand the size, shape, and distributions of lesions more clearly and in 3D. This technology makes the relationship between target lesions, OARs, and surface anatomy appear more obvious. While there are challenges in scaling the use of this technology, the potential benefits entice us to continue to work toward this goal. There are also several areas of potential future expansion in this field through the integration of machine learning and in improvements in automatization of brain segmentation. In addition to facilitating technical discussions, NeuroVis may help optimize SRS case planning by creating more efficient treatment planning workflows, and ultimately optimize radiosurgical treatment delivery efficiency and safety, with an end goal of improving patient outcomes and quality of care.

Challenges and Limitations

As with all new technologies, there are challenges to scaling the implementation of XR use in radiosurgical case planning. For instance, as previously mentioned, accurate 3D segmentation is a critical step in creating precisely reconstructed holograms to be integrated into the HoloLens headset from 2D MRI scans. Software such as FreeSurfer, Vbm, Ibaspm, and others provide the ability to segment the normal brain [33,34]. However, performing segmentation of the brain for patients with brain tumors is more complicated and often requires the combination of multiple modalities [34,35]. Most radiosurgical treatments rely on effective detection and precise segmentation of lesions. Thus, in radiosurgery, there are opportunities for further innovation with many methods of automatic brain segmentation based on deep learning technologies. These methods are being developed for pretreatment segmentation of gliomas and brain metastases for the purpose of maximizing safety during high-dose radiation treatments [35]. These advanced methods of automatic segmentation can also be applied to address the segmentation challenges that sometimes arise when creating holograms for XR use in SRS.

Other challenges to consider relate to the headset. These include the hurdle of acquiring the somewhat rare headset devices on a large scale at academic centers. The authors are optimistic that with the advent of newer, cheaper, and scalable production of XR headsets, this issue will be easily addressed in the near future. Regarding the portability and comfort of wearing such devices, an improvement in terms of design and fit has already been obtained using HoloLens versions 1 and 2 (Microsoft Inc). Despite a small improvement in the quality of the rendered holograms, the comfort of the second version of the device makes this technology much more suitable in case discussion where the device needs to be worn for many minutes. However, given the expanding market for XR in both medical and nonmedical sectors, design evolution is expected to occur rapidly.

In order for this technology to be successfully incorporated in case discussions, each institution must establish a methodology of transferring the requisite imaging data for each patient among team members and allocating tasks in creating and uploading holograms prior to MDT case conferences. In our preliminary experience with creating and executing these holograms, the

XSL•FO
RenderX

workflow can be successfully established with a few team meetings to delegate tasks.

Future Directions

Many of the challenges in scaling the use of this technology in fact highlight opportunities for growth and expansion. Having demonstrated proof of concept for NeuroVis in this technical report, in future studies, we plan to compare NeuroVis to conventional 3D imaging modalities such as 3D MRI angiography or 3D CT angiography, which are frequently used in cases that involve complicated neuroanatomical correlates to further investigate and measure the added benefit of our application in interdisciplinary case discussions and planning of SRS cases. Furthermore, a future study with questionaries and usability scores would be a meaningful next step to further test this application. Moreover, there is emerging literature on the changes in neurosurgical practice brought on by the onset of the COVID-19 pandemic [36]. The most prevalent changes as a result of this pandemic to health care and neurosurgery hinge on the increased use of telemedicine and remote tele-immersive conferencing [37]. This shift to remote communication will also continue to affect our MDT meetings in radiosurgery, and as such, there is a unique opportunity in this space for the incorporation of XR technologies to improve our remote case discussions and communication. Furthermore, there is great potential for the amalgamation of machine learning and artificial intelligence with the field of XR in medicine. Machine learning can help deepen our ability to more accurately segment MRI scans and coregister images in AR and MR settings. The horizon for innovation in this field is bright and full of opportunities for more technological innovation.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Demonstration of the key features of the NeuroVis extended reality application system.
[MP4 File (MP4 Video), 6485 KB - neuro_v1i1e36960_app1.mp4]

References

1. Guha D, Alotaibi NM, Nguyen N, Gupta S, McFaul C, Yang VXD. Augmented Reality in Neurosurgery: A Review of Current Concepts and Emerging Applications. Can J Neurol Sci 2017 May;44(3):235-245. [doi: 10.1017/cjn.2016.443] [Medline: 28434425]
2. Meola A, Cutolo F, Carbone M, Cagnazzo F, Ferrari M, Ferrari V. Augmented reality in neurosurgery: a systematic review. Neurosurg Rev 2017 Oct;40(4):537-548 [FREE Full text] [doi: 10.1007/s10143-016-0732-9] [Medline: 27154018]
3. Meulstee JW, Nijsink J, Schreurs R, Verhamme LM, Xi T, Delye HHK, et al. Toward Holographic-Guided Surgery. Surg Innov 2019 Feb 27;26(1):86-94. [doi: 10.1177/1553350618799552] [Medline: 30261829]
4. Birt J, Stromberga Z, Cowling M, Moro C. Mobile Mixed Reality for Experiential Learning and Simulation in Medical and Health Sciences Education. Information 2018 Jan 31;9(2):31. [doi: 10.3390/info9020031]
5. Moro C, Birt J, Stromberga Z, Phelps C, Clark J, Glasziou P, et al. Virtual and Augmented Reality Enhancements to Medical and Science Student Physiology and Anatomy Test Performance: A Systematic Review and Meta-Analysis. Anat Sci Educ 2021 May;14(3):368-376. [doi: 10.1002/ase.2049] [Medline: 33378557]
6. Moro C, Phelps C, Redmond P, Stromberga Z. HoloLens and mobile augmented reality in medical and health science education: A randomised controlled trial. Br J Educ Technol 2020 Dec 02;52(2):680-694. [doi: 10.1111/bjet.13049]
7. Moro C, Štromberga Z, Raikos A, Stirling A. The effectiveness of virtual and augmented reality in health sciences and medical anatomy. Anat Sci Educ 2017 Nov;10(6):549-559. [doi: 10.1002/ase.1696] [Medline: 28419750]
8. van Doormaal TPC, van Doormaal JAM, Mensink T. Clinical Accuracy of Holographic Navigation Using Point-Based Registration on Augmented-Reality Glasses. Oper Neurosurg (Hagerstown) 2019 Dec 01;17(6):588-593 [FREE Full text] [doi: 10.1093/ons/opz094] [Medline: 31081883]
9. Incekara F, Smits M, Dirven C, Vincent A. Clinical Feasibility of a Wearable Mixed-Reality Device in Neurosurgery. World Neurosurg 2018 Oct;118:e422-e427. [doi: 10.1016/j.wneu.2018.06.208] [Medline: 30257298]
10. Kubben P, Sinlae RN. Feasibility of using a low-cost head-mounted augmented reality device in the operating room. Surg Neurol Int 2019;10(1):26 [FREE Full text] [doi: 10.4103/sni.sni_228_18] [Medline: 31123633]
11. Lee C, Wong GKC. Virtual reality and augmented reality in the management of intracranial tumors: A review. J Clin Neurosci 2019 Apr;62:14-20. [doi: 10.1016/j.jocn.2018.12.036] [Medline: 30642663]
12. Li Y, Chen X, Wang N, Zhang W, Li D, Zhang L, et al. A wearable mixed-reality holographic computer for guiding external ventricular drain insertion at the bedside. J Neurosurg 2018 Oct 01:1-8. [doi: 10.3171/2018.4.JNS18124] [Medline: 30485188]
13. Chidambaram S, Winston GM, Knisely JPS, Ramakrishna R, Juthani R, Salah K, et al. A Multidisciplinary Team Approach to Brain and Spine Stereotactic Radiosurgery Conferences: A Unique Institutional Model. World Neurosurg 2019 Nov;131:159-162. [doi: 10.1016/j.wneu.2019.08.012] [Medline: 31408748]

XSL•FO
RenderX

14. Mahajan A, Ahmed S, McAleer MF, Weinberg JS, Li J, Brown P, et al. Post-operative stereotactic radiosurgery versus observation for completely resected brain metastases: a single-centre, randomised, controlled, phase 3 trial. Lancet Oncol 2017 Aug;18(8):1040-1048 [FREE Full text] [doi: 10.1016/S1470-2045(17)30414-X] [Medline: 28687375]
15. Soliman H, Ruschin M, Angelov L, Brown PD, Chiang VL, Kirkpatrick JP, et al. Consensus Contouring Guidelines for Postoperative Completely Resected Cavity Stereotactic Radiosurgery for Brain Metastases. Int J Radiat Oncol Biol Phys 2018 Feb 01;100(2):436-442. [doi: 10.1016/j.ijrobp.2017.09.047] [Medline: 29157748]
16. Prabhu RS, Patel KR, Press RH, Soltys SG, Brown PD, Mehta MP, et al. Preoperative Vs Postoperative Radiosurgery For Resected Brain Metastases: A Review. Neurosurgery 2019 Jan 01;84(1):19-29. [doi: 10.1093/neuros/nyy146] [Medline: 29771381]
17. Angelov L, Mohammadi A, Bennett E, Abbassy M, Elson P, Chao S, et al. Impact of 2-staged stereotactic radiosurgery for treatment of brain metastases ≥ 2 cm. J Neurosurg 2018 Aug;129(2):366-382. [doi: 10.3171/2017.3.JNS162532] [Medline: 28937324]
18. Scoccianti S, Detti B, Gadda D, Greto D, Furfaro I, Meacci F, et al. Organs at risk in the brain and their dose-constraints in adults and in children: a radiation oncologist's guide for delineation in everyday practice. Radiother Oncol 2015 Feb;114(2):230-238. [doi: 10.1016/j.radonc.2015.01.016] [Medline: 25701297]
19. Loeffler JS, Siddon RL, Wen PY, Nedzi LA, Alexander E. Stereotactic radiosurgery of the brain using a standard linear accelerator: a study of early and late effects. Radiother Oncol 1990 Apr;17(4):311-321. [doi: 10.1016/0167-8140(90)90005-h] [Medline: 2343148]
20. Bhatnagar AK, Flickinger JC, Kondziolka D, Lunsford LD. Stereotactic radiosurgery for four or more intracranial metastases. Int J Radiat Oncol Biol Phys 2006 Mar 01;64(3):898-903. [doi: 10.1016/j.ijrobp.2005.08.035] [Medline: 16338097]
21. Soike MH, Hughes RT, Farris M, McTyre ER, Cramer CK, Bourland JD, et al. Does Stereotactic Radiosurgery Have a Role in the Management of Patients Presenting With 4 or More Brain Metastases? Neurosurgery 2019 Mar 01;84(3):558-566 [FREE Full text] [doi: 10.1093/neuros/nyy216] [Medline: 29860451]
22. Yamamoto M, Serizawa T, Shuto T, Akabane A, Higuchi Y, Kawagishi J, et al. Stereotactic radiosurgery for patients with multiple brain metastases (JLGK0901): a multi-institutional prospective observational study. Lancet Oncol 2014 Apr;15(4):387-395. [doi: 10.1016/S1470-2045(14)70061-0] [Medline: 24621620]
23. Zindler JD, Bruynzeel AME, Eekers DBP, Hurkmans CW, Swinnen A, Lambin P. Whole brain radiotherapy versus stereotactic radiosurgery for 4-10 brain metastases: a phase III randomised multicentre trial. BMC Cancer 2017 Jul 25;17(1):500 [FREE Full text] [doi: 10.1186/s12885-017-3494-z] [Medline: 28743240]
24. Kida Y, Mori Y. Radiosurgery for Patients with More Than Ten Brain Metastases. Cureus 2020 Jan 21;12(1):e6728 [FREE Full text] [doi: 10.7759/cureus.6728] [Medline: 32133254]
25. Vergalasova I, Liu H, Alonso-Basanta M, Dong L, Li J, Nie K, et al. Multi-Institutional Dosimetric Evaluation of Modern Day Stereotactic Radiosurgery (SRS) Treatment Options for Multiple Brain Metastases. Front Oncol 2019;9:483 [FREE Full text] [doi: 10.3389/fonc.2019.00483] [Medline: 31231614]
26. Hatiboglu M, Chang E, Suki D, Sawaya R, Wildrick D, Weinberg J. Outcomes and prognostic factors for patients with brainstem metastases undergoing stereotactic radiosurgery. Neurosurgery 2011 Oct;69(4):796-806; discussion 806. [doi: 10.1227/NEU.0b013e31821d31de] [Medline: 21508879]
27. Trifiletti DM, Lee C, Kano H, Cohen J, Janopaul-Naylor J, Alonso-Basanta M, et al. Stereotactic Radiosurgery for Brainstem Metastases: An International Cooperative Study to Define Response and Toxicity. Int J Radiat Oncol Biol Phys 2016 Oct 01;96(2):280-288 [FREE Full text] [doi: 10.1016/j.ijrobp.2016.06.009] [Medline: 27478166]
28. Trifiletti DM, Lee C, Winardi W, Patel NV, Yen C, Larner JM, et al. Brainstem metastases treated with stereotactic radiosurgery: safety, efficacy, and dose response. J Neurooncol 2015 Nov;125(2):385-392. [doi: 10.1007/s11060-015-1927-6] [Medline: 26341374]
29. Winograd E, Rivers CI, Fenstermaker R, Fabiano A, Plunkett R, Prasad D. The case for radiosurgery for brainstem metastases. J Neurooncol 2019 Jul;143(3):585-595. [doi: 10.1007/s11060-019-03195-y] [Medline: 31127508]
30. Kondziolka D, Mousavi SH, Kano H, Flickinger JC, Lunsford LD. The newly diagnosed vestibular schwannoma: radiosurgery, resection, or observation? FOC 2012 Sep;33(3):E8. [doi: 10.3171/2012.6.focus12192]
31. Chung L, Ung N, Sheppard J, Nguyen T, Lagman C, Choy W, et al. Impact of Cochlear Dose on Hearing Preservation following Stereotactic Radiosurgery and Fractionated Stereotactic Radiotherapy for the Treatment of Vestibular Schwannoma. J Neurol Surg B Skull Base 2018 Aug;79(4):335-342 [FREE Full text] [doi: 10.1055/s-0037-1607968] [Medline: 30009113]
32. van Linge A, van Os R, Hoekstra N, Heijmen B, Stienstra L, Dallenga A, et al. Progression of hearing loss after LINAC-based stereotactic radiotherapy for vestibular schwannoma is associated with cochlear dose, not with pre-treatment hearing level. Radiat Oncol 2018 Dec 24;13(1):253 [FREE Full text] [doi: 10.1186/s13014-018-1202-z] [Medline: 30583739]
33. Cline HE, Lorensen WE, Kikinis R, Jolesz F. Three-dimensional segmentation of MR images of the head using probability and connectivity. J Comput Assist Tomogr 1990;14(6):1037-1045. [doi: 10.1097/00004728-199011000-00041] [Medline: 2229557]
34. Hou X, Yang D, Li D, Liu M, Zhou Y, Shi M. A new simple brain segmentation method for extracerebral intracranial tumors. PLoS One 2020;15(4):e0230754 [FREE Full text] [doi: 10.1371/journal.pone.0230754] [Medline: 32302315]

XSL•FO
RenderX

35. Charron O, Lallement A, Jarnet D, Noblet V, Clavier J, Meyer P. Automatic detection and segmentation of brain metastases on multimodal MR images with a deep convolutional neural network. Comput Biol Med 2018 Apr 01;95:43-54. [doi: 10.1016/j.compbiomed.2018.02.004] [Medline: 29455079]
36. Pannullo S, Chidambaram S, Brandmaier A, Knisely J, Adler J. Clinical Considerations in Neurosurgical Radiosurgery in the Time of COVID-19. Cureus 2020 Apr 14;12(4):e7671 [FREE Full text] [doi: 10.7759/cureus.7671] [Medline: 32419998]
37. Ohl S. Tele-Immersion Concepts. IEEE Trans Visual Comput Graphics 2018 Oct 1;24(10):2827-2842. [doi: 10.1109/tvcg.2017.2767590]

Abbreviations

AR: augmented reality
CT: computed tomography
MDT: multidisciplinary team
MR: mixed reality
MRI: magnetic resonance imaging
MRTK: Mixed Reality Toolkit Library
OAR: organ at risk
PTV: planning treatment volume
SRS: stereotactic radiosurgery
VS: vestibular schwannoma
XR: extended reality

Edited by P Kubben, T Leung; submitted 06.02.22; peer-reviewed by J Egger, C Moro; comments to author 25.04.22; revised version received 07.05.22; accepted 19.05.22; published 01.06.22.

Please cite as:
Chidambaram S, Palumbo MC, Stifano V, McKenna J, Redaelli A, Olivi A, Apuzzo M, Pannullo S
The Potential for Using Extended Reality Technology in Interdisciplinary Case Discussions and Case Planning in Stereotactic Radiosurgery: Proof-of-Concept Usability Study
JMIR Neurotech 2022;1(1):e36960
URL: https://neuro.jmir.org/2022/1/e36960
doi:10.2196/36960
PMID:

©Swathi Chidambaram, Maria Chiara Palumbo, Vito Stifano, John McKenna, Alberto Redaelli, Alessandro Olivi, Michael Apuzzo, Susan Pannullo. Originally published in the Journal of Neurotechnology (https://neuro.jmir.org), 01.06.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. The complete bibliographic information, a link to the original publication on https://www.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Interrater Agreement on National Institutes of Health Stroke Scale Between Paramedics and Stroke Physicians: Validation Study for the Digital Training Model in the Paramedic Norwegian Acute Stroke Prehospital Project

Mona Guterud[1,2,3], MSc; Helge Fagerheim Bugge[1,3,4], MD; Jo Røislien[1], PhD; Karianne Larsen[1,5], MD; Erik Eriksen[4], MD; Svein Håkon Ingebretsen[4], MD; Martin Lerstang Mikkelsen[4], MD; Jo Kramer-Johansen[2,3], MD, PhD; Kristi G Bache[5,6], PhD; Else Charlotte Sandset[1,4], MD, PhD; Maren Ranhoff Hov[1,4,7], MD, PhD

[1]Department of Research, Norwegian Air Ambulance Foundation, Oslo, Norway
[2]Division of Prehospital Services, Oslo University Hospital, Oslo, Norway
[3]Institute of Clinical Medicine, University of Oslo, Oslo, Norway
[4]Department of Neurology, Stroke Unit, Oslo University Hospital, Oslo, Norway
[5]Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway
[6]Research and Dissemination, Østfold University College, Halden, Norway
[7]Department of Health Science, Oslo Metropolitan University, Oslo, Norway

Corresponding Author:
Mona Guterud, MSc
Department of Research
Norwegian Air Ambulance Foundation
Postboks 414
Sentrum
Oslo, 0103
Norway
Phone: 47 41557580
Email: mona.guterud@norskluftambulanse.no

Abstract

Background: Time spent in the prehospital phase of acute stroke care is multifactorial and has an effect on the possibilities for acute treatment. Communication between paramedics and the in-hospital stroke team directly affects time to treatment. A mutual stroke scale such as the National Institutes of Health Stroke Scale (NIHSS) may improve communication quality. The Paramedic Norwegian Acute Stroke Prehospital Project (ParaNASPP) was a stepped-wedge, randomized trial of stroke screening using NIHSS in the ambulance where the intervention was training paramedics in stroke and the NIHSS, with the use of NIHSS made into a mobile app to guide the examination and facilitate communication with the in-hospital stroke team.

Objective: The aim of this study was to validate the digital training model from the ParaNASPP clinical trial.

Methods: In total, 24 paramedics were recruited from Oslo University Hospital in Norway to complete the ParaNASPP training model; 20 exclusive videos with predefined NIHSS scores were recorded; and 4 stroke physicians from Oslo University Hospital were included for reference. Bland-Altman plots with 95% limits of agreement (LoA) were calculated—first comparing paramedics and stroke physicians to the predefined scores and then with each other. The predefined LoA were set to 3 points. To align with clinical practice, NIHSS scores were also dichotomized into 2 categories: from 0-5 (minor stroke) or ≥6 (moderate and major stroke), and agreement was calculated using Cohen κ.

Results: The videos (n=20) had a median (range) NIHSS score of 7 (0-31). The paramedics' scores were slightly higher than the predefined scores with a mean difference of –0.38 and the LoA ranging from –4.04 to 3.29. The paramedics scored higher than the stroke physicians with a mean difference of –0.39, with the LoA ranging from –4.58 to 3.80. When the NIHSS scores were dichotomized, Cohen κ was 0.89 between the predefined scores and paramedics, 0.92 between the predefined scores and stroke physicians, and 0.81 between the paramedics and stroke physicians, all indicating very good agreement.

XSL•FO
RenderX

Conclusions: The paramedics scored higher than both the predefined scores and stroke physicians' scores, hence the predefined LoA were not met. However, the width of the LoA was smaller than seen when experienced neurologists are compared. When the NIHSS scores were dichotomized, the paramedics achieved very good agreement with both the predefined scores and stroke physicians' scores. This study demonstrates the possibilities for the transfer of clinical competence in digital simulation training.

(JMIR Neurotech 2022;1(1):e39444) doi:10.2196/39444

KEYWORDS

paramedic; stroke; ambulance; National Institutes of Health Stroke Scale; NIHSS; training; digital; interrater; agreement; Norway; acute; treatment; hospital; time; communication; ambulance; mobile application; clinical trial; physician; digital; simulation

Introduction

The correct and timely triage of patients with acute stroke to the right level of care is largely based on the prehospital assessment [1,2]. Prehospital stroke symptom identification and the prenotification of in-hospital stroke teams are known to affect time to acute treatment [3,4]. Prenotification communication with the receiving facility is important as it prepares the stroke team on the patient's condition and secures the efficient in-hospital reception of the patient [2,4]. The National Institutes of Health Stroke Scale (NIHSS; Multimedia Appendix 1) is the most frequently used stroke scale by stroke physicians and stroke nurses today [5]. The NIHSS has been considered too complex and time-consuming and, therefore, less suited for prehospital use [6,7], and consequently, most prehospital scales are the modified and shortened versions of the NIHSS [8,9]. Fair agreement has been found when comparing the NIHSS scores achieved by neurologists and nonneurologists [10-12], but little is known on how the full-scale NIHSS when performed by paramedics compare to stroke physicians' scores. Traditional simulation training is to a large degree based on physical attendance and, thus, is both time- and resource-consuming. Alternative solutions for training medical personnel, including video-based training, have been investigated [13,14] and proven to be reliable in NIHSS training and certification [15,16]. Video-based training supplemented with electronic learning (e-learning) has shown better performance in NIHSS scoring [17]. For the Paramedic Norwegian Acute Stroke Prehospital Project (ParaNASPP)—a stepped-wedge, randomized trial of stroke screening using NIHSS in the ambulance—we developed a complete digital training model for paramedics [18]. An e-learning program was combined with unique videos for scoring NIHSS in the (native) Norwegian language.

The aim of this study was to validate the training model in the ParaNASPP clinical trial.

Methods

Study Setting

In the ParaNASPP clinical trial [18], paramedics in Oslo, Norway, were trained in the full-scale NIHSS as the intervention. The participant enrollment period was from June 3, 2019, to July 1, 2021. The intervention included a structured learning program, a mobile app for NIHSS scoring, and the transfer of data from paramedics to the on-call stroke team physician. In October 2018, we tested the intervention for feasibility and identified the needed adjustments in the e-learning and simulation training before the start of the trial. To validate the training model, we decided to test the interrater agreement between paramedics and stroke physicians, and we planned for a pilot study. Due to the COVID-19 pandemic, a need for digital training emerged. For practical reasons, we decided to test the interrater agreement after digital simulation training.

The validation study took place in Oslo, Norway, in December 2020. Due to pragmatic and organizational reasons, we invited all (N=83) ambulance personnel employed at 3 geographically dispersed ambulance stations in the Prehospital Division of Oslo University Hospital to participate. To become an ambulance personnel in Norway, there is emergency medical technician training from upper secondary school. Paramedic training may be accomplished for emergency medical technicians and nurses with additional courses, and in recent years, a unique bachelor's degree for paramedics has been developed as a higher education. To reflect the diversity in the ParaNASPP clinical trial study setting [18], we needed participants from this spectrum. For simplicity, we refer to the group as paramedics. Based on current protocol in the ambulance service, we expected the paramedics to have no or little formal competence or experience with the NIHSS. For comparison, selected stroke physicians that reflected the variations in the on-call team at the Stroke Unit of the Department of Neurology at Oslo University Hospital were also asked to participate.

Data that were collected from the participants included the number of years of experience in their respective services, level of education, and current status on the international certification in NIHSS [16]. Written consent was obtained from all participants.

Practical Implementation

All enrolled paramedics completed a structured e-learning program in stroke assessment prior to a live, digital simulation training on the Teams chat-based collaboration platform (version 4.7.15.0; Microsoft). The digital simulation training lasted 4 hours. A stroke physician tutored the sessions, where the aim was to build an understanding of the assessment of neurological findings, the concept of the NIHSS, and the practical use of a mobile iOS app (the ParaNASPP app; Multimedia Appendix 2). This is a specially developed app where each item from the NIHSS is displayed in pictograms, explanatory text is presented in a fixed sequence, and a total score is automatically calculated. A separate validation study of the ParaNASPP app has been published [19]. All items in the NIHSS were demonstrated and

XSL•FO
RenderX

simulated. Simulation cases in the live stream were unique and distinct from the forthcoming, predetermined cases to test the interrater agreement. The participants could ask questions, and they received immediate feedback and guidance from the instructors and stroke physician. Immediately after the live stream of the digital simulation training, the paramedics accessed the test material for the study.

In all, 20 exclusive videos (see an example in Multimedia Appendix 3) with the role-playing of the neurological symptoms of a possible acute stroke were developed and used for testing interrater agreement. To achieve a trustworthy acting of neurological findings, a stroke physician performed as the patient in all videos, and a paramedic trained in the ParaNASPP model [18] performed the NIHSS examination. The manuscripts for the videos were prepared in cooperation with stroke physicians who were not involved in this study. The video manuscripts represented the predefined NIHSS scores with a median (range) of 7 (0-31). The videos were intended to comprise the different items of the NIHSS to varying degrees; however, the cases of neurological findings not captured in the NIHSS were also acted out, such as dizziness and dysmetria. The distribution aimed to reflect a real population with stroke [20] and was similar to comparable studies [11,15]. The videos had a mean (SD) duration of 2 minutes and 58 (23) seconds. The videos could be paused and rewound if warranted by the participants. When the paramedics scored the last NIHSS item in the app, a total score was transferred to the database, and this finalized the scoring opportunity for that video.

The paramedics' NIHSS scores were compared to the predefined scores for each video. As this underlying predefinition is not available in clinical practice, the paramedics' scores were also compared to the scores achieved by stroke physicians scoring the same videos.

All paramedics' NIHSS scores were digitally entered in the ParaNASPP app. The time spent on NIHSS registration was recorded by start time (new registration) and end time (data submitted) and directly transferred to the database. The stroke physicians scored according to their daily practice on the original NIHSS paper form, independently from each other and the paramedics. The stroke physicians were responsible for documenting their own time stamps for each video. The time spent on scoring the NIHSS for each video was reported in whole minutes.

Statistical Analysis

We presented continuous data as mean (SD) for symmetric data and median (range) for skewed data and data with outliers.

The NIHSS is a continuous scale, and Bland and Altman's [21] approach for method comparison was applied to assess the interrater agreement. The limits of agreement (LoA) were estimated based on the observed differences between measurement methods, representing the actual variation in the data [22]. These LoA were then compared to the acceptable variation, here set to 3 points on the NIHSS based on a clinical evaluation and the same a priori threshold in a comparable study [14]. Bland and Altman's [21] original method was applied when comparing the NIHSS scores between the paramedics or stroke physicians and the predefined scores in the videos. When assessing the interrater agreement between the paramedics and stroke physicians, a mixed models version of method comparison was applied [23], adjusting for the internal correlation structure in the data resulting from the 24 paramedics and 4 stroke physicians all evaluating the same 20 videos.

In clinical practice, a distinction in treatment regimens is often made for high versus low NIHSS scores [24,25], and thus, in a secondary analysis, the interrater agreement for dichotomized NIHSS values were explored. The continuous NIHSS scores were dichotomized into a low-score category, from 0-5 (minor stroke), and a high-score category, ≥6 (moderate and major stroke). Cohen κ was used to calculate the agreement of the dichotomized data: first, between the paramedics or stroke physicians and the predefined scores and second, between the paramedics and stroke physicians. Note that currently, no version of the mixed models of Cohen κ exists, and the traditional Cohen κ used will likely underestimate the uncertainty in the Cohen κ estimate.

In the literature, κ≤0.2 is taken to represent poor agreement, 0.21-0.40 as fair agreement, 0.41-0.60 as moderate agreement, 0.61-0.80 as good agreement, and 0.81-1.0 as very good agreement [26].

Statistical analyses were performed with Stata statistical software (version 16.1; StataCorp) [27] and R statistical software (version 4.0.3; R Foundation for Statistical Computing) [28].

Ethical Considerations

The local data protection office at Oslo University Hospital approved of the handling of the data from the volunteers and consenting paramedics and stroke physicians employed at Oslo University Hospital (approval 19/00667). No institutional review board approval was sought since no actual patients were involved in this study, as outlined by Norwegian guidelines.

Results

This study enrolled all (N=24) paramedics that volunteered and recruited 4 volunteer stroke physicians. The characteristics of the participants are described in Table 1.

Time spent on evaluating the videos contained 2 extreme values (196 minutes and 5768 minutes), likely a result of starting a video, pausing, and completing it at a later time point. These outliers were therefore excluded from the analysis.

Comparing the paramedics' score to the predefined scores in the videos resulted in 480 unique NIHSS assessments. Similarly, the stroke physicians enrolled in the study's evaluation of the 20 videos resulted in 80 unique NIHSS scores. The paramedics' scores were on average somewhat higher than the predefined scores (Figure 1), with a mean difference of –0.38 and the LoA ranging from –4.04 to 3.29 between the paramedics' scores and the predefined scores (Figure 2). The paramedics scored higher than the stroke physicians, with a mean difference of –0.39 and the LoA ranging from –4.58 to 3.80. The agreements between the paramedics' scores with the predefined scores and stroke physicians' scores were both outside the a priori defined acceptable limit of 3.

XSL•FO
RenderX

The stroke physicians were in agreement with the predefined scores (Figure 3), and the LoA ranged from –2.31 to 2.34 with a mean difference of 0.01, which were well within the limit of 3 (Figure 4).

Differences between the paramedics' scores and the predefined scores in the videos were considerably smaller for lower NIHSS scores. Calculating the LoA for the 2 clinically different regions, we found the LoA to be from –1.42 to 0.88 for NIHSS scores from 0-5 and from –4.90 to 4.03 for NIHSS scores ≥6 (Figure 2).

The paramedics' ability to score patients in the from 0-5 or ≥6 categories showed a Cohen κ of 0.89 as compared to the predefined scores, representing very good agreement. For predefined scores from 0-5, 14 (8.3%) out of 168 paramedics' scores were overestimated, putting patients in the high-score category. For predefined scores ≥6, the paramedics' scores were underestimated in 9 (2.9%) out of 312 videos.

Table 1. Description of the participants.

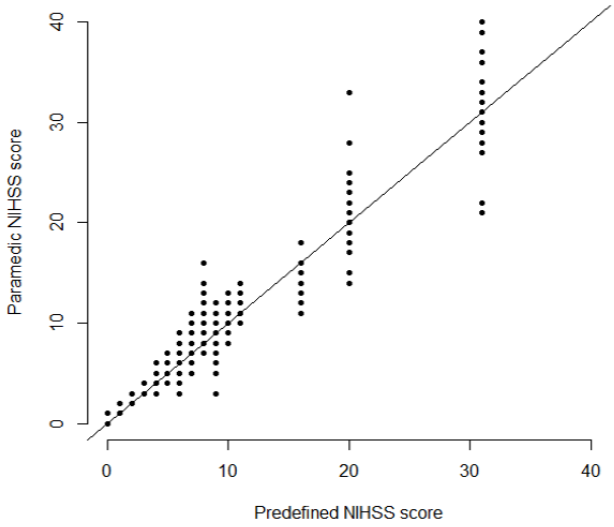
Characteristic	Paramedics (N=24)	Stroke physicians (N=4)
Experience (years), median (range)	4 (1-45)	11 (8-14)
Time in a stroke unit (years), median (range)	—[a]	7 (2-10)
Level of education, n (%)		
EMT[b]	8 (33)	—
Trained paramedics	14 (58)	—
Apprentice EMT	1 (4)	—
Other	1 (4)	—
Specialist in neurology	—	3 (75)
Specialist in geriatric medicine	—	1 (25)
Certification in NIHSS[c], n (%)	5 (21)	4 (100)
Time spent on each case (minutes), median (range)	3 (2-15)	3 (2-4)

[a]Not applicable.

[b]EMT: emergency medical technician.

[c]NIHSS: National Institutes of Health Stroke Scale.

Figure 1. NIHSS scores for the paramedics against the predefined NIHSS scores (raw data). NIHSS: National Institutes of Health Stroke Scale.



XSL•FO
RenderX

Figure 2. NIHSS scores for the paramedics against the predefined NIHSS scores with the corresponding Bland-Altman plot displaying pairwise differences plotted against pairwise means. The limits of agreement are superimposed, calculated both for the total data sample (shaded) and for the from 0-5 versus ≥6 categories separately (dashed line). NIHSS: National Institutes of Health Stroke Scale.

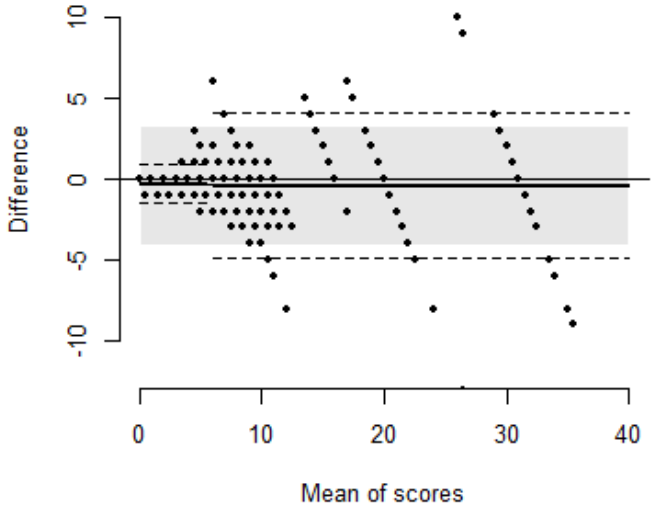


Figure 3. NIHSS scores for the stroke physicians against the predefined NIHSS scores (raw data). NIHSS: National Institutes of Health Stroke Scale.

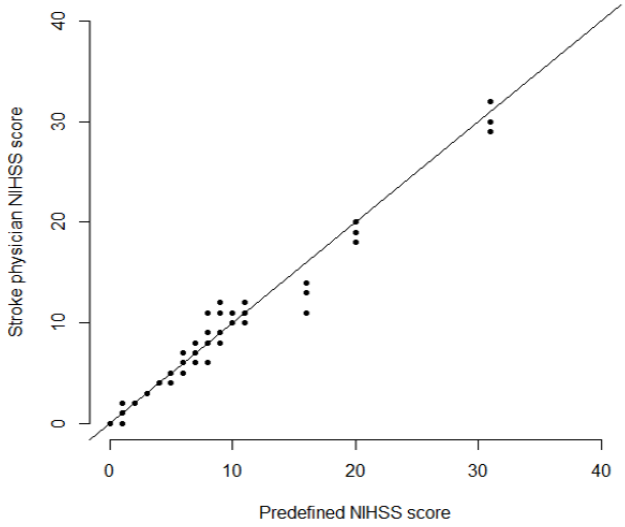
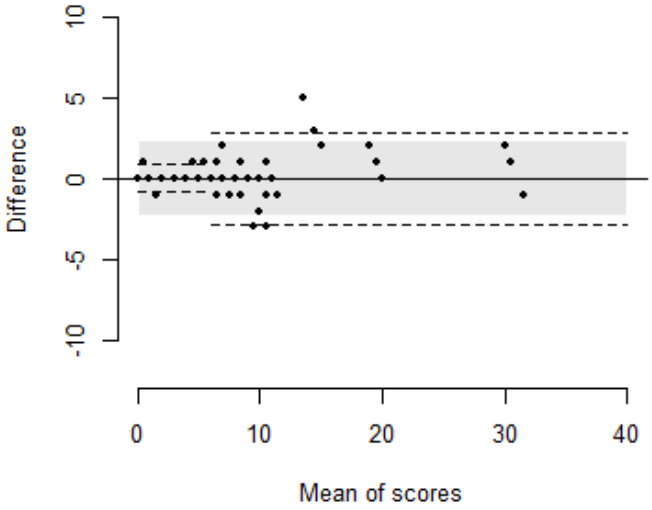


Figure 4. NIHSS scores for the stroke physicians against the predefined NIHSS scores with the corresponding Bland-Altman plot displaying pairwise differences plotted against pairwise means. The limits of agreement are superimposed, calculated both for the total data sample (shaded) and for the from 0-5 versus ≥6 categories separately (dashed line). NIHSS: National Institutes of Health Stroke Scale.



XSL•FO
RenderX

Interrater agreement between the stroke physicians' scores and the predefined scores for the 2 categories was κ=0.92, representing very good agreement. When the predefined scores were from 0-5, the physicians were in complete agreement with predefined scores in 28 (100%) out of 28 videos, and when the predefined scores were ≥6, the stroke physicians' scores were underestimated in 3 (6%) out of 52 videos.

With 20 predefined scores, 24 paramedics, and 4 stroke physicians, we had 1920 paired NIHSS score comparisons which gave an unadjusted Cohen κ of 0.81 and very good agreement in the direct comparison between the paramedics and stroke physicians. The paramedics scored the simulated patients to be in the ≥6 category while the stroke physicians scored in the from 0-5 category in 128 (17.2%) out of 744 comparisons. The opposite occurred in 36 (3.1%) out of 1176 comparisons.

Discussion

Principal Findings

Our findings indicate that paramedics can achieve very good agreement with stroke physicians when tested after a digital training program for NIHSS in the ParaNASPP model.

The paramedics scored higher than both the predefined scores and the stroke physicians' scores when we looked at the scale from 0 to 42 points. Compared to the predefined scores, the paramedics were well within the LoA of 3 in the range of NIHSS scores from 0-5; however, the variation increased with higher scores (≥6). Higher NIHSS scores indicate more complex neurological deficits [5] and have been associated with greater scoring variance in other settings, and a difference of 4 points is not uncommon in video scoring [29]. Nevertheless, we had predefined an acceptable difference in scores of 3 points between raters. This is the same predefined limit used in a study to compare the NIHSS scores of remote and bedside vascular neurologist [14].

In this study, the participants were a heterogenous group, but it was important to test the training model on a group similar to that in the ParaNASPP clinical trial [18]. However, the width of 8.38 on the LoA for the paramedics' and stroke physicians' scores found in our study is smaller than seen when compared to experienced neurologists who achieved a width of 10.05 on the LoA [14]. A grading table for acceptable LoA has been developed, placing the results from our study as Grade A [30]. Based on this, we accept the LoA in our study in spite of not achieving the predefined limit.

The NIHSS scale ranges from 0 to 42 points where higher scores indicate more severe strokes [5] and more complex scoring, but a single number on a scale, or a category when it is applied, is never decisive of treatment. However, prehospital triage decisions are to some extent dependent on this scoring. We decided on a cutoff of 6 points for dichotomizing the scale to be in accordance with a cutoff commonly used [24,31,32]. In a clinical setting, there is an acceptance for overtriage to ensure the identification of patients eligible for acute treatment [7]. An overestimation of a NIHSS score or category from paramedics is for that reason less problematic than an underestimation, which in our study also was lower than seen before [6].

When dichotomized to from 0-5 and ≥6 categories, interrater agreement was very good between the paramedics' scores and the predefined scores. Although a generalization of Bland and Altman's [21] approach for the method comparison of continuous measurements is more than a decade old, when adjusting for replicate measurements and multiple raters, no readily available generalization for Cohen κ exists. However, a crude estimate for comparing categorized NIHSS scores between the paramedics and stroke physicians, combining all value pairs in the same cross table, gave an unadjusted Cohen κ that indicated very good agreement. When not in agreement, the tendency was shifted toward higher NIHSS scores representing the less problematic overtriage from the paramedics.

The duration of evaluating each case referred to the scoring of the simulated symptoms on the videos and does not necessarily reflect the time spent on performing the actual assessment. The stroke physicians scored the videos according to their daily practice with a self-report on case duration, whereas the paramedics were provided with an unfamiliar stroke scale and a new scoring tool that automatically registered case duration. We expected the paramedics to spend more time on scoring the videos based on the novelty, but the time spent did not differ much between the paramedics and stroke physicians. This finding may indicate an instant effect of our training model for the paramedics—an effect that may be sustained [33]. However, the scoring was based on the acting of neurological symptoms that were straight forward and not influenced by confounders seen in a real-world setting. The time spent on patient evaluation may increase for paramedics in a more complex clinical context.

The training of paramedics in acute stroke assessment can easily be converted to a digital format instead of on-site training [34]. Digital solutions have been suggested as an alternative to face-to-face interactions in simulation training [13], and significant correlation between digital solutions and positive learning outcomes have already been established [17,35]. This knowledge is important when planning for the implementation of new procedures and tools for paramedics. However, the supervision part of digital training is important [36]. A chat function makes the instructors available and provides a great opportunity for participants to interact despite their remote participation.

Recent publications demonstrate reasonable agreement between prehospital and in-hospital NIHSS scores, in both the modified and full-scale versions [30,34]. Importantly, paramedics preferred a hospital-based stroke scale to improve communication with stroke physicians [34]. The development of stroke triage systems has not focused on the standardization of clinical evaluation and communication between paramedics and the on-call stroke physician. Communication quality between paramedics and the on-call stroke team physician directly influences prehospital on-scene time and is a key component in prenotification and triage [37]. Introducing a common clinical language through training paramedics may facilitate this communication [15,37]. We believe that a solid training program is the key to standardizing clinical assessment in acute stroke care and that the reliable use of the NIHSS is related to how paramedics are trained rather than the profession

XSL•FO
RenderX

itself. A compatible stroke scale will improve prehospital to in-hospital communication and the quality of the prenotification but also holds the potential to improve triage, optimize in-hospital reception, and reduce time to treatment. The ParaNASPP clinical trial [18] aims to investigate this.

Limitations

This study was delayed due to organizational issues during the COVID-19 pandemic, and time limits and the pandemic affected our possibilities to engage a larger group.

We decided to use a stroke physician to perform as the patient in the videos to achieve a trustworthy acting of neurological findings. We realize that this is also a limitation as neurological findings in a real-world setting may be influenced by comorbidities, complicating the patient assessment. The results on the interrater agreement achieved in this study may therefore not be directly transferrable to a clinical setting.

The study was performed using a convenience sample, and an a priori power analysis was not performed. The low number of assessments between neurologists and video or paramedics might thus make the Bland-Altman analysis underpowered, with the accompanying increased uncertainty in the LoA estimates.

Only the total NIHSS score, and not the specific NIHSS score for each of the 11 score items, were available for analysis for the paramedics, and as a consequence, we were not able to identify if there were specific items that affected the agreement.

Failing to stay inside the predefined LoA of 3 is fundamentally different depending on if we are evaluating the lower or higher range of the NIHSS score. For future studies, it would be interesting to investigate if a shifting LoA acceptability and different cutoffs for dichotomizing the scale would alter the interrater agreement.

There were 5 paramedics who reported that they had an international certification in NIHSS. The NIHSS was not a part of standard protocol for paramedics, and the rather high proportion of paramedics with extracurricular knowledge may have contributed to a selection bias, since paramedics already interested in the topic were more likely to respond to the advertisement.

Conclusion

The paramedics scored higher than both the predefined scores and the stroke physicians' scores, hence the predefined LoA were not met. However, the width of LoA was smaller than seen when experienced neurologists are compared. When the NIHSS scores were dichotomized, the paramedics achieved very good agreement with both the predefined scores and the stroke physicians' scores. This study demonstrates possibilities for the transfer of clinical competence in digital simulation training. It may facilitate training and implementation in greater scales in different prehospital services and improve the efficacy of training in the future.

Acknowledgments

The study and fee for open access publication were funded by the Norwegian Air Ambulance Foundation. The funder had no influence on study design; the collection, management, analysis, interpretation of data; and the writing and publishing of the report.

We would like to thank Sindre Nilo and Ole Kristian Andreassen for their contribution to the videos; the stroke physicians at Oslo University Hospital, Stroke Unit Ullevaal, and the paramedics at Oslo University Hospital, Prehospital Divisions Lørenskog, Bærum, and Aurskog/Høland for participating in the study; and Fredrik Kaupang at NLA technology for the contribution of the ParaNASPP app.

Authors' Contributions

MG, HFB, and MRH contributed to the conception and design of the study. MG organized the database and performed the statistical analysis with JR. MG wrote the first draft of the manuscript. All authors contributed to manuscript revision and read and approved the submitted version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
National Institutes of Health Stroke Scale, English and Norwegian versions.
[PDF File (Adobe PDF File), 156 KB - neuro_v1i1e39444_app1.pdf]

Multimedia Appendix 2
The Paramedic Norwegian Acute Stroke Prehospital Project (ParaNASPP) app with pictograms.
[PNG File , 4561 KB - neuro_v1i1e39444_app2.png]

Multimedia Appendix 3

XSL•FO
RenderX

Example video.
[MP4 File (MP4 Video), 76542 KB - neuro_v1i1e39444_app3.mp4]

References

1. Berglund A, Svensson L, Sjöstrand C, von Arbin M, von Euler M, Wahlgren N, HASTA Collaborators, et al. Higher prehospital priority level of stroke improves thrombolysis frequency and time to stroke unit: the Hyper Acute STroke Alarm (HASTA) study. Stroke 2012 Oct;43(10):2666-2670. [doi: 10.1161/STROKEAHA.112.652644] [Medline: 22879096]
2. Kobayashi A, Czlonkowska A, Ford GA, Fonseca AC, Luijckx GJ, Korv J, et al. European Academy of Neurology and European Stroke Organization consensus statement and practical guidance for pre-hospital management of stroke. Eur J Neurol 2018 Mar;25(3):425-433. [doi: 10.1111/ene.13539] [Medline: 29218822]
3. Meretoja A, Keshtkaran M, Saver JL, Tatlisumak T, Parsons MW, Kaste M, et al. Stroke thrombolysis: save a minute, save a day. Stroke 2014 Apr;45(4):1053-1058. [doi: 10.1161/STROKEAHA.113.002910] [Medline: 24627114]
4. Patel MD, Rose KM, O'Brien EC, Rosamond WD. Prehospital notification by emergency medical services reduces delays in stroke evaluation: findings from the North Carolina stroke care collaborative. Stroke 2011 Aug;42(8):2263-2268 [FREE Full text] [doi: 10.1161/STROKEAHA.110.605857] [Medline: 21659638]
5. Lyden P. Using the National Institutes of Health Stroke Scale: a cautionary tale. Stroke 2017 Feb;48(2):513-519. [doi: 10.1161/STROKEAHA.116.015434] [Medline: 28077454]
6. Kesinger MR, Sequeira DJ, Buffalini S, Guyette FX. Comparing National Institutes of Health Stroke Scale among a stroke team and helicopter emergency medical service providers. Stroke 2015 Mar;46(2):575-578. [doi: 10.1161/STROKEAHA.114.007850] [Medline: 25538202]
7. Smith EE, Kent DM, Bulsara KR, Leung LY, Lichtman JH, Reeves MJ, American Heart Association Stroke Council. Accuracy of prediction instruments for diagnosing large vessel occlusion in individuals with suspected stroke: a systematic review for the 2018 guidelines for the early management of patients with acute ischemic stroke. Stroke 2018 Mar;49(3):e111-e122 [FREE Full text] [doi: 10.1161/STR.0000000000000160] [Medline: 29367333]
8. Zhelev Z, Walker G, Henschke N, Fridhandler J, Yip S. Prehospital stroke scales as screening tools for early identification of stroke and transient ischemic attack. Cochrane Database Syst Rev 2019 Apr 09;4:CD011427 [FREE Full text] [doi: 10.1002/14651858.CD011427.pub2] [Medline: 30964558]
9. Brandler ES, Sharma M, Sinert RH, Levine SR. Prehospital stroke scales in urban environments: a systematic review. Neurology 2014 Jun 17;82(24):2241-2249 [FREE Full text] [doi: 10.1212/WNL.0000000000000523] [Medline: 24850487]
10. Dewey HM, Donnan GA, Freeman EJ, Sharples CM, Macdonell RA, McNeil JJ, et al. Interrater reliability of the National Institutes of Health Stroke Scale: rating by neurologists and nurses in a community-based stroke incidence study. Cerebrovasc Dis 1999;9(6):323-327. [doi: 10.1159/000016006] [Medline: 10545689]
11. Hov MR, Røislien J, Lindner T, Zakariassen E, Bache KCG, Solyga VM, et al. Stroke severity quantification by critical care physicians in a mobile stroke unit. Eur J Emerg Med 2019 Jun;26(3):194-198 [FREE Full text] [doi: 10.1097/MEJ.0000000000000529] [Medline: 29239899]
12. Goldstein LB, Samsa GP. Reliability of the National Institutes of Health Stroke Scale: extension to non-neurologists in the context of a clinical trial. Stroke 1997 Feb;28(2):307-310. [doi: 10.1161/01.str.28.2.307] [Medline: 9040680]
13. Liang ZC, Ooi SBS, Wang W. Pandemics and their impact on medical training: lessons from Singapore. Acad Med 2020 Sep;95(9):1359-1361 [FREE Full text] [doi: 10.1097/ACM.0000000000003441] [Medline: 32304387]
14. Demaerschalk BM, Vegunta S, Vargas BB, Wu Q, Channer DD, Hentz JG. Reliability of real-time video smartphone for assessing National Institutes of Health Stroke Scale scores in acute stroke patients. Stroke 2012 Dec;43(12):3271-3277. [doi: 10.1161/STROKEAHA.112.669150] [Medline: 23160878]
15. Lyden P, Raman R, Liu L, Grotta J, Broderick J, Olson S, et al. NIHSS training and certification using a new digital video disk is reliable. Stroke 2005 Nov;36(11):2446-2449. [doi: 10.1161/01.STR.0000185725.42768.92] [Medline: 16224093]
16. NIH Stroke Scale. URL: http://www.nihstrokescale.org/ [accessed 2022-05-01]
17. Koka A, Suppan L, Cottet P, Carrera E, Stuby L, Suppan M. Teaching the National Institutes of Health Stroke Scale to paramedics (e-learning vs video): randomized controlled trial. J Med Internet Res 2020 Jun 09;22(6):e18358 [FREE Full text] [doi: 10.2196/18358] [Medline: 32299792]
18. Bugge HF, Guterud M, Bache KCG, Braarud A, Eriksen E, Fremstad KO, et al. Paramedic Norwegian Acute Stroke Prehospital Project (ParaNASPP) study protocol: a stepped wedge randomised trial of stroke screening using the National Institutes of Health Stroke Scale in the ambulance. Trials 2022 Mar 04;23(1):113 [FREE Full text] [doi: 10.1186/s13063-022-06006-4] [Medline: 35120559]
19. Bugge HF, Guterud MM, Røislien J, Larsen K, Ihle-Hansen H, Toft M, et al. National Institutes of Health Stroke Scale scores obtained using a mobile application compared to the conventional paper form: a randomised controlled validation study. BMJ Innov 2022 Jun 16:bmjinnov-2022-000968. [doi: 10.1136/bmjinnov-2022-000968]
20. Fjærtoft H, Skogseth-Stephani R, Indredavik B, Bjerkvik TF, Varmdal T. Norwegian Stroke Registry: annual report 2019. Article in Norwegian. Trondheim. 2020 Oct 1. URL: https://www.kvalitetsregistre.no/sites/default/files/1_arsrapport_2019_norsk_hjerneslagregister_justert_21.10.2020.pdf [accessed 2022-07-29]

XSL•FO
RenderX

21. Bland JM, Altman DG. Statistical methods for assessing agreement between two methods of clinical measurement. Lancet 1986 Mar 08;1(8476):307-310. [Medline: 2868172]
22. Giavarina D. Understanding Bland Altman analysis. Biochem Med (Zagreb) 2015;25(2):141-151 [FREE Full text] [doi: 10.11613/BM.2015.015] [Medline: 26110027]
23. Carstensen B, Simpson J, Gurrin LC. Statistical models for assessing agreement in method comparison studies with replicate measurements. Int J Biostat 2008;4(1):Article 16 [FREE Full text] [doi: 10.2202/1557-4679.1107] [Medline: 22462118]
24. Heldner MR, Zubler C, Mattle HP, Schroth G, Weck A, Mono M, et al. National Institutes of Health Stroke Scale score and vessel occlusion in 2152 patients with acute ischemic stroke. Stroke 2013 Apr;44(4):1153-1157. [doi: 10.1161/STROKEAHA.111.000604] [Medline: 23471266]
25. Dobrocky T, Piechowiak EI, Volbers B, Slavova N, Kaesmacher J, Meinel TR, et al. Treatment and outcome in stroke patients with acute M2 occlusion and minor neurological deficits. Stroke 2021 Mar;52(3):802-810. [doi: 10.1161/STROKEAHA.120.031672] [Medline: 33494637]
26. Brennan P, Silman A. Statistical methods for assessing observer variability in clinical measures. BMJ 1992 Jun 06;304(6840):1491-1494 [FREE Full text] [doi: 10.1136/bmj.304.6840.1491] [Medline: 1611375]
27. StataCorp. Stata Statistical Software: Release 16. Stata. 2019. URL: https://www.stata.com/ [accessed 2022-07-29]
28. R Core Team. R: a language and environment for statistical computing. R Foundation for Statistical Computing. 2014. URL: https://www.r-project.org/ [accessed 2022-07-29]
29. Josephson SA, Hills NK, Johnston SC. NIH Stroke Scale reliability in ratings from a large sample of clinicians. Cerebrovasc Dis 2006;22(5-6):389-395. [doi: 10.1159/000094857] [Medline: 16888381]
30. Larsen K, Jæger HS, Hov MR, Thorsen K, Solyga V, Lund CG, et al. Streamlining acute stroke care by introducing National Institutes of Health Stroke Scale in the emergency medical services: a prospective cohort study. Stroke 2022 Jun;53(6):2050-2057 [FREE Full text] [doi: 10.1161/STROKEAHA.121.036084] [Medline: 35291821]
31. Scheitz JF, Abdul-Rahim AH, MacIsaac RL, Cooray C, Sucharew H, Kleindorfer D, SITS Scientific Committee. Clinical selection strategies to identify ischemic stroke patients with large anterior vessel occlusion: results from SITS-ISTR (Safe Implementation of Thrombolysis in Stroke International Stroke Thrombolysis Registry). Stroke 2017 Feb;48(2):290-297. [doi: 10.1161/STROKEAHA.116.014431] [Medline: 28087804]
32. Hansen CK, Christensen A, Ovesen C, Havsteen I, Christensen H. Stroke severity and incidence of acute large vessel occlusions in patients with hyper-acute cerebral ischemia: results from a prospective cohort study based on CT-angiography (CTA). Int J Stroke 2015 Apr;10(3):336-342. [doi: 10.1111/ijs.12383] [Medline: 25319377]
33. Anderson A, Klein J, White B, Bourgeois M, Leonard A, Pacino A, et al. Training and certifying users of the National Institutes of Health Stroke Scale. Stroke 2020 Mar;51(3):990-993 [FREE Full text] [doi: 10.1161/STROKEAHA.119.027234] [Medline: 31986988]
34. Mulkerin WD, Spokoyny I, Francisco JT, Lima B, Corry MD, Nudelman MJR, et al. Prehospital identification of large vessel occlusions using modified National Institutes of Health Stroke Scale: a pilot study. Front Neurol 2021;12:643356 [FREE Full text] [doi: 10.3389/fneur.2021.643356] [Medline: 34054691]
35. Chung C, Cooper SJ, Cant RP, Connell C, McKay A, Kinsman L, et al. The educational impact of web-based and face-to-face patient deterioration simulation programs: an interventional trial. Nurse Educ Today 2018 May;64:93-98. [doi: 10.1016/j.nedt.2018.01.037] [Medline: 29459198]
36. Austlid I, Arkestaal KL, Kibsgaard HP. Skill learning and retention. J Trauma Acute Care Surg 2017 Jun;82(6S):S103-S106. [doi: 10.1097/ta.0000000000001429]
37. Drenck N, Viereck S, Bækgaard JS, Christensen KB, Lippert F, Folke F. Pre-hospital management of acute stroke patients eligible for thrombolysis - an evaluation of ambulance on-scene time. Scand J Trauma Resusc Emerg Med 2019 Jan 09;27(1):3 [FREE Full text] [doi: 10.1186/s13049-018-0580-4] [Medline: 30626404]

Abbreviations

e-Learning: electronic learning
LoA: limits of agreement
NIHSS: National Institutes of Health Stroke Scale
ParaNASPP: Paramedic Norwegian Acute Stroke Prehospital Project

XSL•FO
RenderX

Edited by P Kubben; submitted 10.05.22; peer-reviewed by H Zhao, PV Eswaradass; comments to author 22.06.22; revised version received 02.07.22; accepted 29.07.22; published 11.08.22.

Please cite as:
Guterud M, Bugge HF, Røislien J, Larsen K, Eriksen E, Ingebretsen SH, Mikkelsen ML, Kramer-Johansen J, Bache KG, Sandset EC, Hov MR
Interrater Agreement on National Institutes of Health Stroke Scale Between Paramedics and Stroke Physicians: Validation Study for the Digital Training Model in the Paramedic Norwegian Acute Stroke Prehospital Project
JMIR Neurotech 2022;1(1):e39444
URL: https://neuro.jmir.org/2022/1/e39444
doi:10.2196/39444
PMID:

©Mona Guterud, Helge Fagerheim Bugge, Jo Røislien, Karianne Larsen, Erik Eriksen, Svein Håkon Ingebretsen, Martin Lerstang Mikkelsen, Jo Kramer-Johansen, Kristi G Bache, Else Charlotte Sandset, Maren Ranhoff Hov. Originally published in JMIR Neurotechnology (https://neuro.jmir.org), 11.08.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Neurotechnology, is properly cited. The complete bibliographic information, a link to the original publication on https://neuro.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Editorial

JMIR Neurotechnology: Connecting Clinical Neuroscience and (Information) Technology

Pieter Kubben[1], MD, PhD

Faculty of Health, Medicine and Life Sciences, School for Mental Health and Neuroscience, Maastricht University Medical Center, Maastricht, Netherlands

Corresponding Author:
Pieter Kubben, MD, PhD
Faculty of Health, Medicine and Life Sciences
School for Mental Health and Neuroscience
Maastricht University Medical Center
PO Box 616
Maastricht, 6200 MD
Netherlands
Phone: 31 43 388 2222
Email: pieter.kubben@maastrichtuniversity.nl

(JMIR Neurotech 2022;1(1):e41122) doi:10.2196/41122

KEYWORDS

neurotechnology; neurological disorders; treatment tools; chronic neurological disease; information technology

I am happy to announce the launch of a new member of JMIR Publications' open access family of journals, *JMIR Neurotechnology* (JNT). We are now accepting articles for submission and are waiving open access fees until we are indexed in PubMed.

Why JNT Now?

Neurological diseases are an increasing concern for modern societies around the planet as rates of related disabilities and mortality have risen steadily over the past 2 decades [1]. Neurological disorders lead to significant reductions in the quality of life of those they afflict [2]. They are also clearly associated with steadily increasing costs of diagnosis and patient care, with estimates varying between US $650 and $800 billion per year [3]. Recent and numerous studies worldwide have confirmed that neurological diseases are becoming more widespread and chronic, and more expensive to treat and manage [1,2,4,5]. Such increases heighten the urgent need for more quality research coupled with the development of affordable tools to help diagnose and treat these complex and multivariate disorders.

Many areas of research and development come into play in the process of diagnosing and treating the expanding array of neurological disorders. Advances in many domains are providing valuable contributions, ranging from new findings from basic research aimed at unraveling fundamental, underlying neurological mechanisms to the evolving recognition of the potential of applied behavioral approaches (eg, mindfulness and meditation training) to improve neurological functions and health-related quality of life. Many of these advances are anchored in novel neurotechnology that provides both scientists and patients with new tools for research and treatment. In this context, we pragmatically define neurotechnology as the use of information technology to diagnose or treat chronic neurological disease.

Building on the JMIR foundation, JNT intends to support the development of novel diagnostic and treatment tools and paradigms for neurological diseases, leveraging recent insights from clinical neuroscience and information technology. Our hope is to foster the explicit linking of two domains into a merged domain and a single, coherent neurotechnology community, pragmatically defined as those exploring the use of technologies to diagnose and treat chronic neurological diseases. This community has formed as improvements in both hardware and software have paved the way for new paradigms in diagnostics and treatment through the merger of the clinical and information engineering worlds.

The Aims and Scope of JNT

JNT aims to be a platform where applied human research can connect patients, caregivers, and information engineers active in any neurological domain. The journal editors welcome and will consider work in all relevant *clinical* domains including, but are not limited to, neurology, neurosurgery, neurorehabilitation, neuroradiology, and beyond. We also encourage the submission of work exploring the needs of professional and informal caregivers, all of whom need practical tools to inform and support patients in managing their neurological challenges. We hope that the journal will serve as a gathering place for those involved in patient care, whether

XSL•FO
RenderX

directly or indirectly, since we believe that understanding and managing chronic diseases is and must be a team endeavor, involving different people serving in a wide assortment of complementary roles.

JMIR Publications and the JNT editors also recognize the value of public/private partnerships and hope the journal can support collaboration and foster sustainable innovation between these critical players. JNT aims to become a primary venue for the output of neurotechnology-focused joint ventures and more generally serve as a trusted resource for objectively reviewed and validated neurotechnology.

We explicitly want to connect these various domains, which typically are separate, and hope to do so in part by including a short, author-written statement, which we call a "handshake box" with every article. Authors of clinically oriented articles will be asked to write a handshake text that concisely articulates the technical implications of their findings, and authors of technical work will similarly write a handshake text to articulate the clinical implications of their work.

The goal of including these short, plain-language texts is to build a strong and trusted communication bridge to be shared by clinicians, caregivers, technologists, and engineers, a place to openly share, collaborate, and improve ideas and approaches. We hope to make authors feel comfortable in articulating their findings in digestible terms for all those involved in understanding neurological diseases. The worlds of all those involved in these challenges are not different and should not be separated; JNT's handshake box is meant to close this common communication gap across domains.

The Shapes of JNT

JNT offers 3 categories of article types.

First, JNT will welcome manuscripts in standard categories that are available in most research journals, including the JMIR family of journals, such as original papers, reviews, early reports, and commentaries. These article types will have typical formats, making it easier for authors to transfer papers between JMIR journals in cases where topics do not fall appropriately into the scope of JNT and instead are more appropriate for a different JMIR journal.

Second, you will be able to submit articles that explicitly contribute to open and reproducible science via the article types JNT Data and JNT Code. Research published as a JNT Data article should be focused on sharing data in accordance with the FAIR (Findability, Accessibility, Interoperability, and Reuse of digital assets) Principles [6]. Articles published under the JNT Code category will need to share code in a detailed and well-documented style, for example, as outlined by Jupyter Notebook [7]. These two article types will allow readers to learn from specific approaches by having details provided and explained in depth.

Third, authors will be encouraged to submit articles under the JNT Handshake article type. Besides the mandatory handshake boxes in other original work, we will welcome articles written with the specific purpose to solidify the aforementioned bridge. This article type will allow us to publish more free-form materials—perspectives, educational articles, and other narratives written by clinicians, caregivers, patients, and engineers—provided they clearly share experiences and expertise to facilitate understanding across domains.

Welcome Aboard!

As broad and welcoming as we want JNT to be, we do have limits to our scope. JNT is not interested in fundamental neuroscience or in animal research. We aim to keep things on the applied side, where patient benefit is clear for all involved.

We warmly welcome you onto our JNT bridge and hope to see you there as part of our evolving community!

Conflicts of Interest

PK is the Editor-in-Chief, JMIR Neurotechnology (JNT).

References

1. Feigin V, Nichols E, Alam T, Bannick MS, Beghi E, Blake N, et al. . [doi: 10.1016/S1474-4422(18)30499-X] [Medline: 30879893]
2. GBD 2017 US Neurological Disorders Collaborators, Feigin VL, Vos T, Alahdab F, Amit AML, Bärnighausen TW, et al. Burden of neurological disorders across the US from 1990-2017: a global burden of disease study. JAMA Neurol 2021 Feb 01;78(2):165-176 [FREE Full text] [doi: 10.1001/jamaneurol.2020.4152] [Medline: 33136137]
3. Neurodegenerative disease costs exceed $655 billion a year in medical expenses and economic losses. Partnership to Fight Chronic Disease. 2021 May 27. URL: https://www.fightchronicdisease.org/latest-news/neurodegenerative-disease-costs-exceed-655-billion-year-medical-expenses-and-economic [accessed 2022-07-26]
4. Luo Z, Lv H, Chen Y, Xu X, Liu K, Li X, et al. Years of life lost due to premature death and their trends in people with selected neurological disorders in Shanghai, China, 1995–2018: a population-based study. Front Neurol 2021;12:625042 [FREE Full text] [doi: 10.3389/fneur.2021.625042] [Medline: 33746880]
5. Carroll WM. The global burden of neurological disorders. Lancet Neurol 2019 May;18(5):418-419. [doi: 10.1016/S1474-4422(19)30029-8]
6. GO FAIR. URL: https://www.go-fair.org/fair-principles/ [accessed 2022-07-19]
7. Jupyter. URL: https://jupyter.org/ [accessed 2022-07-19]

XSL•FO
RenderX

Abbreviations

FAIR: Findability, Accessibility, Interoperability, and Reuse of digital assets
JNT: *JMIR Neurotechnology*

Edited by A Mavragani; submitted 15.07.22; this is a non–peer-reviewed article;accepted 19.07.22; published 11.08.22.

Please cite as:
Kubben P
JMIR Neurotechnology: Connecting Clinical Neuroscience and (Information) Technology
JMIR Neurotech 2022;1(1):e41122
URL: https://neuro.jmir.org/2022/1/e41122
doi:10.2196/41122
PMID:

©Pieter Kubben. Originally published in JMIR Neurotechnology (https://neuro.jmir.org), 11.08.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Neurotechnology, is properly cited. The complete bibliographic information, a link to the original publication on https://neuro.jmir.org/, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Design Innovation for Engaging and Accessible Digital Aphasia Therapies: Framework Analysis of the iReadMore App Co-Design Process

Tom Langford[1], MSc; Victoria Fleming[1,2], PhD; Emily Upton[1], MSc; Catherine Doogan[1], DClinPsy; Alexander Leff[1], PhD; Daniela M Romano[3,4], PhD

[1]UCL Queen Square Institute of Neurology, University College London, London, United Kingdom

[2]Department of Psychology and Language Sciences, University College London, London, United Kingdom

[3]School of Information Studies, University College London, London, United Kingdom

[4]Institute of Artificial Intelligence, School of Computer Science and Informatics, De Montfort University, Leicester, United Kingdom

Corresponding Author:
Tom Langford, MSc
UCL Queen Square Institute of Neurology
University College London
17-19 Queen Square
London, WC1N 3AZ
United Kingdom
Phone: 44 20 7679 1129
Email: thomas.langford.18@ucl.ac.uk

Abstract

Background: iReadMore is a digital therapy for people with acquired reading impairments (known as alexia) caused by brain injury or neurodegeneration. A phase II clinical trial demonstrated the efficacy of the digital therapy research prototype for improving reading speed and accuracy in people with poststroke aphasia (acquired language impairment) and alexia. However, it also highlighted the complexities and barriers to delivering self-managed therapies at home. Therefore, in order to translate the positive study results into real-world benefits, iReadMore required subsequent design innovation. Here, we present qualitative findings from the co-design process as well as the methodology.

Objective: We aimed to present a methodology for inclusive co-design in the redesign of a digital therapy prototype, focusing on elements of accessibility and user engagement. We used framework analysis to explore the themes of the communications and interactions from the co-design process.

Methods: This study included 2 stages. In the first stage, 5 in-person co-design sessions were held with participants living with poststroke aphasia (n=22) and their carers (n=3), and in the second stage, remote one-to-one beta-testing sessions were held with participants with aphasia (n=20) and their carers (n=5) to test and refine the final design. Data collection included video recordings of the co-design sessions in addition to participants' written notes and drawings. Framework analysis was used to identify themes within the data relevant to the design of digital aphasia therapies in general.

Results: From a qualitative framework analysis of the data generated in the co-design process, 7 key areas of consideration for digital aphasia therapies have been proposed and discussed in context. The themes generated were agency, intuitive design, motivation, personal trajectory, recognizable and relatable content, social and sharing, and widening participation. This study enabled the deployment of the iReadMore app in an accessible and engaging format.

Conclusions: Co-design is a valuable strategy for innovating beyond traditional therapy designs to utilize what is achievable with technology-based therapies in user-centered design. The co-designed iReadMore app has been publicly released for use in the rehabilitation of acquired reading impairments. This paper details the co-design process for the iReadMore therapy app and provides a methodology for how inclusive co-design can be conducted with people with aphasia. The findings of the framework analysis offer insights into design considerations for digital therapies that are important to people living with aphasia.

(JMIR Neurotech 2022;1(1):e39855) doi:10.2196/39855

XSL•FO
RenderX

KEYWORDS

aphasia; reading impairment; co-design; framework analysis; speech and language therapy; digital health; accessibility

Introduction

Background

Alexia is an acquired impairment of the ability to read, typically caused by a focal brain injury, such as that resulting from a stroke. People with alexia read slowly with substantial effort and make frequent word-based errors [1]. Some people experience alexia without other language impairments (pure alexia). More commonly, alexia occurs as part of a generalized language disorder known as aphasia, where the other domains of language (speaking, listening, and writing) may also be impaired. A third of stroke survivors develop some form of aphasia [2], and two-thirds of people with aphasia present with alexia [3]. The loss of reading ability can preclude many areas of life participation, such as socializing, working, and living independently. It is therefore not surprising that people with alexia report feelings of loss, frustration, and dissatisfaction [4,5].

Aphasia rehabilitation requires substantial hours (ranging from 20 to 100+ hours) of therapy to improve language abilities significantly [6-9]. Health care providers, however, are not always able to provide the level of specialized rehabilitation services required, and the National Health Service offers, on average, only 12 hours of aphasia therapy [10,11]. Perhaps unsurprisingly, almost half of stroke survivors report feeling abandoned following hospital discharge [12,13].

With an estimated 80 million stroke survivors globally as of 2016 [14] and an expected 25% increase in the number of stroke survivors by 2035 [15], there is a substantial need for health care providers to increase capacity for stroke rehabilitation services in order to meet the growing clinical demand. The adoption of digital technologies may offer a feasible solution to increasing individual therapy doses and may enable scalability to meet the increased service demands of larger stroke survivor populations in the years to come.

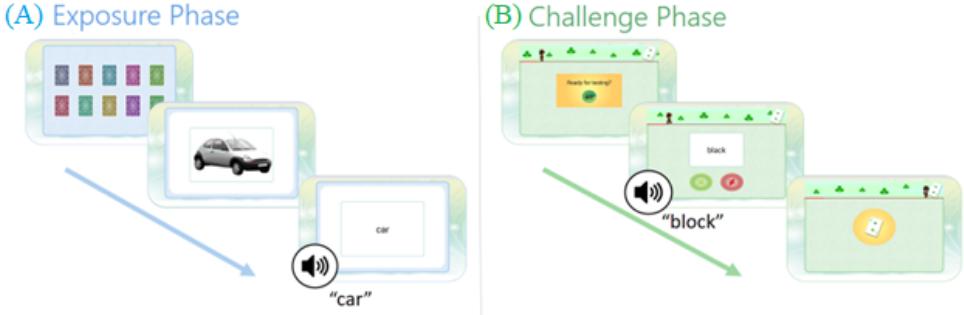
iReadMore

iReadMore is a rehabilitation app that delivers single word reading therapy to train both reading accuracy and speed. It is intended to be used independently at home by people with alexia. The therapy involves mass practice of spoken-to-written word matching challenges with elements of gamification. The therapy has 2 phases (exposure phase and challenge phase). In the initial exposure phase, the user views 10 flashcards displaying congruent pairings of a written word, spoken word, and image. Following this, in the challenge phase, the user must decide whether a written word and a spoken word presented in unison are congruent or incongruent by clicking 1 of 2 buttons. The iReadMore therapy algorithm includes multiple parameters that personalize the difficulty level to suit the users' reading abilities and keep the therapy challenging over time. This is achieved by altering the words that are presented in the therapy, the difficulty of each trial, and the amount of reading time provided for each trial. Figure 1 presents images of the therapy phases as seen in the trial version (prior to co-design). In this version, users did not receive information on their progress, such as reading test performance or therapy dose achieved.

A randomized controlled trial with 21 participants with poststroke alexia showed that iReadMore significantly improved word reading speed and accuracy following 4 weeks of therapy with an average dose of 34 hours, using the prototype app presented in Figure 1 [16]. Further research revealed that the therapy strengthened neural connectivity within the reading networks of stroke survivors [17].

Impairment-based interventions (such as iReadMore) can be effective and are well supported by a sound evidence base. However, the repetitive nature of these therapies can lead to some therapy users becoming disengaged or frustrated [18]. In the iReadMore trial, participants demonstrated significant clinical gains, and received support and motivation from the research team throughout the trial. However, informal feedback from participants highlighted the repetitive nature of the therapy and the low user acceptability of the app design. This put into question the ecological validity of the findings as a self-managed therapy. By employing a co-design approach to redesign the iReadMore app, we intend to innovate an effective therapy that is also accessible and engaging for users.

Figure 1. Therapy flow in the original iReadMore app design (prior to co-design). (A) Exposure phase that includes congruent pairings of written and spoken words on flashcards. (B) Challenge phase that includes both congruent and incongruent trials. In this example, there is an incongruent pairing of a written word and a spoken word, and the user would respond correctly by clicking the red "does not equal" button. The speaker icon denotes audio information.



XSL•FO
RenderX

Co-Design, Aphasia, and Digital Technology

Motivation is a key contributing factor in the success of stroke rehabilitation. For a self-managed therapy, maintaining long-term user motivation is vital to achieving the high therapy doses that are needed for therapeutic improvements [19,20]. A number of barriers to the uptake of digital therapies for people with aphasia are related to their communication impairment, co-morbidities, and level of prior experience with digital technologies [21,22]. One approach that can be used to improve the acceptability and accessibility of a therapy is to design it with the target user demographic, and this is known as co-design.

Co-design has been used in a number of digital applications for poststroke aphasia therapy in recent years [23-26]. EVA Park is an example of a co-designed therapist-led therapy delivered in an online virtual environment. It was found that users responded positively to the novelty of the co-designed therapy, as evaluated in terms of both a zero percent therapy dropout rate [24] and high acceptability deduced from qualitative interviews [27].

The perspectives of individuals with aphasia on literacy therapies have been explored in a handful of studies. Kjellén et al concluded that therapy design should be conducted in collaboration with people with aphasia, taking account of their personal goals and incorporating therapies into their daily life in a meaningful context [4]. The researchers also highlighted that people with aphasia felt “mechanical” therapies were not motivating enough, and the therapy content and mechanism need to be meaningful and interesting in order to stimulate recovery. Therefore, an effort is required to make aphasia therapies functional and personally relevant.

Gamification

Gamification is an overarching term used to denote applying a diverse array of game design elements in nongame tasks in order to increase motivation and engagement. Increased levels of motivation can improve therapeutic outcomes for people with aphasia [19,20], and a number of studies have demonstrated positive clinical findings for aphasia therapies that were gamified [16,24,28-31]. Conroy et al reported anecdotally that users found their gamified therapy “especially engaging and motivating,” and the authors believed gamification contributed to the significant clinical gains by stimulating users’ executive and attentional functions, in addition to the speech production system, resulting in improved learning and retention [30].

More generally, a number of studies have found that commonly applied game design elements do not tend to appeal to older populations and can be regarded as either valueless or pressurizing [32,33]. However, the same game design elements will have different effects in different applications. Therefore, it is recommended to conduct context-specific research on gamification [34]. Despite the positive clinical findings mentioned previously, there is a lack of studies reporting on the views of people with aphasia regarding gamification in therapies. Thus, co-designing the gamification elements of therapy with the intended user group in the proposed research will provide further insights for developing self-managed therapies for people with aphasia.

Objectives

We aimed to use a co-design approach to highlight a novel method for the inclusive redevelopment of an existing prototype therapy into a functional engaging therapy app that can be delivered at home and used independently by a person living with acquired alexia. In particular, we aimed to focus on key aspects of the user experience, including accessibility, gamification, and therapy engagement. By publishing this research, we hope to add to the growing literature on inclusive co-design and provide a case study for how co-design can be conducted in an inclusive manner.

By using a framework analysis of the data collected, themes were generated to better understand the requirements and desires of the user groups, which will be applied to inform the development of our future digital aphasia therapies.

Methods

Participants and Recruitment

Participants were recruited using stratified purposive sampling with convenience sampling through research group and institutional mailing lists, and other individuals known to the participants in this study. Participants included people with chronic alexia and their partners or carers. We aimed to get a diverse group of participants by stratifying for age, gender, experience with digital devices, and commonly co-occurring stroke morbidities, such as physical, visual, auditory, and cognitive impairments.

Table 1 reports the participant demographics. Twenty-five participants took part in 1 of 5 co-design sessions (4-6 participants per group). Participants varied in age from 29 to 78 years (mean 57, SD 12 years), and 52% (13/25) were female. Of the 25 participants, 19 had central alexia (alexia and aphasia), 3 had pure alexia and hemianopia, and 3 were partners or carers of someone with acquired alexia. With regard to prior experience with technology, 19 participants had a smartphone or tablet and 6 never owned a smartphone or tablet. Moreover, 10 participants had gained substantial experience using one of our digital therapies in a previous clinical trial.

XSL•FO
RenderX

Table 1. Demographic data of the participants who participated in the co-design group sessions.

Demographic	Value (N=25)
Female sex, n (%)	13 (52)
Age (years), mean (range)	57 (29-78)
Diagnosis, n	
Central alexia (alexia and aphasia)	19
Pure alexia	3
No alexia (partner/carer)	3
Prior technology experience, n	
Has a smartphone or tablet	19
Has never owned a smartphone or tablet	6
Previous participant in digital therapy app research	10

Ethics Approval

Ethics approval for this study was granted by the University College London Research Ethics Committee (project ID: 15423/001). All participants provided written informed consent prior to commencement of the sessions.

Study Design and Setting

Five in-person co-design sessions were held between June 2019 and January 2020 at the Institute of Cognitive Neuroscience, University College London in an accessible location. The sessions were facilitated by a multidisciplinary team of speech and language therapists (SLTs; VF and EU), a clinical psychologist (CD), and a medical design engineer (TL). All facilitators had completed professional training in qualitative health research at University College London or had prior experience in facilitating focus groups with people with aphasia. An app developer also observed the sessions. Sessions were limited to 4-6 participants to allow for group discussions without restricting each participant's time to contribute. The number of sessions conducted was based on the iterative framework analysis process that was conducted after each session to reflect on whether subsequent sessions would be beneficial to further investigate the areas of interest. Sessions lasted between 1 and 2 hours, including breaks and time for refreshments. Further details are provided in Textbox 1.

Group discussions were held in a communal meeting room. When participants were testing the app prototypes, they could decide to do this in the meeting room using headphones or in a private side room, which provided less distractions. Semistructured questions were used to guide the discussions and were provided to all facilitators prior to the session. A framework analysis was conducted after each session to reflect on the discussions and develop the session guide and materials for the next session. Study reporting has been conducted in line with the COREQ checklist (Multimedia Appendix 2).

Textbox 1. Co-design focus group session structure.

Session structure

The content of the sessions varied, but all contained the following core structure:

1. Welcome and introductions (5-10 minutes): Participants are welcomed and introduced to one another. Facilitators introduce themselves, and basic participation tips for the sessions are provided.
2. iReadMore instructions (5 minutes): Instructions for using the therapy are delivered by a member of the research team using a presentation and live demonstration, followed by answering questions from the group. In later sessions, this was replaced by an instruction video co-designed by participants, which was tested for inclusion in the app.
3. Independent use of the app (10-15 minutes): Following this, the latest prototype version of iReadMore therapy was tested on an Android tablet device, followed by an open discussion of the first impressions of the therapy.
4. Group discussion/ideation (20-40 minutes): Afterwards, discussions would lead into a problem and idea generation session, using a preplanned semistructured session guide.
5. Refreshments and open discussion (20-40 minutes): Finally, participants were offered refreshments and were able to talk freely. This gave participants the time to make any further points they would like and ask further questions in a less structured manner.

Procedure and Co-Design

After participants were welcomed and provided informed consent, the aims of the co-design process were presented along with participation tips for the group discussion. Following this, participants tested the latest app prototypes by independently using the therapy with provided instructions. Facilitators would observe 1 or 2 participants' interactions with the app. Facilitators assisted participants if required and made notes on any difficulties they were encountering.

XSL•FO
RenderX

Discussions began by asking participants about their experiences of testing the therapy prototype. This would then lead into a semiguided discussion based on preselected topics targeting key aspects of the therapy design, settings, functionality, interface, accessibility issues, and motivational/gamification concepts. Issues or difficulties raised during the interaction with the app acted as starting points for the co-design process, and participants then collaborated with each other and the facilitators to generate potential design solutions to address these issues. Where participants had a difference of opinion on the value of a design concept, an effort was made by the facilitators to see whether it could be refined in a way that led to a consensus. In addition, the mechanism of action of the therapy was not altered in the co-design process, as this was previously demonstrated to be clinically efficacious [16]. If a co-design concept could potentially preclude therapy effectiveness or participation for other users (eg, for those with visual or hearing impairments), it was highlighted and withdrawn from the process. The participants' co-designed ideas were then developed further in collaboration with the research team and app developer using mock-ups and prototyping software, and taken to the following co-design session for the next group to try out.

In order to facilitate total communication and analysis of nonverbal output, the sessions were video recorded by 2 video cameras, and a variety of resources were available to participants, including paper, pens, visual analog mood scales, and printed visuals of the app. Questions to participants were also presented with visual aids to support comprehension. All notes and drawings made in the sessions were scanned and used alongside the video recordings and transcripts in the data analysis. To support the inclusion of participants with moderate to severe communication impairments, participants could bring a partner or carer, or be paired with a SLT to help facilitate participation. After the session, participants were contacted via phone or email to enquire if they had any further comments they wished to contribute.

Following the completion of the co-design group sessions, one-to-one beta-testing sessions were held to further refine the outcome of the co-design process and prepare the app for public release. This phase was conducted remotely due to the coronavirus pandemic. A further 25 participants were recruited through our mailing list and social media for the remote testing phase. Participants were provided with a tablet containing the iReadMore app or they downloaded iReadMore onto their personal device using the TestFlight app on iOS. Participants in this phase tested the app for a period ranging from 5 to 14 weeks and provided feedback on subsequent versions at monthly catch-ups and in between the assessments when issues arose.

Data Collection and Analysis

Video recordings, notes, and drawings from participants and facilitators were analyzed using framework analysis, which utilizes a process of iterative refinement of themes in a data-driven approach [35]. Transcripts were developed from the session videos for annotation purposes. Both the videos and transcripts were analyzed to ensure nonverbal data (such as gestures and expressions) were not lost in the transcription process. Framework analysis was selected for its suitability in analyzing qualitative data at a group level in research that has a specific goal-based intention, such as co-design. There are 5 interconnected stages in framework analysis, and these were conducted in this study as described in Textbox 2. The analysis was conducted in Microsoft Excel (Microsoft Corp) by 2 researchers. Where disagreements occurred over codes, the 2 researchers discussed their conflicting interpretations and aimed to reach a consensus, potentially generating new codes as a result. Data saturation was discussed by the 2 researchers coding the data, who jointly decided when saturation had been achieved based on no further themes and codes being generated after the focus groups.

Textbox 2. Framework analysis methodology.

Framework analysis

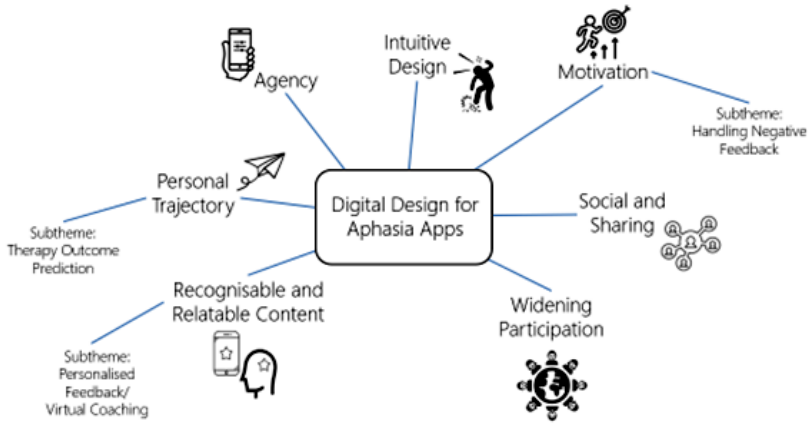
1. Familiarization: The data were studied in order to gain an insight into key concepts and recurrent themes. After each session, new data were analyzed. This allowed for initial codes and themes to be generated. After all sessions were complete, the data set was analyzed again in full.
2. Identifying a thematic framework: Emerging themes and subthemes were established and developed through discussions between the researchers. Data summaries were produced to represent the data in a succinct format.
3. Indexing: The generated codes and themes were applied to the data summaries. Although not part of the framework analysis, related quotes were also identified and sorted.
4. Charting: Data summaries were reorganized under the generated themes in the framework and rewritten in a more abstract manner to reflect the themes.
5. Mapping and interpretation: After charting, theme summaries were generated to represent the findings at a high level in the context of the research question. Descriptions and interpretations of the themes are presented below. Explanations and insights into the themes are considered in the Discussion section.

Results

The framework analysis generated 7 distinct themes of key considerations for the design of a digital intervention for aphasia rehabilitation. The themes generated were agency, intuitive design, motivation, personal trajectory, recognizable and relatable content, social and sharing, and widening participation. Figure 2 displays a thematic map of the themes and key subthemes. The complete list of app features generated in the co-design process is listed in Multimedia Appendix 1.

XSL•FO
RenderX

Figure 2. Thematic map displaying the themes and subthemes generated in the framework analysis of the iReadMore co-design process.



Theme 1: Agency

A prominent theme generated from the co-design process was to establish a stronger sense of agency for therapy users. Many participants mentioned the lack of control they felt in other aspects of their life as a result of their communication impairment and emphasized that restoring feelings of agency, even in small ways, was of significant value.

> *[On self-managed therapy] I think iReadMore is good because it gives X something for himself, something he can complete and be in control of, and I think that gives a big boost to his confidence.* [Partner of a stroke survivor with aphasia, 70-year-old female]

In practical terms, ways to increase agency that were suggested included giving users more control over therapy parameters and settings. Participants were interested in the workings of the therapy progression algorithm and suggested that an additional mechanism that allows users to adjust the therapy difficulty themselves would be valued as they could progress more easily to a difficulty level that suited them. Participants also preferred to decide their own therapy duration each day rather than have sessions of a fixed length. Further, it was mentioned that making the therapy easy to use without assistance would be empowering.

Notifications and pop-up reminders were viewed as superfluous and an annoyance, as users should know when to use the therapy and should know that performing the therapy is a significant activity in their daily lives, which should be motivated intrinsically by a desire to improve on their impairments. In specific circumstances, infrequent reminders would be more tolerable as long as they were providing useful information.

Theme 2: Intuitive Design

Simplicity of the app design and ease of use were important considerations. Regardless of whether participants were experienced technology users, there was a unanimous preference for an app that was easy to pick up. Participants reported that difficulty in starting with a new therapy can lead to feelings of frustration and helplessness. In terms of iReadMore, the initial lack of clarity around where to tap on the screen during the exposure phase of the therapy led some participants to doubt their ability to use the therapy unassisted, while others felt frustrated. To resolve this, it was decided that a stronger visual contrast between clickable and nonclickable content would be needed, along with additional audio instructions and the use of animations to highlight fields that need to be clicked if no interaction is detected.

> *I think if you didn't get it immediately, because for me if I can't get something because of … things. I tend to give up and try something I can do. Because it'll make me feel better [laughs]* [Stroke survivor with pure alexia, 46-year-old male]

> *[On being unsure how to use an app] wouldn't have … confidence … to ask for help* [Stroke survivor with aphasia, 65-year-old male]

To further simplify the app experience, a more linear flow was implemented with buttons always present in the same locations. The visual appeal of the app design was of little or no importance to the majority of participants. Alternative designs for the main menu that involved more immersive and visually stimulating experiences were viewed as visually cluttered or difficult to interpret, with concerns about learning to use a more complicated app independently. Instead, a simplified more functional navigation to the therapy, help section, and feedback graphs was largely preferred (Figure 3).

XSL•FO
RenderX

Figure 3. iReadMore main menu displaying therapy dose information; time to the next test; and buttons to start therapy, access help, and display statistics on therapy progress and test scores.

Theme 3: Motivation

Motivation unpinned many of the discussions in the co-design process. Participants thought that users of digital aphasia therapies do not need a lot of "bells and whistles," as they are highly (intrinsically) motivated by the desire to improve on their impairments and do not respond enthusiastically to many traditional features of gamification aimed at improving extrinsic motivation.

> *Colors make a big difference. For using everyday, I need something a bit fun.If it's a bit simple [gestures down with hands], but colors make it [gestures upward motion with hands]* [Stroke survivor with aphasia, 29-year-old female]

One facilitator asked the following question:

> *Would it be demotivating to get negative feedback?*

The response was as follows:

> *No, no. For me personally, if I'm getting it wrong but going forward, then I'm going forward … good for my understanding.* [Stroke survivor with aphasia, 56-year-old female]

Some did not understand the gamification concepts (such as points, high scores, avatars, and badges) or their intended purposes, while others felt they were not of value for this demographic.

Participants thought that features to support motivation were needed later in the therapy to maintain usage over weeks to months. They proposed that the main driver of motivation long term was the ability to track and interpret their own therapy progress using the in-app reading tests, which are completed after every 5 hours of therapy. Many styles of presentation for this information were discussed and prototyped. The final designs were highly visual, with minimal lexical information and multiple representations of the scores to increase accessibility (Figure 4).

Adding in visual novelty was seen as another way to maintain interest and denote progression through the therapy. Therefore, a number of designs were suggested, and finally, a travel-based concept with 10 destinations that users fly to around a 3-dimensional world was implemented (Figure 5). As such, when users complete 20 minutes of therapy, they visit a new destination. Users were advised to use the therapy for 30 minutes a day, so that they would visit a new location at least once a day at this rate. The destination backgrounds in the therapy were static to prevent distraction from the therapy task, and they acted as borders without text elements or animations.

The concept of receiving negative feedback was a key subtheme in the discussions of the workshops, with varied responses from participants. When asked about how they responded to the negative feedback, many believed it was acceptable and appropriate. Some thought it was key to motivating them to improve and was part of the process. However, 1 participant reported that he would like the option to hide the test results depending on his mood. The participant felt that being confronted by the impairment too often would be demotivating or upsetting, making him less likely to engage with the therapy. All agreed that being able to choose was a beneficial addition to the therapy, and as such, test results could be viewed by clicking on the "Statistics" button on the main menu (Figure 3).

XSL•FO
RenderX

Figure 4. iReadMore feedback graphs and personalized messages for (A) reading test accuracy and (B) training time. On the graph, the stickers denote each day where 30 minutes of therapy were completed.

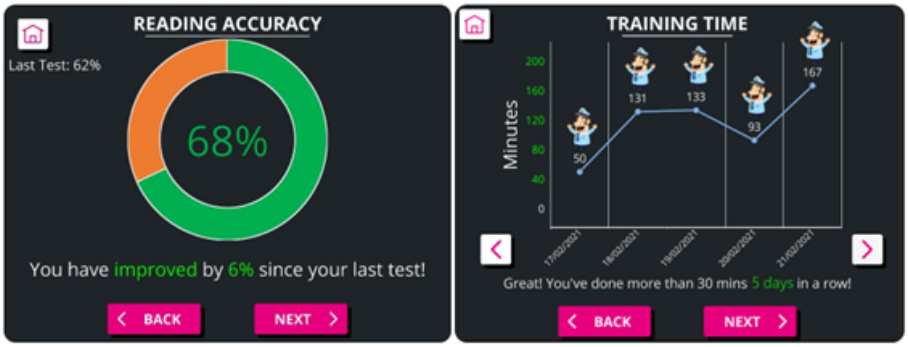


Figure 5. Therapy design travel concept.

Theme 4: Personal Trajectory

Clear and consistent perspectives from participants were that stroke survivors with alexia are on individual journeys of rehabilitation and that gamification concepts of competition, leaderboards, and other comparisons between users are viewed negatively and are seen as detrimental to user motivation. Collaboration was also seen as pressurizing due to negative feelings arising from letting others down. Instead, participants wanted to focus on their personal progress in the therapy through regular feedback and praise for consistent use of the therapy.

> *Everyone has a different rate of improvement … So therefore, you don't want to benchmark yourself against others… I think the challenge is with you and progressing where you are and what you can do.* [Stroke survivor with aphasia, 75-year-old male]

A subtheme of whether being able to predict an individual's future therapeutic outcomes was of value had a mixed response from the groups. There were concerns over inaccuracies as well as denial of service if it appeared it would not be beneficial. Participants reported they would prefer to try the therapy and decide whether it is not working for themselves or decide collaboratively with their clinician. However, it was also suggested that predictions could be a useful motivational tool to inspire users to continue progressing with the therapy if they were reported after the interval reading tests to motivate users to continue with the therapy. This concept will be explored further in future work looking into the feasibility of in-app therapy prediction.

Theme 5: Recognizable and Relatable Content

This theme relates to participants' preferences on how information is presented in the app. It was thought that a large proportion of digital therapies were designed with a young demographic in mind. However, a surprising outcome for the researchers was the pervasiveness and appeal of emoticons (emojis). Participants reported using emojis in place of words when they were having word-finding difficulties.

> *Because it feels quite young, it doesn't make you feel good about doing the exercise. It makes you feel like your level of understanding is lower* [Stroke survivor with pure alexia, 46-year-old male]

> *Yes, it suggests you're doing this at school and not as an adult. It needs to be something that we're accustomed to seeing and understanding.* [Stroke survivor with pure alexia, 78-year-old male]

Some participants did not understand or engage with the gamification concepts of points and scores. Further, some individuals had difficulty in number reading and found numerical scores distracting when incorporated into the therapy,

XSL•FO
RenderX

so these were removed. The numeric point system was replaced with visual and audio content delivered through an animated cartoon character (Figure 6) to provide immediate performance feedback on a therapy challenge.

Participants thought the language used in instructions in the app and guidance for using the therapy should be simple and unambiguous. A couple of participants referred to frustration from not receiving clear guidance on how to use a therapy effectively. The group felt that quantified realistic goals would inspire regular use and confidence that they are using the app correctly. Ambiguous guidance, such as "use the therapy as much as you can," was seen as unhelpful. One participant described that previous experiences of using therapies for long continuous periods in the first instances led to fatigue and would not be feasible longer term. On the other hand, clearer guidance, such as "use the app for 30 minutes a day," was seen as motivating, achievable, and providing evidence-based advice. Therefore, this was implemented in the app.

Exploration of implementing a virtual coach in the app received mixed feedback. Some participants thought this would distract from the therapy or overcomplicate what users would like to receive from the therapy. However, the implementation of personalized positive feedback without the embodiment of a virtual coach was unanimously supported. Examples of feedback included how often participants were using the app, their performance, and their overall progression in the therapy in terms of reading accuracy and speed test scores. Participants felt that once or twice a week was an appropriate frequency for these types of messages and that it needed to feel sporadic and related to their personal performance.

Figure 6. iReadMore character design and challenge phase feedback reactions.

Theme 6: Social and Sharing

Participants wanted to be able to share their therapy progress with personal contacts and clinicians. Many participants were eager to incorporate a screenshot, which they could share with their family and friends to share their therapy progression. One participant mentioned that it could help to act as an icebreaker and enable open discussion about their condition, something which they currently find difficult to do. Only a few participants wanted to be able to share this feedback on social media. Many wanted to share this information with close personal contacts, either in person or via email, text message, or a messaging app, such as WhatsApp.

> *When I finish and go 'yay!', I want to show my family. [Picks up phone and opens WhatsApp] I love send photos!* [Stroke survivor with aphasia, 60-year-old female]

> *Would be great to show to my therapist. That way she'll know that I'm actually doing the home practice! [laughs]* [Stroke survivor with pure alexia, 50-year-old female]

The other aspect of this theme was being able to share information with their clinicians, in particular, SLTs, or with facilitators and group members at their aphasia support groups. This was suggested as a feature that would be an additional benefit of using the app, as it could demonstrate their therapy compliance and progression, which could be used to report competence and willingness. Further, 2 participants mentioned that this could aid discussions with their clinical team over clinical decision-making, where the SLT could advise on whether the therapy is working for them.

Theme 7: Widening Participation

The final theme relates to accessibility barriers for digital therapies. Issues relating to usability of the app in the context of aphasia as well as prevalent co-morbidities, such as physical (hemiplegia and hemiparesis), visual (hemianopia, color blindness, and visual neglect), auditory (high frequency hearing loss), and working memory impairments were raised. Based on these, the groups developed design refinements that would make the app more accessible. For example, the app does not require using more than one finger to operate and does not need to be held while in use, buttons and important visual content are always located centrally on the screen, the words in the therapy are read out twice in both female and male voices, and if no response is detected, spoken instructions are repeated and, in some cases, highlighted on the screen through animations.

> *Can't do! When you first start, you need to focus on the word… and don't want distractions. Not for me with distractions, not for me.* [Stroke survivor with aphasia, 38-year-old female]

An early prototype used animations throughout the therapy trials to make it more visually stimulating; however, this prevented a number of participants from knowing where to focus on the screen and was regarded as a distraction. As a result, animations were limited to reporting feedback after the user has answered a trial, as a balance between making the therapy visually stimulating and minimizing distractions.

Another significant barrier to access arose from minimal prior experience with technology. Issues were related to the technical difficulties of setting up and using a tablet device, and downloading the therapy. In response, aphasia-friendly

XSL•FO
RenderX

instructions and frequently asked questions that were generated in the co-design process were integrated into the app. Participants wished to be able to contact the team directly for technical support or guidance. Therefore, an anonymous "Contact us" button was added to the "Help" section of the app. This allowed the research team to assist users whilst maintaining anonymity in line with our ethical approval and data security regulations.

Finally, concerns were raised over deploying the app solely on Android tablets as initially intended due to financial constraints. Some participants were unsure of what kind of device was required to use the therapy. The majority of the group did not have a tablet at home, and the minority that did were split between Apple devices and Android devices. As a result, the app was developed for Apple and Android phones and tablets.

Discussion

Overview

Conducting a framework analysis alongside co-design allowed for the dual development of app design and qualitative themes in a way that was synergistic and efficient.

The inclusive co-design methodology highlighted the need for a number of additional features in the app that had not been previously considered by the researchers. They arose from the designs and discussions of the participants, which were novel and informative. The iterative phases of co-design allowed us to not only capture the comments and reactions to a particular aspect of the app, but also verify that the redesign was congruent with the participants' expectations. In this way, co-design can be a useful tool for stepping out of the traditional paper-based or clinician-led therapy tasks and innovating new therapies that go beyond what is achievable without technology.

Themes

It was particularly pertinent for participants to promote a sense of agency in the therapy, which they may be lacking elsewhere. In the sessions, participants mentioned that not being able to use digital therapies, which are specifically aimed at their demographic, led to feelings of inadequacy and low competence, and prevented further engagement with those therapies. Recently, another study reported similar findings on the impact that digital technologies can have on feelings of agency and self-identity for people with aphasia [36]. On the other hand, digital therapies that can effectively be used independently were reported to have positive effects on personal empowerment and routine building.

The visual appeal of the app content was found to not be a primary concern for many participants. This finding is in contrast with previous findings on co-designed digital therapies, such as EVA Park [37] and GeST [25], both of which utilize immersive virtual worlds. We found that our participants preferred simpler navigation and intuitive app flow with less overtly gamified approaches to therapy. This could be due to fundamental differences in the therapy delivery, as EVA Park and GeST are SLT-led therapies for communication production. Co-design is by nature context-specific research, and therefore, it can be expected to produce contrasting findings for different applications. In our case, participants may have been prioritizing ease of use over immersion in the context of a self-managed therapy. However, visual (nonlexical) communication underpins many of the aspects on effectively communicating feedback through graphical or symbolic means.

Maintaining motivation was reported to be driven by intrinsic motivation and self-monitoring reading improvements through graphs or personalized messages. When participants were presented with variations of gamified therapy prototypes aimed at promoting extrinsic motivation, it was often felt that these alone would have little impact on their decision to use the therapy. The subtheme on receiving negative feedback was in contrast with the concept of errorless learning, which is often applied in rehabilitation technologies, and more in line with error-reducing learning [38]. However, it may be important to consider that people with aphasia who actively take part in research may display higher intrinsic motivation than those who do not. Many of these participants had taken part in previous studies involving highly gamified digital therapies, and this may have shaped their perspective. Therefore, the findings may not relate to the experience of people with aphasia and lower intrinsic motivation. In order to try and gain a wider perspective in future work, all users of the therapy will be able to anonymously provide qualitative feedback through the app.

Discussions on integrating recognizable and relatable content have similarities with design concepts being explored in other aphasia therapies, such as Web ORLA, which utilizes an embodied virtual therapist in the program [39]. Within the timeframe and financial limits available for this research, exploring the implementation of a virtual coach in iReadMore was deemed unfeasible, and personalized feedback on therapy usage and progress was seen as an appropriate alternative to this (Figure 4). There were also concerns it may lead to accessibility issues that could preclude some users from being able to engage with the therapy due to the technical and linguistic requirements of communicating with a virtual coach. Research exploring the feasibility of applying virtual coaches in rehabilitation for older adults, including people with aphasia, is ongoing [40]; however, this study also excluded those with global aphasia.

The emphasis on integrating social opportunities into the therapy is an understudied and somewhat underutilized concept in digital therapies at present, and participants generally felt this was a key area for improvement. This relates to previous research, which has found that people with aphasia tend to have a reduced social network and less frequent social interactions [41] while also experiencing an overall reduction in quality of life compared to stroke survivors without aphasia [42]. It was noted by the researchers that the participants who felt they would not want to see their own progress (as highlighted in the motivation theme) also did not want to share their progress with a clinician or friends and family. Their focus was on making the app independently and privately usable, whereas other participants wanted features that would enable real-world connections by sharing this information to prompt conversations about their condition with friends and family. Therefore, a balance is required to appeal to these conflicting perspectives. However, there are also a number of obstacles to integrating aspects of

XSL•FO
RenderX

the social and sharing theme into a digital therapy, including concerns of data security, regulatory affairs, content moderation, and the complexity of the design required, which will need to be considered.

The theme of widening participation has parallels to the findings of a recent clinical review of technology use in aphasia [43]. This survey revealed that people with aphasia are more likely to have access to a tablet device than a mobile phone or computer. However, the population assessed was currently receiving speech and language therapy, and it was more likely that the tablet was owned by the clinical service than the person with aphasia. Therefore, in order to reach people who are not currently receiving speech and language therapy, it is important to release the application on tablet and mobile devices across platforms, and in the future, it is important to develop a desktop version of the app.

A number of themes generated in this study have theoretical underpinnings in the self-determination theory [44,45]. The themes of agency, motivation, social and sharing, and personal trajectory all relate to fulfilling aspects of the fundamental psychological needs of autonomy, competence, and relatedness as proposed by the theory. This theory is often applied to health intervention and gamification research and has significant parallels with theories of motivation specific to aphasia rehabilitation literature, such as person-centered life participation [46], and social approaches [47] to aphasia intervention, which both have parallels with the social and sharing theme in particular.

Reflections and Future Work

This study reinforces the current literature on the ability to successfully conduct a co-design study with people with aphasia. A core component of the co-design process is establishing total communication techniques that enable participants to engage meaningfully. These techniques include incorporating drawing, writing, gesturing, visual aids, and emotion scales in the co-design sessions [48]. It can be beneficial to know the communication profiles of participants ahead of time in order to support specific communication needs and explore how participants can be best supported to contribute [49]. In addition, involving carers and partners in the co-design sessions can further enable effective communication, particularly for individuals with more severe impairments [50]. Finally, the technique of asking participants to consider the perspectives of other individuals with aphasia who they knew personally was particularly useful in addressing issues, which would form the basis of the widening participation theme. Participants were asked to think of other individuals they knew with alexia or aphasia, and were asked what would help make the therapy accessible and appealing to them. Additionally, participants were asked to reflect on other apps that they use for therapy purposes or use generally.

The implications of the COVID-19 pandemic led us to conduct testing remotely in people with aphasia using the therapy at home, with their own devices where possible. Testing the therapy in the same setting as it is intended to be used was highly valuable and enabled the inclusion of participants outside of our usual catchment area as an added benefit. Stratifying users by technology usage and prior participation in a digital therapy clinical trial was important for ensuring the development of an app that was accessible to first-time users while also remaining engaging after use for a substantial period of time required to achieve therapeutic gains. However, we found similar trends for both those with and without prior technology experience in wanting to prioritize the ease of use of the app over design novelty or complexity. This was in order for users to feel confident in using the app independently, as the frustration of not knowing what to do with a digital therapy was highlighted as a key reason for therapy disengagement.

Design changes as suggested here have been implemented into the app, and the app has been released on the Apple App Store and Google Play Store. A mixed methods roll-out trial (NCT04849091) has been started to evaluate the clinical effectiveness of the app for real-world users, with study registration and data collection being conducted entirely through the app. Further research will involve a trial of iReadMore in people with a reading impairment resulting from primary progressive aphasia, a language-led dementia [51].

Conclusions

This study offers tangible rationale to support the application of inclusive co-design procedures for persons with reading and language impairments, and elucidates the methods used. The findings of the framework analysis offer insights into design aspects that are important to people living with alexia and aphasia in the innovation of digital therapies. The co-designed version of the iReadMore app is available now for use in the rehabilitation of acquired reading impairments.

Acknowledgments

We would like to thank all participants in this study for their time, creativity, and enthusiasm. We would also like to thank Pedro Quijada Leyton (Quiley Ltd) for his meticulous work as the software developer of the iReadMore app. Funding for this project was provided by an MRC Industrial Collaborative Awards in Science and Engineering (iCASE) studentship held by TL (MR/R015759/1). The redevelopment of the iReadMore app was funded by a Research England Higher Education Innovation Fund grant (KEI2019-06-01). VF, EU, and AL were funded by a National Institute for Health Research (NIHR) award (NIHR-RP-2015-06-012). The views expressed in this publication are those of the authors and not necessarily those of the NIHR.

Conflicts of Interest

AL is the co-owner of the iReadMore therapy app and its related intellectual property along with University College London.

XSL•FO
RenderX

Multimedia Appendix 1
iReadMore design changes.
[PDF File (Adobe PDF File), 142 KB - neuro_v1i1e39855_app1.pdf]

Multimedia Appendix 2
COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist.
[PDF File (Adobe PDF File), 483 KB - neuro_v1i1e39855_app2.pdf]

References

1. Leff M, Starrfelt R. Alexia: Diagnosis, Treatment and Theory. New York, NY: Springer; 2013.
2. Feigin VL, Norrving B, Mensah GA. Global burden of stroke. Circ Res 2017 Feb 03;120(3):439-448. [doi: 10.1161/circresaha.116.308413]
3. Brookshire CE, Wilson JP, Nadeau SE, Gonzalez Rothi LJ, Kendall DL. Frequency, nature, and predictors of alexia in a convenience sample of individuals with chronic aphasia. Aphasiology 2014 Aug 12;28(12):1464-1480. [doi: 10.1080/02687038.2014.945389]
4. Kjellén E, Laakso K, Henriksson I. Aphasia and literacy-the insider's perspective. Int J Lang Commun Disord 2017 Sep 31;52(5):573-584 [FREE Full text] [doi: 10.1111/1460-6984.12302] [Medline: 28039933]
5. Webster J, Morris J, Malone J, Howard D. Reading comprehension difficulties in people with aphasia: investigating personal perception of reading ability, practice, and difficulties. Aphasiology 2020 Mar 15;35(6):805-823. [doi: 10.1080/02687038.2020.1737316]
6. Bhogal SK, Teasell R, Speechley M. Intensity of aphasia therapy, impact on recovery. Stroke 2003 Apr;34(4):987-993. [doi: 10.1161/01.STR.0000062343.64383.D0] [Medline: 12649521]
7. Brady M, Kelly H, Godwin J, Enderby P. Speech and language therapy for aphasia following stroke. Cochrane Database Syst Rev 2012 May 16(5):CD000425. [doi: 10.1002/14651858.CD000425.pub3] [Medline: 22592672]
8. Dignam J, Copland D, McKinnon E, Burfein P, O'Brien K, Farrell A, et al. Intensive versus distributed aphasia therapy: A nonrandomized, parallel-group, dosage-controlled study. Stroke 2015 Aug;46(8):2206-2211. [doi: 10.1161/STROKEAHA.115.009522] [Medline: 26106114]
9. REhabilitationrecovery of peopLE with Aphasia after StrokE (RELEASE) Collaborators. Dosage, intensity, and frequency of language therapy for aphasia: A systematic review-based, individual participant data network meta-analysis. Stroke 2022 Mar;53(3):956-967 [FREE Full text] [doi: 10.1161/STROKEAHA.121.035216] [Medline: 34847708]
10. Clarke DJ, Burton L, Tyson SF, Rodgers H, Drummond A, Palmer R, et al. Why do stroke survivors not receive recommended amounts of active therapy? Findings from the ReAcT study, a mixed-methods case-study evaluation in eight stroke units. Clin Rehabil 2018 Aug 27;32(8):1119-1132 [FREE Full text] [doi: 10.1177/0269215518765329] [Medline: 29582712]
11. Palmer R, Witts H, Chater T. What speech and language therapy do community dwelling stroke survivors with aphasia receive in the UK? PLoS One 2018 Jul 10;13(7):e0200096 [FREE Full text] [doi: 10.1371/journal.pone.0200096] [Medline: 29990345]
12. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, et al. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – A systematic review and meta-ethnography. PLoS ONE 2018 Feb 21;13(2):e0192533. [doi: 10.1371/journal.pone.0192533]
13. A New Era for Stroke. Stroke Association. URL: https://www.stroke.org.uk/get-involved/campaigning/new-era-for-stroke [accessed 2022-05-30]
14. Johnson C, Nguyen M, Roth G, Nichols E, Alam T, Abate D, et al. Global, regional, and national burden of stroke, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. The Lancet Neurology 2019 May 06;18(5):439-458 [FREE Full text] [doi: 10.1016/S1474-4422(19)30034-1]
15. Wafa HA, Wolfe CD, Emmett E, Roth GA, Johnson CO, Wang Y. Burden of stroke in Europe: Thirty-year projections of incidence, prevalence, deaths, and disability-adjusted life years. Stroke 2020 Aug;51(8):2418-2427 [FREE Full text] [doi: 10.1161/STROKEAHA.120.029606] [Medline: 32646325]
16. Woodhead Z, Kerry S, Aguilar O, Ong YH, Hogan JS, Pappa K, et al. Randomized trial of iReadMore word reading training and brain stimulation in central alexia. Brain 2018 Jul 01;141(7):2127-2141 [FREE Full text] [doi: 10.1093/brain/awy138] [Medline: 29912350]
17. Kerry SJ, Aguilar OM, Penny W, Crinion JT, Leff AP, Woodhead ZV. How does iReadMore therapy change the reading network of patients with central alexia? J. Neurosci 2019 May 13;39(29):5719-5727. [doi: 10.1523/jneurosci.1426-18.2019]
18. Kurland J, Wilkins AR, Stokes P. iPractice: piloting the effectiveness of a tablet-based home practice program in aphasia treatment. Semin Speech Lang 2014 Mar;35(1):51-63 [FREE Full text] [doi: 10.1055/s-0033-1362991] [Medline: 24449465]
19. Hallams S, Baker K. The development of a questionnaire to assess motivation in stroke survivors: a pilot study. New Zealand Journal of Physiotherapy 2009;37(2):55.
20. Cahana-Amitay D, Albert ML, Pyun S, Westwood A, Jenkins T, Wolford S, et al. Language as a stressor in aphasia. Aphasiology 2011 Apr 19;25(2):593-614 [FREE Full text] [doi: 10.1080/02687038.2010.541469] [Medline: 22701271]

XSL•FO
RenderX

21. Munsell M, De Oliveira E, Saxena S, Godlove J, Kiran S. Closing the digital divide in speech, language, and cognitive therapy: Cohort study of the factors associated with technology usage for rehabilitation. J Med Internet Res 2020 Feb 07;22(2):e16286 [FREE Full text] [doi: 10.2196/16286] [Medline: 32044752]
22. Menger F, Morris J, Salis C. Aphasia in an Internet age: wider perspectives on digital inclusion. Aphasiology 2015 Nov 07:1-21. [doi: 10.1080/02687038.2015.1109050]
23. Marshall J, Roper A, Galliers J, Wilson S, Cocks N, Muscroft S, et al. Computer delivery of gesture therapy for people with severe aphasia. Aphasiology 2013 Sep;27(9):1128-1146. [doi: 10.1080/02687038.2013.786803]
24. Marshall J, Booth T, Devane N, Galliers J, Greenwood H, Hilari K, et al. Evaluating the benefits of aphasia intervention delivered in virtual reality: Results of a quasi-randomised study. PLoS One 2016 Aug 12;11(8):e0160381 [FREE Full text] [doi: 10.1371/journal.pone.0160381] [Medline: 27518188]
25. Wilson S, Roper A, Marshall J, Galliers J, Devane N, Booth T, et al. Codesign for people with aphasia through tangible design languages. CoDesign 2015 Jan 09;11(1):21-34 [FREE Full text] [doi: 10.1080/15710882.2014.997744]
26. Messamer P, Ramsberger G, Atkins A. BangaSpeak: an example of app design for aphasia clients and SLP users. Aphasiology 2015 Oct 27:1-22. [doi: 10.1080/02687038.2015.1102856]
27. Amaya A, Woolf C, Devane N, Galliers J, Talbot R, Wilson S, et al. Receiving aphasia intervention in a virtual environment: the participants' perspective. Aphasiology 2018 Jan 26;32(5):538-558. [doi: 10.1080/02687038.2018.1431831]
28. Katz R. Computers in the treatment of chronic aphasia. Semin Speech Lang 2010 Mar 10;31(1):34-41. [doi: 10.1055/s-0029-1244951] [Medline: 20221953]
29. Des Roches CA, Kiran S. Technology-based rehabilitation to improve communication after acquired brain injury. Front Neurosci 2017 Jul 28;11:382 [FREE Full text] [doi: 10.3389/fnins.2017.00382] [Medline: 28804443]
30. Conroy P, Sotiropoulou Drosopoulou C, Humphreys G, Halai A, Lambon Ralph MA. Time for a quick word? The striking benefits of training speed and accuracy of word retrieval in post-stroke aphasia. Brain 2018 Jun 01;141(6):1815-1827. [doi: 10.1093/brain/awy087] [Medline: 29672757]
31. Fleming V, Brownsett S, Krason A, Maegli MA, Coley-Fisher H, Ong Y, et al. Efficacy of spoken word comprehension therapy in patients with chronic aphasia: a cross-over randomised controlled trial with structural imaging. J Neurol Neurosurg Psychiatry 2020 Nov 05;92(4):418-424 [FREE Full text] [doi: 10.1136/jnnp-2020-324256] [Medline: 33154182]
32. Gerling KM, Schild J, Masuch M. Exergame design for elderly users: the case study of SilverBalance. In: ACE '10: Proceedings of the 7th International Conference on Advances in Computer Entertainment Technology. 2010 Presented at: Advances in Computer Entertainment Technology Conference; November 17-19, 2010; Taipei, Taiwan p. 66-69. [doi: 10.1145/1971630.1971650]
33. Altmeyer M, Lessel P, Krüger A. Investigating Gamification for Seniors Aged 75+. In: DIS '18: Proceedings of the 2018 Designing Interactive Systems Conference. 2018 Presented at: Designing Interactive Systems Conference; June 9-13, 2018; Hong Kong, China p. 453-458. [doi: 10.1145/3196709.3196799]
34. Deterding S. Skill Atoms as Design Lenses for User-Centred Gameful Design. Gamification Research. URL: http://gamification-research.org/wp-content/uploads/2013/03/Deterding.pdf [accessed 2022-09-30]
35. Richie J, Spencer L. Qualitative data analysis for applied policy research. In: Analyzing Qualitative Data. London, United Kingdom: Routledge; 1994.
36. Taubner H, Hallén M, Wengelin Å. Still the same? – Self-identity dilemmas when living with post-stroke aphasia in a digitalised society. Aphasiology 2019 Mar 22;34(3):300-318. [doi: 10.1080/02687038.2019.1594151]
37. Marshall J, Devane N, Edmonds L, Talbot R, Wilson S, Woolf C, et al. Delivering word retrieval therapies for people with aphasia in a virtual communication environment. Aphasiology 2018 Jun 23;32(9):1054-1074. [doi: 10.1080/02687038.2018.1488237]
38. Middleton EL, Schwartz MF. Errorless learning in cognitive rehabilitation: a critical review. Neuropsychol Rehabil 2012 Apr;22(2):138-168 [FREE Full text] [doi: 10.1080/09602011.2011.639619] [Medline: 22247957]
39. Cherney LR, Lee JB, Kim KA, van Vuuren S. Web-based Oral Reading for Language in Aphasia (Web ORLA): A pilot randomized control trial. Clin Rehabil 2021 Jul 20;35(7):976-987. [doi: 10.1177/0269215520988475] [Medline: 33472420]
40. Kyriazakos S, Schlieter H, Gand K, Caprino M, Corbo M, Tropea P, et al. A novel virtual coaching system based on personalized clinical pathways for rehabilitation of older adults-requirements and implementation plan of the vCare project. Front Digit Health 2020 Oct 5;2:546562 [FREE Full text] [doi: 10.3389/fdgth.2020.546562] [Medline: 34713034]
41. Vickers CP. Social networks after the onset of aphasia: The impact of aphasia group attendance. Aphasiology 2010 Jun 07;24(6-8):902-913. [doi: 10.1080/02687030903438532]
42. Hilari K. The impact of stroke: are people with aphasia different to those without? Disabil Rehabil 2011 Sep 23;33(3):211-218. [doi: 10.3109/09638288.2010.508829] [Medline: 20712416]
43. Technology and Aphasia Review. Aphasia Rehab. 2018. URL: https://aphasia-rehab.slhs.uconn.edu/wp-content/uploads/sites/958/2019/03/technology-and-aphasia.pdf [accessed 2022-05-30]
44. Deci EL, Ryan RM. Intrinsic Motivation and Self-Determination in Human Behavior. New York, NY: Springer; 1985.
45. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. American Psychologist 2000;55(1):68-78. [doi: 10.1037/0003-066X.55.1.68]

XSL•FO
RenderX

46. Chapey R, Duchan J, Elman R, Garcia L, Kagan A, Lyon J, et al. Life Participation Approach to Aphasia: A Statement of Values for the Future. ASHA Leader. URL: https://leader.pubs.asha.org/doi/10.1044/leader.FTR.05032000.4 [accessed 2022-09-30]
47. Simmons-Mackie N. Social approaches to aphasia intervention. In: Chapey R, editor. Language Intervention Strategies in Aphasia and Related Neurogenic Communication Disorders. Philadelphia, PA: Lippincott, Williams & Wilkins; 2012:290-318.
48. Neate C, Orcid A, Neate T. Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In: CHI '19: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. 2019 Presented at: Conference on Human Factors in Computing Systems; May 4-9, 2019; Glasgow, Scotland, UK p. 1-12. [doi: 10.1145/3290605.3300880]
49. Wilson C, Kim ES. Qualitative data collection: considerations for people with aphasia. Aphasiology 2019 Nov 18;35(3):314-333. [doi: 10.1080/02687038.2019.1693027]
50. Prior S, Miller A, Campbell S, Linegar K, Peterson G. The challenges of including patients with aphasia in qualitative research for health service redesign: Qualitative interview study. J Particip Med 2020 Mar 07;12(1):e12336 [FREE Full text] [doi: 10.2196/12336] [Medline: 33064093]
51. Marshall CR, Hardy CJD, Volkmer A, Russell LL, Bond RL, Fletcher PD, et al. Primary progressive aphasia: a clinical approach. J Neurol 2018 Jun 1;265(6):1474-1490 [FREE Full text] [doi: 10.1007/s00415-018-8762-6] [Medline: 29392464]

Abbreviations

SLT: speech and language therapist

Edited by P Kubben; submitted 30.05.22; peer-reviewed by Z Zrubka, T Neate; comments to author 25.08.22; revised version received 16.09.22; accepted 22.09.22; published 18.10.22.

Please cite as:
Langford T, Fleming V, Upton E, Doogan C, Leff A, Romano DM
Design Innovation for Engaging and Accessible Digital Aphasia Therapies: Framework Analysis of the iReadMore App Co-Design Process
JMIR Neurotech 2022;1(1):e39855
URL: https://neuro.jmir.org/2022/1/e39855
doi:10.2196/39855
PMID:

©Tom Langford, Victoria Fleming, Emily Upton, Catherine Doogan, Alexander Leff, Daniela M Romano. Originally published in JMIR Neurotechnology (https://neuro.jmir.org), 18.10.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Neurotechnology, is properly cited. The complete bibliographic information, a link to the original publication on https://neuro.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Remote Consultations for People With Parkinson Disease and Cognitive Impairment: Interview Study With Patients, Caregivers, and Health Care Professionals

Jennifer Sarah Pigott[1]; Megan Armstrong[2]; Elizabeth Chesterman[1]; Joy Read[1]; Danielle Nimmons[2]; Kate Walters[2]; Nathan Davies[2]; Anette Schrag[1]

[1]Queen Square Institute of Neurology, University College London, London, United Kingdom

[2]Centre for Ageing Population Studies, Research Department of Primary Care and Population Health, University College London, London, United Kingdom

Corresponding Author:
Jennifer Sarah Pigott
Queen Square Institute of Neurology
University College London
Neurology Department, U3 Floor
Royal Free Hospital
London, NW3 2PF
United Kingdom
Phone: 44 2080168132
Email: j.pigott@ucl.ac.uk

Abstract

Background: The COVID-19 pandemic led to many consultations being conducted remotely. Cognitive impairment is recognized as a potential barrier to remote health care interactions and is common and heterogeneous in Parkinson disease. Studies have shown remote consultations in Parkinson disease to be feasible, but little is known about real-life experience, especially for those with cognitive impairment. We explored the experiences and perceptions of remote consultations for people with Parkinson disease and cognitive impairment.

Objective: This study aimed to explore the experiences of remote consultations for people with Parkinson disease and cognitive impairment from the perspective of service users and professionals and investigate considerations for future service delivery.

Methods: Semistructured interviews were conducted remotely with 11 people with Parkinson disease and cognitive impairment, 10 family caregivers, and 24 health care professionals (HCPs) between 2020 and 2021. Purposive sampling was used. Interviews were audio-recorded, transcribed, and analyzed using reflexive thematic analysis.

Results: Overall, four themes were identified: “the nature of remote interactions,” “challenges exacerbated by being remote,” “expectation versus reality,” and “optimizing for the future.” Remote consultations were considered as “transactional” and less personal, with difficulties in building rapport, and considered to play a different role from that of in-person consultations. The loss of nonverbal communication and ability of HCPs to sense led to remote consultations being perceived as riskier by all groups. Issues arising from communication and cognitive impairment, balancing the voices of the person with Parkinson disease and the caregiver, and discussions of the future affect this population specifically. Remote consultations were reported to have been more successful than anticipated in all 3 groups. Obstacles were not always as expected; for example, age was less of a barrier than predicted. Video consultations were perceived as being preferable to telephone consultations by many participants, but not accessible to all people with Parkinson disease. With widespread expectation of ongoing remote consultations, potential improvements for these 3 groups and health care services were identified, including practice, preparation, increased awareness of issues, expectation management by HCPs, and more time and flexibility for consultations.

Conclusions: Advantages and challenges of remote consultations for this population are identified. Consultations could be improved with increased support, practice, preparation, awareness of issues, and more time and flexibility within services.

(JMIR Neurotech 2022;1(1):e39974) doi:10.2196/39974

XSL•FO
RenderX

KEYWORDS

remote consultations; telehealth; telemedicine; Parkinson disease; cognitive impairment; Parkinson dementia; neurodegenerative condition; telephone appointments; video appointments; qualitative

Introduction

Background

On declaring COVID-19 as a pandemic in March 2020, the World Health Organization advocated strict social distancing and quarantine measures to avoid virus spread [1]. Health services rapidly used telemedicine to deliver care for many conditions, including Parkinson disease [2-6]. Telemedicine is the delivery of health care services, where distance is a critical factor, using information and communication technologies [7].

Parkinson disease is a heterogeneous neurodegenerative condition, affecting >6.1 million people globally, with rates rising [8]. People with Parkinson disease frequently experience cognitive symptoms [9], with impairment increasing with age and duration of disease: 80% of people with Parkinson disease have dementia by 20 years of disease duration [10].

Remote consultations (telephone or video call) are not completely new. Studies have shown feasibility of specialist consultations and delivery of therapy for people with Parkinson disease [11-15], and high rates of interest in telemedicine among people with Parkinson disease have been reported [16,17]. Patient perspectives have tended to be explored within research contexts, a qualitative survey within a US-based trial of Parkinson disease specialist internet-based visits collated feedback from specialist and patient participants [18]. They identified positive and negative perceptions driven by three themes: personal benefits (eg, lack of travel and frustration), perceived quality of care (eg, more frequent visits and technical troubles), and quality of interpersonal engagement (eg, liked the physician and difficult communication). Studies of remote consultations in Parkinson disease have predominantly been undertaken with educated, digitally literate samples, with digital resources provided and technical support available; therefore, little is known about real-life use. A recent study of neurologists' experiences of remote consultations (not Parkinson disease–specific) found perceived improved access and efficiency and an expectation that telemedicine will continue to be used beyond the pandemic. However, in-person consultations were not felt to be fully replaceable owing to great uncertainty when working remotely, technical and administrative problems, and "difficult consultations." Consultations reported as "difficult" included those with new patients and those with cognitive impairment and consultations requiring difficult decisions or significant discussions (eg, breaking bad news) [4]. A recent qualitative study exploring the impact of the COVID-19 pandemic on Parkinson disease management, from the perspective of people with Parkinson disease and health care professionals (HCPs), reported mixed reactions to remote consultations [19]. Most study participants were able to use internet-based technologies, which the authors acknowledged may be unrepresentative of the wider older population living with Parkinson disease, and cognitive impairment was not explored.

A qualitative study exploring the experiences of remote consultations for people living with non-Parkinson dementia and their carers identified various difficulties: the lack of prompts to remember problems, dealing with new emerging difficulties, rescheduling or missed calls, and inclusion of the voice of the person with dementia [20]. However, to the best of our knowledge, no studies have investigated remote consultations for people with Parkinson disease who have cognitive impairment. The combination of physical and cognitive impairments and the pattern of cognitive deficits in Parkinson disease differs from other types of dementia [21-24], which may convey different experiences and needs.

Objective

This study aimed to explore the experiences of remote consultations for people with Parkinson disease and cognitive impairment and investigate considerations for future service delivery.

Methods

Design

An exploratory qualitative design using semistructured interviews, analyzed using thematic analysis, with reporting guided by the Standards for Reporting Qualitative Research framework [25].

Ethics Approval

This study was approved by the London Queen Square Research Ethics Committee (18/LO/1470).

Sample and Recruitment

Overall, three groups of participants were recruited between October 2020 and July 2021: people with Parkinson disease and cognitive impairment, family caregivers, and HCPs working with this group. People with Parkinson disease and caregiver participants were purposively sampled to ensure representation of different clinical and social backgrounds in terms of age, ethnicity, education, living arrangements, duration of disease, and severity of impairments (functional and cognitive) managed through different health care services. Potential participants were identified through clinicians in primary and secondary care, or participants self-presented to the research team following charity sector advertisement. Additional recruitment sites were approached in more ethnically diverse areas to try to improve recruitment from ethnic minorities.

For HCPs, a range of different professional backgrounds was sought, working within different geographical areas and services, with a variety of experience of remote consultations. HCP participants were also identified through snowballing, using professional networks. HCP participants needed adequate experience of working with people with Parkinson disease to recall clinical encounters for discussion, but a range of expertise was sought. To represent the broad range of disciplines involved in the care of people with Parkinson disease [26], greater

XSL•FO
RenderX

numbers of HCPs compared with people with Parkinson disease and caregivers were required. All potential participants were screened for eligibility using inclusion and exclusion criteria presented in Textbox 1 and sent detailed information via post or email. All participants provided formal consent, in the form of written, digital, or audio-recorded verbal consent.

Textbox 1. Inclusion and exclusion criteria.

Inclusion criteria for people with Parkinson disease and cognitive impairment

- Diagnosis of idiopathic Parkinson disease made by a clinical specialist
- Cognitive symptoms, based on subjective report (participants reporting subjective cognitive symptoms, identified by a clinician as having cognitive impairment, were included even in absence of formal diagnosis because cognitive symptoms are common, but often missed in clinical practice [27]. Participants were not included if they denied cognitive symptoms despite a clinician identifying them, because it would not be appropriate to attempt detailed interview discussion of these symptoms with them)—described in lay terms as "changes in memory, thinking, concentration"

Exclusion criteria for people with Parkinson disease and cognitive impairment

- Care home residents
- Individuals with atypical Parkinsonian disorders
- Individuals anticipated to be approaching end of life

Inclusion criteria for caregivers

- A person who closely supported the person with Parkinson disease (person being supported must meet inclusion criteria mentioned previously)

Inclusion criteria for health care professionals

- A person working within or in collaboration with health care, who encounters people with Parkinson disease and cognitive impairment in a professional capacity

Data Collection

Topic guides were designed following a review of the literature and refined with multidisciplinary and patient and public involvement (PPI) input, to explore experiences and perceptions of remote interactions for health and social support. Interviews were conducted by JP (a geriatrician trained in qualitative research methods), via either telephone or video call. Interviews were audio-recorded and transcribed. Data collection continued until the team was confident that the breadth of representation and the depth of information obtained was sufficient to address the study's aim.

Analysis

Interviews were transcribed verbatim and analyzed using reflexive thematic analysis within a predominantly experiential qualitative framework [28,29]. The coding framework was generated following discussions among the team members, who had read a sample of transcripts; revised iteratively as it was applied to remaining transcripts (JP and EC); and presented for wide team review. Line-by-line coding was conducted using NVivo (version 12; QSR International) [30]. All extracts assigned to each code were reviewed and grouped to organize themes and further refined through discussion and interpretation with the research team and PPI. The multidisciplinary team included those with background in geriatric medicine (JP), nursing (EC and JR), psychology (MA, ND, and JR), neurology (AS) and general practice (DN and KW).

Results

Overview

In total, 11 people with Parkinson disease, 10 caregivers, and 24 HCPs were interviewed. Overall, 5 interviews were conducted as people with Parkinson disease–caregiver dyad interviews, with 10% (1/10) of the caregivers subsequently also interviewed alone. In total, 5 individual caregiver interviews were conducted where the people with Parkinson disease felt unable to participate. Overall, 47% (8/17) of interviews with people with Parkinson disease and caregiver were conducted via video call and 53% (9/17) via telephone call, with duration ranging from 41 to 121 minutes. Of the 24 HCP interviews, 21 (88%) were conducted via video call, 2 (8%) were via telephone call, and 1 (4%) was in person, with duration ranging from 41 to 98 minutes. All people with Parkinson disease (11/11, 100%) and caregiver participants (10/10, 100%) were from the Southeast or East of England; HCPs were from the Southeast of England, the Midlands, and Scotland. Demographic details about the participants are presented in Tables 1 and 2.

XSL•FO
RenderX

Table 1. Demographic details for people with Parkinson disease and caregivers.

Group and characteristics	Participants
People with Parkinson disease represented by interviews with people with Parkinson disease and caregivers (n=15)	
Age (years), mean (SD)	75.7 (8.2)
Sex, n (%)	
Male	9 (60)
Female	6 (40)
Ethnicity, n (%)	
White—British	12 (80)
White—other	1 (7)
Asian—Indian	1 (7)
Black—other	1 (7)
Duration of Parkinson disease (years), mean (SD); range	13.6 (6.7); 2-25
Cognitive impairment, n (%)	
Subjective symptoms, without formal diagnosis (varying severity)	8 (53)
Existing diagnosis of mild cognitive impairment	1 (7)
Existing diagnosis of dementia[a]	6 (40)
Educational background[b]	
Age at leaving full-time education (years), range	14-25
Schwab and England scale [31][c] (%), mean (SD); range	47.5 (30); 10-100
Living arrangements, n (%)	
Live with spouse or partner	6 (40)
Live with family	4 (27)
Live alone	5 (33)
Location, n (%)	
Urban or suburban	13 (87)
Semirural	1 (7)
Rural	1 (7)
Caregivers (n=10)	
Relationship, n (%)	
Spouse	5 (50)
Daughter	5 (50)
Age (years), mean (SD); range	62.8 (11.1); 46-78
Sex, n (%)	
Male	3 (30)
Female	7 (70)
Ethnicity, n (%)	
White—British	8 (80)
Asian—Indian	1 (10)
Black—Caribbean	1 (10)

[a]Of the 6 participants, 2 (33%) were interviewed directly, and for the remaining 4 (67%), interviews were conducted with caregiver only.

[b]Qualifications range from none through to degrees.

[c]Indicates degree of impairment, with 100% being independent and 0% being fully dependent.

XSL•FO
RenderX

Table 2. Roles of health care professional participants (n=24).

Professional role	Participants, n (%)
Parkinson disease nurse specialist	4 (17)
Neurologist	3 (13)
Geriatrician	3 (13)
General practitioner	3 (13)
Clinical neuropsychologist	2 (8)
Speech and language therapist—neurology services	2 (8)
Occupational therapist—memory service	1 (4)
Occupational therapist—movement disorders service	1 (4)
Physiotherapist—movement disorders service	1 (4)
Older adult psychiatrist	1 (4)
Mental health nurse—memory service	1 (4)
Palliative care physician	1 (4)
Charity sector—Parkinson's UK local advisor[a]	1 (4)

[a]Charity sector role to help people with Parkinson disease, including providing advice and information and supporting access to services.

Participants described the uses of remote communication technology in different aspects of their lives. All people with Parkinson disease and caregiver participants used telephones for personal communications; several of them had used video calls socially in the past, and all of them had used it during the pandemic. All people with Parkinson disease and caregivers had experienced telephone consultations, but only few of them had experienced video consultations; thus, they spoke about their experience of video technology in general. HCPs' experience of video consultations was varied, with most consultations conducted via telephone (experienced by all; 24/24, 100%). Although not the focus of discussion, some participants described the use of asynchronous email or SMS text message communication. All remote consultations had been a result of the pandemic, with a few now expressing it as a preference. Several caregivers for people with Parkinson disease with severe impairments explained that the people with Parkinson disease could not use the telephone or video themselves. All people with Parkinson disease and caregiver participants had established Parkinson disease; HCPs recalled experience of both new and established patient encounters. The interview discussions led to four themes: "the nature of remote interactions," encompassing subthemes "a transactional exchange," "is it real?" and "a risky process"; "challenges exacerbated by being remote," encompassing subthemes "communication and understanding," "interpersonal dynamics," and "significant discussions"; "expectation versus reality," encompassing subthemes "anticipated barriers" and "expected advantages"; and "optimizing for the future," encompassing subthemes "support for people with Parkinson disease and cognitive impairment and caregivers," "professional development," and "service improvement" (Textbox 2). Additional quotes from participants are provided in Multimedia Appendix 1.

XSL•FO
RenderX

Textbox 2. Themes and subthemes.

Theme 1

- The nature of remote interactions
- Subthemes
  - A transactional exchange
  - Is it *real*?
  - A risky process

Theme 2

- Challenges exacerbated by being remote
- Subthemes
  - Communication and understanding
  - Interpersonal dynamics
  - Significant discussions

Theme 3

- Expectation versus reality
- Subthemes
  - Anticipated barriers
  - Expected advantages

Theme 4

- Optimizing for the future
- Subthemes
  - Support for people with Parkinson disease and cognitive impairment and caregivers
  - Professional development
  - Service improvement

The Nature of Remote Interactions

Differences in the interaction via remote technologies were described, typically regarding the lack of physical contact (including examinations) and visual information and cues. The consequences are encompassed by three subthemes: "a transactional exchange," "is it real?" and "a risky process."

A Transactional Exchange

Participants described the "transactional" nature of remote consultations. Most participants, across the groups, felt that building rapport was more difficult remotely, which is exacerbated by technical issues. Some felt this improved over time with multiple consultations and with video over telephone. Many HCPs found it more difficult to manage people with Parkinson disease and caregiver emotions and offer reassurance remotely, for both video and telephone consultations. Many participants, particularly people with Parkinson disease, perceived the consultation as more automatic and functional, with less personalization:

> *I don't always feel that there is a proper dialogue. It's a question-and-answer sort of thing that goes on. But it sounds a bit mechanical. Sort a list of things to tick off.* [Person with Parkinson disease 1]

HCPs often attributed the dynamic to the lack of physical contact or visual interaction or environmental factors, affecting both telephone and video consultations, but more so with telephone consultation:

> *I think when they're with you in a room and they feel safe in that environment then they will talk to you more.* [HCP 25; occupational therapist; OT]

In contrast, people with Parkinson disease and caregivers were more likely to attribute this to the clinician's approach and style of questioning (such as checklists). They felt more rushed, thus sensing they were a burden:

> *I think it removes some of the pastoral nature of the role, because it feels like you're just taking up their time.* [Caregiver 2]

HCPs reported using techniques such as checklists and closed questioning, trying to overcome the difficulties of assessing remotely:

XSL•FO
RenderX

> *I have found a checklist works really well, because when you're trying to juggle the phone and the video or whatever, knowing I'm going through a checklist and I know where I am.* [HCP 19; neurologist]

Several participants reflected on a nebulous concept of human interaction, "hard to put into words" that is lost remotely, whether telephone or video consultation, leading to less "enjoyable" or "fulfilling" interactions. It is something more than just visual, related to "more dimensions of engagement" (HCP 24; palliative care physician) with physical presence. This affected satisfaction across participant groups.

Is It Real?

Some participants perceived remote consultation to take a different role than in-person consultation, with some HCPs observing that people with Parkinson disease did not "count" remote consultations, "they don't see it as a consultation" (HCP 21; Parkinson disease nurse specialist), but rather perceived them as an informal "chat" or "check-in," in some cases, as a "stepping-stone" to in-person consultation. This impression was substantiated across all groups by participants' language, contrasting remote consultations to "real life" (HCP 10; geriatrician) or referring to in-person consultations as being "properly seen" (caregiver 14). This was reported for both telephone and video consultations, but more emphasized for telephone consultations. Consequences of this were the impact on the professional-patient relationship. HCPs implied that they detected less respect for remote consultations:

> *But patients will say, "Yes, yes, that's fine. I can do that," and then they don't turn up [for the video call]. And I find they haven't even bothered to try. They've gone in the garden because, actually, it just seemed like too much bother.* [HCP 27; physiotherapist]

In contrast, a sense of distrust emerged from some people with Parkinson disease and caregivers:

> *They didn't say they got it [prescription] wrong. But I still don't know whether they, they had got it wrong. So there's that element in view of the virus, doing it all from arm's length...if I'm being honest, I wasn't totally sure that they were being that straight with me.* [Person with Parkinson disease 1]

A Risky Process

Participants from all 3 groups spoke of deficiencies in remote consultations, both telephone and video consultations, that generated anxiety. Several HCPs were concerned about the medicolegal standing and "unintentionally being negligent" owing to lack of "standardized procedure" (HCP 24; palliative care physician). Increased risk was described in relation to perceiving a high chance of error. HCPs universally reported difficulty in making assessments without the usual information, frequently citing the importance of physical examination or observing task performance for Parkinson disease and cognitive assessments, particularly in diagnostic contexts. Several participants were concerned about not getting the "full picture" remotely, where during in-person consultations, they would rely on different information streams (eg, verbal and nonverbal cues, observation, and examination) especially for complex cases. This could be moderately alleviated by good quality video consultations, but observation via video was frequently inadequate, and it still lacked hands-on examination. Some participants elaborated further, describing reliance on a "sense" for clinical judgments when in person:

> *As psychologists there is a lot of, you know, you can feel from people, you know, there is, kind of, actually, "I feel that you seemed quite upset when I said that," and that's sometimes difficult to do over Near Me [video conferencing] apparatus, as well. So, it's the kind of, non-spoken subtleties I think that you miss sometimes over the technology.* [HCP 18; neuropsychologist]

All participant groups were concerned that impairments could be concealed in remote consultations, which may have been identified in person. From the people with Parkinson disease and caregiver perspective, there was a sense of unease about HCP judgments relying on their symptom descriptions during telephone calls:

> *...Sometimes you get a doctor who I've never met, and you're talking to you over the phone. They've never met my father, and it's, it just feels a bit tenuous. Can you – can you really? It feels, it's too much responsibility to me. Have I described everything?* [Caregiver 2]

Further risk related to who is present for remote consultations: both expressing concern if consultations were unsupervised and the presence of unknown others (not visible during telephone consultation and out of view during video consultation). HCPs reported that people with Parkinson disease were potentially exposed to physical risk while performing assessment tasks or emotional vulnerability when discussing sensitive topics, if they are alone:

> *There have been occasions where patients with low mood do, kind of, talk about suicidal thoughts and things like that, in the hospital environment it feels safe enough to discuss those sorts of things, whereas, when you're not with the patient I wouldn't feel comfortable about those kinds of things with them.* [HCP 25; OT]

Some participants from each group questioned digital security, nonprivate health care work environments, and confidentiality with others on the call:

> *I just think that everyone seems to be talking at once at all times and you don't know who you're talking to as a GP, and it makes me feel a bit uncomfortable like who actually is in the room.* [HCP 13; general practitioner; GP]

Challenges Exacerbated by Being Remote

Participants described challenges in health care interactions driven by the condition, many of which were exacerbated by being remote. They were grouped into three subthemes: "communication and understanding," "interpersonal dynamics," and "significant discussions."

XSL•FO
RenderX

Communication and Understanding

The dual impact of physical (eg, quiet speech) and cognitive (eg, difficulty in multitasking and memory problems) symptoms of Parkinson disease impeded communication, sometimes compounded by, for example, hearing impairment. They led to problems for people with Parkinson disease in understanding and retaining information or instructions. HCPs described frustration at not being able to physically *show* people with Parkinson disease what to do or give hard copies of information leaflets as they would in person. These communication difficulties were felt to be even more challenging remotely, owing to unfamiliarity with technology for video and reliance on verbal communication for telephone:

> *I hate using the phone. I get on the phone and then I don't understand people.* [Person with Parkinson disease 6]

Some participants from each group described people with Parkinson disease finding it more difficult to keep up with conversation over remote communication methods (both video and telephone) owing to slowed speech, slowed processing, and forgetting:

> *He can't really remember what's been said, so he finds it difficult to process the information. So, having a telephone conversation with him is even more difficult than a face-to-face conversation.* [Caregiver 12]

Difficulties in sustaining engagement, perhaps related to concentration or apathy, were worse remotely owing to additional distractions and lack of eye contact. The pace of conversation needed to be slower. Breakdown of video feeds owing to unstable connections could interfere with communication and telephone pauses could be misinterpreted owing to lack of visual cues:

> *On the phone the other day there were these silences and I was thinking, have they not heard, are they shaking their heads or are they tutting, what's going on at the other end, you know, I had no idea, it was a bit unsettling.* [HCP 17; geriatrician]

For all types of remote consultation, the lack of usual contextual cues could lead to increased disorientation for the people with Parkinson disease—several HCPs described people with Parkinson disease forgetting the purpose of a call or who they were. The cognitive burden, and in some cases, associated anxiety, of remote consultations, particularly video consultations, was typically perceived as greater:

> *If there is cognitive impairment that's massive, actually, yes, that's quite a big deal because, again, the multiple stimuli that you have can confuse the conversation.* [HCP 24; palliative care physician]

However, this was not universal—a few participants described finding the familiarity of their own environment more relaxed and conducive to remembering and understanding:

> *You're in your own comfort zone and you absorb it better than what you do when you have to travel.* [Caregiver 3]

Interpersonal Dynamics

Although similar to in-person appointments, the additional communication and technical challenges of remote consultations led to increased need for people with Parkinson disease who had cognitive impairment to have caregiver support. In many cases, there was increased reliance on family or friends beyond a spousal care partnership to use remote technologies because caregivers also had difficulties. Many participants found that these increased support needs led to great tendency to exclude the person with Parkinson disease, either through the consultation being solely with the caregiver or the person with Parkinson disease being *spoken for* within a joint consultation:

> *I think the patient is a bit more cut out, and I'm aware of that, that when they're in the clinic and I talk to both, it's a bit more the carer but the patient is still there.* [HCP 19; neurologist]

Many participants appeared dissatisfied with this shift in dynamic. At times, it was implied or requested by the people with Parkinson disease, but by and large, it appeared to be automatic, that is, from perceived necessity:

> *...It's quite hard, because sometimes I feel like I could take over from it. I try not to; I try to get her to explain herself, but she does – I feel like she's not explaining herself properly. So I end up, OK, then I'll explain what I've seen to the doctor.* [Caregiver 15]

Significant Discussions

Diagnoses and prognoses were considered as potentially difficult conversations for HCPs delivering them and for people with Parkinson disease and caregivers receiving them. There was universal agreement that these should be conducted in person rather than remotely. Discussions about progression, the future, and advanced care planning were perceived by HCPs as difficult but important topics, particularly in this population. Most HCPs found them to be even more challenging through remote interactions:

> *It [talking about the future remotely] probably takes longer, in that people- it's probably slightly more intense, you can't soften it as much. Being in person you can probably soften those conversations a bit more and make them slightly less stark.* [HCP 8; GP]

The difficulties may even prevent them from being held:

> *I've been terrible at doing it [advanced care planning].* [HCP 14; neurologist]

Participants from all groups indicated that people with Parkinson disease and caregivers may feel less confident or secure to ask about the future in a remote consultation, with a few participants feeling that video consultation was marginally less of a barrier than telephone consultation:

> *Yeah...not on the phone I think...I think it's having the confidence to speak to them and if I've got any questions and the thought of really having something bad going on in your head, that's, that's the frightening bit.* [Person with Parkinson disease 3]

XSL•FO
RenderX

Expectation Versus Reality

With the rapid implementation of remote consultations owing to the COVID-19 pandemic, many participants reflected on what they had expected the experience to be compared with the reality. This is encompassed by two subthemes: "anticipated barriers" and "expected advantages."

Anticipated Barriers

Although participants reported their experiences critically by reporting challenges, most participants actually indicated being "surprised" at how well remote consultations had been experienced. They reported it being easier and more similar to in-person consultation than expected, for video consultation and even telephone consultation:

> *In some respects that's exactly what we would be doing when we saw them face-to-face.* [HCP 5; OT]

Across all groups, many participants anticipated older age to be a barrier to video consultations, but this was often not the case. Some HCPs indicated that older people with Parkinson disease had more reservations or difficulties with the technology, but most of them thought that the barrier was lack of experience or personality rather than age. The reported use of technology by the people with Parkinson disease and caregiver participants also suggested that familiarity was more relevant than age:

> *If it's not someone who's familiar with a computer, an iPad, for example, then it's all new learning and it's quite a lot of ask. But, if somebody is familiar with it and has been using it during their life, which lots of people have and do, irrelevant of age, actually, then there's a bit of that information already there.* [HCP 9; neuropsychologist]

However, there were some descriptions of remote technology being embraced more by young generations, owing to convenience:

> *It suits working people that they can just duck out, make a phone call and then they can go back to work.* [HCP 15; GP]

In addition, even if people with Parkinson disease owned and were familiar with digital devices, they may be anxious:

> *The fact is that they haven't got the confidence to press that button.* [HCP 12; Parkinson's UK advisor]

Cognitive impairment was not a universal barrier to using remote technology, but use rather depended on the degree of impairment and support provided. Difficulties with technology were reported across the participant groups, likely related to cognition. All except the people with Parkinson disease with severe impairment appeared to be able to undertake telephone consultations (some requiring support), but HCP participants had found that video consultations were less accessible for this population, and people with Parkinson disease and caregiver participants reported barriers to use of video calls in their personal lives. For some people with Parkinson disease, cognitive impairment prevented new learning, and even some individuals with past experience had lost their technological capability:

> *I just find anything I do, on a laptop or a computer, never seems to work out the way it's supposed to.* [Person with Parkinson disease 4]

Several issues that were described, such as lack of visual and touch information, although perceived as challenging, were not *as* restrictive as had been anticipated; more could be achieved remotely than expected. Universally, discussing potentially sensitive symptoms (eg, bowels or sexual function) remotely was not considered problematic:

> *I mean sensitive is sensitive.* [Person with Parkinson disease 1]

Ease of discussion was more dependent on the individuals involved, their relationship, and manner in which it was approached, rather than method of consultation; however, some topics, particularly mental health, were more difficult, typically owing to lack of rapport. However, across the groups, a few participants expressed opposing views, finding the remoteness helpful for sensitive topics:

> *I feel I can have quite probing conversations and not feel awkward. So maybe for me that layer of the subconscious awkwardness has been stripped off and therefore they can respond to that over the phone.* [HCP 10; geriatrician]

Expected practical barriers were sometimes a reality for all 3 groups (with regional variation in health care infrastructure), for example, poor quality connections or lack of digital device; however, they rarely prevented consultations. Over time, familiarity increased confidence, individuals overcame *some* reservations, and some reported improved quality of interactions:

> *It [telephone consultation] is quite different, but I think I've got used to it.* [Person with Parkinson disease 13]

Expected Advantages

Some advantages of remote consultations over in-person consultations, particularly for people with Parkinson disease and caregivers, were reported across the participant groups as having been a reality, including comfort ("Sitting here, he was relaxed" [caregiver 4]) and saving travel ("It did save us a long train journey" [caregiver 11]).

Expectations of improved efficiency and cost-effectiveness existed from participants ("I thought I would be quicker" [HCP 19; neurologist]), organizations ("Our practice thought that telephone consultations would be quicker" [HCP 13; GP]), and those in authority ("The government and stuff think this is going to save time" [HCP 11; neurologist]). However, HCPs were disappointed to find this was not the case, as more time was needed to circumvent limitations:

> *At times they're even taking a little bit longer because you haven't got your eyes on the patient and you can't reassure yourself that they look OK.* [HCP 13; GP]

In contrast, many people with Parkinson disease and caregivers still held this perception that HCPs were "freed up" by remote consultations:

XSL•FO
RenderX

> *And the doctor is quite busy anyway and I know with a phone call, it frees his time up a bit more.* [Caregiver 3]

Advantages of video consultations over telephone consultations were frequently described, such as the addition of visual information. Several people with Parkinson disease and caregivers who commented on telephone consultations felt that communication and rapport would improve with video. Some HCP participants with great expertise with video calls reported that with well positioned cameras, body language could be discerned and observational components of clinical examination could be conducted. It appeared that more specialist HCPs (neurologists, Parkinson disease nurse specialists, and neurotherapists) placed greater value in these advantages than generalists (GPs and geriatricians), who were less convinced that the benefits outweighed the obstacles:

> *I'm not getting that much extra information from a phone call to a video, generally.* [HCP 8; GP]

Although better than telephone consultation, many participants still felt that communication, rapport, observation, and examination over video consultations were inferior to those in in-person consultations. Subtleties may be lost, eye contact was not possible, field of view was incomplete, and breakdown in digital connection was disruptive.

Optimizing For the Future

Participants from all 3 groups anticipated that remote technology will continue to be used in health care beyond the pandemic and reflected on how that could best be navigated. Their suggestions cover three domains: "support for people with Parkinson disease and cognitive impairment and caregivers," "professional development," and "service improvement."

Support for People With Parkinson Disease and Cognitive Impairment and Caregivers

Given the range of potential barriers to remote consultations, participants felt that support needs should be tailored to the individual user:

> *Identifying why that person's a bit afraid of doing that, or put off by it, and then working with that.* [HCP 7; mental health nurse]

Participants described ways that practical help could be or had been beneficial, with greater need for help with video consultation than telephone consultation. For some people with Parkinson disease, support was required to initiate the call (video or telephone), then it could be undertaken independently; for others, technological checks or a trial run was helpful; and for many participants, troubleshooting technological issues was the priority. Some participants felt that technical training would be helpful, although capacity to learn may vary, and many felt this required a person to teach step-by-step:

> *It would be very nice if you could afford to have somebody in to teach you how to use things, to make it easier for yourself.* [Person with Parkinson disease 9]

Actions that people with Parkinson disease and caregivers could undertake to optimize the consultation were proposed, including practicing the technology and reflecting on their condition in advance:

> *Because you've got to be prepared. I did my research, I interviewed my mother beforehand, found out how she was feeling therefore what I wanted to know. So, I was ready for the call.* [Caregiver 10]

Ways for HCPs to support people with Parkinson disease and caregivers were raised. It was universally emphasized that they required time—to tackle communication barriers, provide explanations and reassurance, and allow for technological obstacles. Several HCPs described introducing the consultation with an explanation of the process and backup plan to reassure people with Parkinson disease:

> *I explain that all [back-up plans etc] but it's to reduce that anxiety, and I don't need to do that when I'm face-to-face, so that's taking up another ten minutes of my time.* [HCP 18; neuropsychologist]

Participants from across the groups felt that guidance was needed to set up optimally for video consultations, including camera position and choice of device (HCPs generally recommended laptops over telephones). HCPs described ways to maintain people with Parkinson disease–caregiver balance, such as agreeing a time for the caregiver to leave and ensuring both can be seen on video:

> *If you set up on a sofa with the iPhone pressed up against your face, which is what people often do, then that isn't very helpful really. Whereas if you were to have it on a table with a couple of chairs behind it so that you're getting a good view of the person, a good view of the relative, you can interact with both of them, and you can have some room behind them to get them to walk.* [HCP 11; neurologist]

Many participants described the existing instructions provided for using technology, but also felt that it needed simplification, and in some cases, written information was not sufficient:

> *Some of the information that is provided to help you solve problems that come along is not as clear as it might be...Partly language and partly generations I think. People who live in certain environments, in IT environments, learn to have their own language and think everyone else understands it.* [Person with Parkinson disease 1]

Professional Development

HCPs held varied views about training for remote consultations. Some felt that attitudes toward video consultation needed to change first, through better understanding of the benefits. Many participants identified an initial hurdle that required optimism and confidence to jump. HCPs recalled experiencing or witnessing improvement and increased confidence over time—a participant recalled having previously found video consultations "much harder" and "come out feeling quite tired" (HCP 11; neurologist), but this had improved:

> *I think a lot of it is just being familiar with what you're doing, being happy with using the technology*

XSL•FO
RenderX

> *and using your devices and so forth.* [HCP 11; neurologist]

Varying degrees of confidence in using technology were expressed. Some had received training on the digital platforms, many had picked it up through use, and others felt they needed training to get started. Similar to people with Parkinson disease, many HCPs desired ongoing support and troubleshooting rather than training. Although generally feeling confident using video technology themselves, several HCPs felt that they could not help patients if something went wrong at their end.

Beyond technology, some HCPs felt that remote consultations required the same skills as in-person consultations, whereas others felt that they demanded new trainable skills. Some of the techniques used for in-person consultations were described to be adapted for telephone and video consultations:

> *The same as phone consults; trying to build that rapport, the active listening skills, and you just need to be a little bit more pronounced in your active listening.* [HCP 13; GP]

Some HCPs described modifications to their consultations; for example, questions to remotely assess cognition or subjective reports of function where objective physical measures would have been used in person, but several participants desired a standardized approach:

> *What I would like: a validated video exam that we all get used to doing. It'd be nice to get a validated telephone exam.* [HCP 14; neurologist]

There was a sense among many HCPs that what an *optimal* remote consultation entailed remained unknown; several participants asked what other participants had said or described learning from colleagues. All participants, especially HCPs, shared recommendations for HCPs undertaking remote consultations, as summarized in Multimedia Appendix 2.

Service Improvement

Most participants across the groups favored a blended model for the future—in-person or remote consultations depending on context, necessitating changes to services to enable personalization. Participants described who remote consultations should be used for, how services need to adapt, what is needed to deliver a better service, and why improvement is needed.

Who?

Remote consultations were felt to be most suited for routine appointments for stable conditions and when a person with Parkinson disease.

HCP relationship already existed, whereas in-person consultations were thought to be better for complex cases or those experiencing complications and consultations involving significant discussions (eg, advanced care planning):

> *The only time you need to see a doctor, I think, if things are not going too well.* [Caregiver 3]

However, caution may be needed. Some people with Parkinson disease hypothesized that if their appointment were changed to in-person consultation, they would anticipate bad news:

> *Trouble is if the doctor says to you now, "come in and let's talk about it" then you start to worry even more.* [Person with Parkinson disease 5]

Overall, participants felt that the method of consultation should be tailored to the individual by assessing the pros and cons on a case-by-case basis; by considering the resource, access, and capability of the individual to use remote communication technology, in particular, considering their communication and cognitive symptoms, to ensure that value is added to their care; and based on the preferences of people with Parkinson disease and caregivers:

> *...For lots of things, it has been useful. And then for certain people, it's just not useful at all. So, it is again about thinking about the individual and what is potentially best for them.* [HCP 5; OT]

How?

Participants discussed how this can be operationalized, potentially using telephone triage and categorizing to consultation type. Several participants emphasized the importance of contingency planning, for example, being able to undertake in-person assessment if the remote consultation is unsuccessful.

For service delivery, all participants felt that having flexibility and adequate time was essential, with many HCPs emphasizing that remote consultations did not save time. Sometimes separate consultations for people with Parkinson disease and caregiver may be required, and some participants felt that more frequent appointments were preferable over very long ones to reduce the risk of tiring. Some HCPs had experienced problems of fixed scheduling, whereas others positively recounted flexible systems:

> *The nice thing about telephone consultation clinics is actually there's a bit more flexibility so we're not giving patients specific times of when they'll be called, we're giving them windows. So we can be slightly flexible if people then say, "No, can you call me at this time?"* [HCP 8; GP]

What?

There was evidence of variation in equipment availability, administrative support, and suitable environments across services, which correlated to the apparent success of remote consultations. Use of asynchronous remote communication, such as simple and responsive SMS text messaging and emails were valuable for some participants from all groups. Overall, the need for improvement to infrastructure was emphasized:

> *...Just making sure every computer you use has got the access to it all, I think that's really important.* [HCP 25; OT; Parkinson disease service]

Several participants across the groups reported issues related to people with Parkinson disease lacking simple and suitable devices for video calls. Many HCPs felt that the platforms currently used in health care settings needed to be improved. Many participants reflected that platforms popular for personal use, such as Zoom, Skype, and WhatsApp, were more easily managed and that familiarity could help in overcoming barriers:

XSL•FO
RenderX

> *People that had previously been a little bit, "oh, I'm not sure about the technology," realized they were quite capable of using Zoom, it was an easy platform.* [HCP 20; speech and language therapist]

Why?

The importance of improving services was emphasized by several participants, typically citing concerns about exclusion through "provision disparity" (HCP 8; GP) or competence and confidence in using them:

> *The people that do take the service up are probably the people that least need it.* [HCP 12; Parkinson's UK advisor]

Discussion

Summary

HCPs, people with Parkinson disease, and caregivers perceived remote interactions as more transactional, lacking personalization, and challenging for building rapport. They questioned whether remote consultations could be used as a substitute for *real* in-person consultations. Limitations of remote consultations were perceived, particularly, in conferring great risk. These issues were more prominently perceived for telephone consultation than video consultations, but existed for both modes of communication, with most participants considering them inferior to in-person consultations.

Issues for this population were intensified through remote technology, including communication and cognitive challenges, balancing people with Parkinson disease and caregivers within consultations, and significant discussions (eg, about the future). Perspectives had evolved, with some anticipated barriers not materializing (such as age being a restriction to access) and some expected advantages not coming to fruition (such as saving time). Although participants were generally surprised by the relative success of remote consultations and confidence in remote technologies was increasing, most participants still preferred in-person consultations. People with Parkinson disease, and caregivers, compared with HCPs had divergent perceptions about efficiency of remote consultations, with the former reporting them to improve efficiency and save time, but the latter typically rejected the notion of time being saved. Participants proposed ideas to improve services, anticipating a combination of remote and in-person health care consultations moving forward.

Context of Existing Literature

To the best of our knowledge, this is the first study to explore remote consultations for people with Parkinson disease in a real-life setting, to explore these 3 groups' perspectives, and to focus on people with Parkinson disease and cognitive impairment.

Both human and technical aspects of telemedicine have been identified as contributing to quality [32], which were also apparent in our study. Within Parkinson disease, telemedicine has been shown to be both feasible [11-14] and associated with high rates of satisfaction both in studies [13,14,18,33,34] and in the limited reports of real-life application [35,36]. Studies have been small and heterogeneous (eg, regarding frequency of consultation and whether telemedicine replaced or supplemented routine care) and produced mixed results regarding quality of life and clinical outcomes [37]. As such, effectiveness of remote models compared with in-person consultation remains inconclusive. The advantage of reduced travel burden for patients and the barriers from technological problems and limited physical examination have been consistently reported. Studies have recruited predominantly digitally literate, well-educated, White samples, which may not be representative of the wider population with Parkinson disease [37], and few studies report cognitive status. Studies typically provided equipment, software, and technical support, with consultations delivered by clinicians trained and experienced in telemedicine, which may not be applicable to standard clinical care models. This study gives insight into the real-life experiences of clinical remote consultations in a typically understudied population, within the UK National Health Service. An evolving body of literature, typically based on HCP reports of personal experience, offers tips to clinicians undertaking remote consultations [38-41]. This study bolsters this with the patient and caregiver perspective and nuance for this population.

Accounts of remote consultations as "transactional" are consistent with those reported in the study of other conditions and contexts [4,42]. An analysis of primary care telephone encounters found more biomedical information exchange than psychosocial communication, and the telephone consultations were a less patient-centered approach, which could be attributed to the short duration of interaction [42]; however, in our study, remote consultations were not thought to be shorter in this population. The relationship between duration and quality of consultation is debated [43,44]. Participants in our study strongly believed that more consultation time was beneficial, perhaps reflecting the condition complexity. However, the inconsistency suggests that loss of personability remotely is not purely time driven. A qualitative study of neurology consultations identified a "business-like" style and ability to "take control" in remote consultations, which were perceived as advantageous. However, the perception of the dynamic as "transactional" was portrayed as a *disadvantage* by people with Parkinson disease, caregivers, and some HCPs in our study. The reduced HCP enjoyment of interactions when remote resonates with reduced consultation satisfaction previously reported [4].

Although not widely reported previously, the perception of remote consultations as not being *real* resonates with a primary care study reporting that some people expected telephone encounters to determine if or when they would be seen in person [42]. This may be more pronounced in this study owing to the rapid shift to remote consultations during the pandemic and highlights the need to promote understanding of their purpose. The perception of increased risk with remote consultations is mirrored in studies of clinicians' perspectives within primary and secondary care [4,45]. The importance of observation and physical examination is particularly widely reported in neurology [4] and Parkinson disease [6,16,18]; however, there has been less attention to clinicians *sensing* clinical judgments, which was marked in our study. Clinicians' *sixth sense* has been

XSL•FO
RenderX

discussed in psychology and acute care patient safety literature [46], but perhaps is more widely applicable.

Communication problems in Parkinson disease are well known [47,48], and health communication research has long established the importance of nonverbal communication [49], which is unavailable in telephone consultations. Difficulties relating to memory and discussion being directed to caregivers with risk of exclusion of the patient themselves have been reported in remote consultations for dementia [20]. Cognitive impairments are widely perceived to be potential barriers to remote consultations [4,39,40,50]; consideration of mental capacity for suitability of remote consultation is highlighted in the UK General Medical Council guidance [51]. The effect of nonmemory cognitive impairments, such as executive dysfunction [52], alongside speech and behavioral symptoms, may create even more difficulty in sustaining complex discussions for people with Parkinson disease. This is particularly relevant for significant discussions (such as diagnoses and prognoses), which are difficult remotely, across disciplines [4,53].

In a recent study of remote primary care consultations for people with dementia [20], older age conferred more barriers, but this was not replicated in this study, where mixed experiences were reported, but not predictable from age. Instead, familiarity with technology was a facilitator; however, those with more significant cognitive impairment may have lost digital skills and confidence or be unable to transfer it to a new context. Increased confidence with remote consultations over time has been recognized during the pandemic [45,54], thus supporting the concept of practice. Advantages regarding convenience and comfort for remote consultations appear widespread [4,6,53], but perhaps more so in Parkinson disease owing to exacerbation of symptoms with stress [55,56]. A qualitative study of the effects of the COVID-19 pandemic, which touched on remote consultations [57], and another study of experiences of people with Parkinson disease and HCPs regarding Parkinson disease management during the COVID-19 pandemic [19] similarly found mixed opinions of remote consultations. In the latter, several HCPs reported improved service efficiency, which was not experienced by the HCP participants of our study. This may be a particular issue for those with cognitive impairment, which was not explored as a factor in either of these studies.

The need for evolution of platforms, infrastructure, and resource within clinical health care systems such as the National Health Service, while preventing health inequalities, corresponds with other UK-based studies of remote consultations [4,53,54], but with specific needs of this population: time, simplicity, and flexibility. Flexibility is recognized to be necessary in delivering personalized care [58]. The expectations of remote consultations are varied, and importantly, perceptions of efficiency and saving of time differed among people with Parkinson disease and caregivers, compared with HCPs. This discrepancy may lead to dissatisfaction on both sides. Our findings highlight that *cognitive impairment* covers a range of abilities and support for individuals varies; therefore, blanket procedures will not be appropriate. The barriers to remote consultations were mostly portrayed as *challenges* rather than absolute *disadvantages*, perhaps owing to the expectation that remote models of care will continue and the hope that these issues can be surmounted.

Strengths and Limitations

This is the first study including an underrepresented population (people with Parkinson disease and cognitive impairment) and triangulating the perspectives of patients, caregivers, and HCPs. Conducting the study remotely enabled inclusion of health services from multiple geographical areas, and snowballing enabled a wide reach, but may have predominantly reached individuals with specific interest in the topic. Inclusion of participants with subjective cognitive symptoms rather than a formal diagnostic process prevented being restricted by underdiagnosis, which is a recognized problem [27]. However, we cannot formally consider interpretation by objective severity of impairment. As has been a long-standing issue in Parkinson disease research [59], challenges were faced in recruitment of ethnic minority participants, despite targeted efforts, which may limit the applicability of the findings to these groups. Clinical audit data show 92% of people with Parkinson disease in neurology and Elderly Care Services in the United Kingdom to be White individuals [60], but even the use of primary care recruitment in ethnically diverse areas did not increase the diversity of our participants. Validity of interpretation was ensured through PPI consultation and a multidisciplinary clinical and academic team.

An unavoidable challenge of research in this population is that the condition often causes communication difficulties. Some participants had difficulty in expressing their views, and caregivers proxy views could be biased. Individuals who are not comfortable or able to communicate via telephone or video or with limited English language skills may be underrepresented. Although the range of professional backgrounds represented brings richness to these data, it is important to recognize regional variation in health services [61]; many people with Parkinson disease will not routinely encounter this range of specialist professionals [62]. The study was conducted within the United Kingdom and may not be representative of health services in other countries.

Implications for Clinical Practice and Research

This study adds to the literature on remote consultations, with consideration to this subset of patients and caregivers. Although it was clear that care and consultation method needs to be personalized to the individual, awareness of these issues and the suggested improvements can help to manage expectations and optimize remote interactions, as summarized in Textbox 3. Future studies should continue to evaluate remote service delivery in real life as it evolves and as the pandemic situation changes. Further studies on advantages of video consultations over telephone consultations and on asynchronous remote e-consultations with people with Parkinson disease would also be valuable.

XSL•FO
RenderX

Textbox 3. Key messages for clinical practice.

Lessons for health care professionals (HCPs)

- HCPs should be aware of the perceived transactional nature of checklists and closed questions.
- HCPs should be aware of potential exclusion of the voice of people with Parkinson disease.
- Pauses by telephone can be difficult to interpret, but caution must be taken to not interrupt as they may need more time for communication.
- Manage expectations, clarify the role of the consultation, and offer reassurance and a backup plan.

Tips for people with Parkinson disease and caregivers

- Practice using the technology and platform in advance.
- Preparation can improve the quality of consultation:
  - Reflect and record points for discussion in advance.
  - Optimize the environment and device used for the consultation.
- Inform the health care providers about the better times for your condition, eg, when medication is working best.

Considerations for service design

- Written guidance for remote consultations may not be sufficient to enable use. Guided use of technology may be necessary for people with Parkinson disease and cognitive impairment and caregivers.
- Services should be flexible, enabling individually optimized timing and communication methods for interactions and avoiding exclusion of those with impairments that affect use of remote interactions.
- Platforms for remote consultations should be simplified by using familiar concepts from those widely used for personal communications.
- Telemedicine should not be assumed to be quick or more efficient—more time is needed for consultations with this population; however, this may be best achieved through increased frequency of appointments to minimize risk of tiring in very long appointments.

Conclusions

Many advantages and challenges of remote consultations are universal, but there are some specific issues to consider for those with cognitive impairment in Parkinson disease, owing to the combination of physical and cognitive symptoms and psychological factors, such as exacerbation of impairments because of anxiety. HCPs, people with Parkinson disease, and caregivers perceived remote interactions as more transactional, lacking personalization, challenging for building rapport, not *real* consultations, and riskier owing to their limitations. This applied particularly to telephone consultations, but also to video calls, to a lesser extent. Access and technical barriers limited the use of video consultations. In contrast to perceptions of people with Parkinson disease and caregivers and reports in previous studies of people with Parkinson disease, HCPs denied time being saved with the change to remote consultations.

Although challenges and descriptions of negative experiences were universal, in practice, remote consultations had worked better than expected by many participants, and some anticipated barriers were not actually experienced; for example, many older people were unexpectedly accessing consultations remotely. These experiences should be considered when planning future remote health care for people with Parkinson disease.

Acknowledgments

The authors would like to thank the patient and public involvement group for their input in this study: Karla Lee, Maria Carmody, Mary Carmody, Anne Godfrey, and Ruth Green. They contributed throughout the project, providing input at conceptualization and advice and review of topic guide questions, participant information, recruitment, interpretation of findings, and summaries of the project. The authors would also like to thank all participants of the study. This report is independent research funded by the Rosetrees Trust, Royal College of Physicians (RCP-2020\11), National Institute for Health Research (NIHR; Program Grants for Applied Research; Personalized care for people with Parkinson's Disease: PD-Care, RP-PG-1016-20001), and NIHR School of Primary Care Research (SPCR-2014-10043). The views expressed in this paper are those of the authors and not necessarily those of the National Health Service, NIHR, or Department of Health.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional quotes from participants.

XSL•FO
RenderX

[DOCX File , 35 KB - neuro_v1i1e39974_app1.docx]

Multimedia Appendix 2
Recommendations for health care professionals undertaking remote consultations.
[DOCX File , 17 KB - neuro_v1i1e39974_app2.docx]

References

1. Archived: WHO Timeline - COVID-19. World Health Organization. 2020 Apr 27. URL: https://www.who.int/news/item/27-04-2020-who-timeline---covid-19 [accessed 2022-11-02]
2. Fearon C, Fasano A. Parkinson's disease and the COVID-19 pandemic. J Parkinsons Dis 2021;11(2):431-444 [FREE Full text] [doi: 10.3233/JPD-202320] [Medline: 33492244]
3. Klein BC, Busis NA. COVID-19 is catalyzing the adoption of teleneurology. Neurology 2020 May 26;94(21):903-904. [doi: 10.1212/WNL.0000000000009494] [Medline: 32238505]
4. Courtney E, Blackburn D, Reuber M. Neurologists' perceptions of utilising tele-neurology to practice remotely during the COVID-19 pandemic. Patient Educ Couns 2021 Mar;104(3):452-459. [doi: 10.1016/j.pec.2020.12.027] [Medline: 33478853]
5. Hassan A, Mari Z, Gatto EM, Cardozo A, Youn J, Okubadejo N, International Telemedicine Study Group. Global survey on telemedicine utilization for movement disorders during the COVID-19 pandemic. Mov Disord 2020 Oct;35(10):1701-1711 [FREE Full text] [doi: 10.1002/mds.28284] [Medline: 32833273]
6. van den Bergh R, Bloem BR, Meinders MJ, Evers LJ. The state of telemedicine for persons with Parkinson's disease. Curr Opin Neurol 2021 Aug 01;34(4):589-597 [FREE Full text] [doi: 10.1097/WCO.0000000000000953] [Medline: 33990100]
7. A health telematics policy. World Health Organization. 1997. URL: https://apps.who.int/iris/bitstream/handle/10665/63857/WHO_DGO_98.1.pdf;jsessionid=0C545A06C77E006F462EB2BF4857A6A4?sequence=1 [accessed 2020-08-19]
8. Dorsey ER, Elbaz A, Nichols E, Abbasi N, Abd-Allah F, Abdelalim A, et al. Global, regional, and national burden of Parkinson's disease, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol 2018 Nov;17(11):939-953 [FREE Full text] [doi: 10.1016/S1474-4422(18)30295-3] [Medline: 30287051]
9. Todorova A, Jenner P, Ray Chaudhuri K. Non-motor Parkinson's: integral to motor Parkinson's, yet often neglected. Pract Neurol 2014 Oct;14(5):310-322 [FREE Full text] [doi: 10.1136/practneurol-2013-000741] [Medline: 24699931]
10. Hely MA, Reid WG, Adena MA, Halliday GM, Morris JGL. The Sydney multicenter study of Parkinson's disease: the inevitability of dementia at 20 years. Mov Disord 2008 Apr 30;23(6):837-844. [doi: 10.1002/mds.21956] [Medline: 18307261]
11. Venkataraman V, Donohue SJ, Biglan KM, Wicks P, Dorsey ER. Virtual visits for Parkinson disease: a case series. Neurol Clin Pract 2013 Dec 04;4(2):146-152. [doi: 10.1212/01.cpj.0000437937.63347.5a]
12. Beck CA, Beran DB, Biglan KM, Boyd CM, Dorsey ER, Schmidt PN, Connect.Parkinson Investigators. National randomized controlled trial of virtual house calls for Parkinson disease. Neurology 2017 Sep 12;89(11):1152-1161 [FREE Full text] [doi: 10.1212/WNL.0000000000004357] [Medline: 28814455]
13. Korn RE, Shukla AW, Katz M, Keenan HT, Goldenthal S, Auinger P, et al. Virtual visits for Parkinson disease. Neurol Clin Pract 2017 Jun 13;7(4):283-295. [doi: 10.1212/cpj.0000000000000371]
14. Houston E, Kennedy AG, O'Malley D, Rabinowitz T, Rose GL, Boyd J. Telemedicine in neurology: a scoping review of key outcomes in movement disorders. Telemed J E Health 2022 Mar 01;28(3):295-308. [doi: 10.1089/tmj.2021.0117] [Medline: 34101518]
15. Hatcher-Martin JM, Adams JL, Anderson ER, Bove R, Burrus TM, Chehrenama M, et al. Telemedicine in neurology: telemedicine work group of the American academy of neurology update. Neurology 2020 Jan 07;94(1):30-38. [doi: 10.1212/WNL.0000000000008708] [Medline: 31801829]
16. Spear KL, Auinger P, Simone R, Dorsey ER, Francis J. Patient views on telemedicine for Parkinson disease. J Parkinsons Dis 2019;9(2):401-404. [doi: 10.3233/JPD-181557] [Medline: 31127732]
17. Dorsey ER, Achey MA, Beck CA, Beran DB, Biglan KM, Boyd CM, et al. National randomized controlled trial of virtual house calls for people with Parkinson's disease: interest and barriers. Telemed J E Health 2016 Jul;22(7):590-598 [FREE Full text] [doi: 10.1089/tmj.2015.0191] [Medline: 26886406]
18. Mammen JR, Elson MJ, Java JJ, Beck CA, Beran DB, Biglan KM, et al. Patient and physician perceptions of virtual visits for Parkinson's disease: a qualitative study. Telemed J E Health 2018 Apr;24(4):255-267. [doi: 10.1089/tmj.2017.0119] [Medline: 28787250]
19. Soilemezi D, Roberts HC, Navarta-Sánchez MV, Kunkel D, Ewings S, Reidy C, et al. Managing Parkinson's during the COVID-19 pandemic: perspectives from people living with Parkinson's and health professionals. J Clin Nurs 2022 May 17 (forthcoming) [FREE Full text] [doi: 10.1111/jocn.16367] [Medline: 35581711]
20. Tuijt R, Rait G, Frost R, Wilcock J, Manthorpe J, Walters K. Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers. Br J Gen Pract 2021 Aug;71(709):e574-e582 [FREE Full text] [doi: 10.3399/BJGP.2020.1094] [Medline: 33630749]

XSL•FO
RenderX

21. Sullivan EV, Sagar HJ, Gabrieli JD, Corkin S, Growdon JH. Different cognitive profiles on standard behavioral tests in Parkinson's disease and Alzheimer's disease. J Clin Exp Neuropsychol 1989 Dec;11(6):799-820. [doi: 10.1080/01688638908400937] [Medline: 2592525]
22. Litvan I, Goldman JG, Tröster AI, Schmand BA, Weintraub D, Petersen RC, et al. Diagnostic criteria for mild cognitive impairment in Parkinson's disease: movement disorder society task force guidelines. Mov Disord 2012 Mar;27(3):349-356 [FREE Full text] [doi: 10.1002/mds.24893] [Medline: 22275317]
23. Emre M, Aarsland D, Brown R, Burn DJ, Duyckaerts C, Mizuno Y, et al. Clinical diagnostic criteria for dementia associated with Parkinson's disease. Mov Disord 2007 Sep 15;22(12):1689-707; quiz 1837. [doi: 10.1002/mds.21507] [Medline: 17542011]
24. Williams-Gray CH, Evans JR, Goris A, Foltynie T, Ban M, Robbins TW, et al. The distinct cognitive syndromes of Parkinson's disease: 5 year follow-up of the CamPaIGN cohort. Brain 2009 Nov;132(Pt 11):2958-2969. [doi: 10.1093/brain/awp245] [Medline: 19812213]
25. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014 Sep;89(9):1245-1251 [FREE Full text] [doi: 10.1097/ACM.0000000000000388] [Medline: 24979285]
26. Pedersen S, Suedmeyer M, Liu L, Domagk D, Forbes A, Bergmann L, et al. The role and structure of the multidisciplinary team in the management of advanced Parkinson’s disease with a focus on the use of levodopa–carbidopa intestinal gel. J Multidiscip Healthc 2017 Jan;Volume 10:13-27. [doi: 10.2147/jmdh.s111369]
27. Meireles J, Massano J. Cognitive impairment and dementia in Parkinson's disease: clinical features, diagnosis, and management. Front Neurol 2012;3:88 [FREE Full text] [doi: 10.3389/fneur.2012.00088] [Medline: 22654785]
28. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
29. Braun V, Clarke V. Thematic Analysis A Practical Guide. Thousand Oaks, California: SAGE Publications; 2021.
30. NVivo 12 Pro. QSR International. URL: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home [accessed 2022-11-03]
31. Schwab RS, England AC. Projection technique for evaluating surgery in Parkinson’s disease. In: Third Symposium on Parkinson’s Disease. Edinburgh: Churchill Livingstone; 1969.
32. LeRouge C, Garfield M, Hevner A. Patient perspectives of telemedicine quality. Patient Prefer Adherence 2014 Dec:25. [doi: 10.2147/ppa.s67506]
33. Achey M, Aldred JL, Aljehani N, Bloem BR, Biglan KM, Chan P, International Parkinson Movement Disorder Society Telemedicine Task Force. The past, present, and future of telemedicine for Parkinson's disease. Mov Disord 2014 Jun;29(7):871-883. [doi: 10.1002/mds.25903] [Medline: 24838316]
34. Dorsey ER, Okun MS, Bloem BR. Care, convenience, comfort, confidentiality, and contagion: the 5 C's that will shape the future of telemedicine. J Parkinsons Dis 2020;10(3):893-897. [doi: 10.3233/JPD-202109] [Medline: 32538870]
35. Cilia R, Mancini F, Bloem BR, Eleopra R. Telemedicine for parkinsonism: a two-step model based on the COVID-19 experience in Milan, Italy. Parkinsonism Relat Disord 2020 Jun;75:130-132 [FREE Full text] [doi: 10.1016/j.parkreldis.2020.05.038] [Medline: 32723588]
36. Qiang JK, Marras C. Telemedicine in Parkinson's disease: a patient perspective at a tertiary care centre. Parkinsonism Relat Disord 2015 May;21(5):525-528. [doi: 10.1016/j.parkreldis.2015.02.018] [Medline: 25791380]
37. Ben-Pazi H, Browne P, Chan P, Cubo E, Guttman M, Hassan A, International Parkinson Movement Disorder Society Telemedicine Task Force. The promise of telemedicine for movement disorders: an interdisciplinary approach. Curr Neurol Neurosci Rep 2018 Apr 13;18(5):26. [doi: 10.1007/s11910-018-0834-6] [Medline: 29654523]
38. Duncan C, Macleod AD. Video consultations in ordinary and extraordinary times. Pract Neurol 2020 Oct;20(5):396-403. [doi: 10.1136/practneurol-2020-002579] [Medline: 32862137]
39. Rimmer A. I don't feel confident providing remote consultations. What do I need to know? BMJ 2020 Apr 30;369:m1746. [doi: 10.1136/bmj.m1746] [Medline: 32354876]
40. Nitkunan A, Paviour D, Nitkunan T. COVID-19: switching to remote neurology outpatient consultations. Pract Neurol 2020 May;20(3):222-224 [FREE Full text] [doi: 10.1136/practneurol-2020-002571] [Medline: 32366596]
41. Miele G, Straccia G, Moccia M, Leocani L, Tedeschi G, Bonavita S, Digital Technologies, WebSocial Media Study Group of the Italian Society of Neurology. Telemedicine in Parkinson's disease: how to ensure patient needs and continuity of care at the time of COVID-19 pandemic. Telemed J E Health 2020 Dec;26(12):1533-1536. [doi: 10.1089/tmj.2020.0184] [Medline: 32667839]
42. Innes M, Skelton J, Greenfield S. A profile of communication in primary care physician telephone consultations: application of the Roter Interaction Analysis System. Brit J General Practice 2006:363-368.
43. Campbell SM, Hann M, Hacker J, Burns C, Oliver D, Thapar A, et al. Identifying predictors of high quality care in English general practice: observational study. BMJ 2001 Oct 06;323(7316):784-787 [FREE Full text] [doi: 10.1136/bmj.323.7316.784] [Medline: 11588082]
44. Jenkins L, Britten N, Barber N, Bradley CP, Stevenson FA. Consultations do not have to be longer. BMJ 2002 Aug 17;325(7360):388 [FREE Full text] [doi: 10.1136/bmj.325.7360.388] [Medline: 12183315]

XSL•FO
RenderX

45. Murphy M, Scott LJ, Salisbury C, Turner A, Scott A, Denholm R, et al. Implementation of remote consulting in UK primary care following the COVID-19 pandemic: a mixed-methods longitudinal study. Br J Gen Pract 2021;71(704):e166-e177 [FREE Full text] [doi: 10.3399/BJGP.2020.0948] [Medline: 33558332]
46. Smith AF, Arfanis K. 'Sixth sense' for patient safety. Br J Anaesth 2013 Feb;110(2):167-169 [FREE Full text] [doi: 10.1093/bja/aes473] [Medline: 23319666]
47. Saldert C, Bauer M. Multifaceted communication problems in everyday conversations involving people with Parkinson's disease. Brain Sci 2017 Sep 25;7(10):123 [FREE Full text] [doi: 10.3390/brainsci7100123] [Medline: 28946714]
48. Johansson I, Samuelsson C, Müller N. Patients' and communication partners' experiences of communicative changes in Parkinson's disease. Disabil Rehabil 2020 Jun;42(13):1835-1843. [doi: 10.1080/09638288.2018.1539875] [Medline: 30669899]
49. Stevenson F. Achieving visibility? Use of non-verbal communication in interactions between patients and pharmacists who do not share a common language. Sociol Health Illn 2014 Jun;36(5):756-771 [FREE Full text] [doi: 10.1111/1467-9566.12102] [Medline: 24641161]
50. Greenhalgh T, Wherton J, Shaw S, Morrison C. Video consultations for covid-19. BMJ 2020 Mar 12;368:m998. [doi: 10.1136/bmj.m998] [Medline: 32165352]
51. Remote consultations. General Medical Council. URL: https://www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations [accessed 2021-08-12]
52. Kudlicka A, Hindle JV, Spencer LE, Clare L. Everyday functioning of people with Parkinson's disease and impairments in executive function: a qualitative investigation. Disabil Rehabil 2018 Oct;40(20):2351-2363. [doi: 10.1080/09638288.2017.1334240] [Medline: 28597694]
53. Thiyagarajan A, Grant C, Griffiths F, Atherton H. Exploring patients' and clinicians' experiences of video consultations in primary care: a systematic scoping review. BJGP Open 2020 Mar 17;4(1):bjgpopen20X101020. [doi: 10.3399/bjgpopen20x101020]
54. Donaghy E, Atherton H, Hammersley V, McNeilly H, Bikker A, Robbins L, et al. Acceptability, benefits, and challenges of video consulting: a qualitative study in primary care. Br J Gen Pract 2019 Sep;69(686):e586-e594 [FREE Full text] [doi: 10.3399/bjgp19X704141] [Medline: 31160368]
55. Austin KW, Ameringer SW, Cloud LJ. An integrated review of psychological stress in Parkinson's disease: biological mechanisms and symptom and health outcomes. Parkinsons Dis 2016;2016:9869712-9869715 [FREE Full text] [doi: 10.1155/2016/9869712] [Medline: 28058129]
56. Zach H, Dirkx MF, Pasman JW, Bloem BR, Helmich RC. Cognitive stress reduces the effect of levodopa on Parkinson's resting tremor. CNS Neurosci Ther 2017 Mar;23(3):209-215 [FREE Full text] [doi: 10.1111/cns.12670] [Medline: 28071873]
57. Anghelescu BA, Bruno V, Martino D, Roach P. Effects of the COVID-19 pandemic on Parkinson's disease: a single-centered qualitative study. Can J Neurol Sci 2022 Mar;49(2):171-183 [FREE Full text] [doi: 10.1017/cjn.2021.70] [Medline: 33843516]
58. Mann C, Turner A, Salisbury C. The impact of remote consultations on personalised care. Personalised Care Institute. 2021 May. URL: https://arc-w.nihr.ac.uk/Wordpress/wp-content/uploads/2021/08/Remote-consultation-briefing-website-final.pdf [accessed 2021-11-09]
59. Ben-Joseph A, Marshall CR, Lees AJ, Noyce AJ. Ethnic variation in the manifestation of Parkinson's disease: a narrative review. J Parkinsons Dis 2020;10(1):31-45 [FREE Full text] [doi: 10.3233/JPD-191763] [Medline: 31868680]
60. Past audits. Parkinson’s UK. 2019. URL: https://www.parkinsons.org.uk/professionals/past-audits [accessed 2022-09-13]
61. Services to people with neurological conditions: progress review. House of Commons Committee of Public Accounts. 2016 Feb 26. URL: https://publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf [accessed 2019-08-23]
62. 2019 UK Parkinson’s Audit: Summary Report. Parkinson's UK. URL: https://www.parkinsons.org.uk/sites/default/files/2020-01/CS3524%20Parkinson%27s%20UK%20Audit%20-%20Summary%20Report%202019%20%281%29.pdf [accessed 2022-11-17]

Abbreviations

GP: general practitioner
HCP: health care professional
NIHR: National Institute for Health Research
OT: occupational therapist
PPI: patient and public involvement

XSL•FO
RenderX

Edited by P Kubben; submitted 30.05.22; peer-reviewed by N Busis, H Leach, S Sarejloo; comments to author 11.08.22; revised version received 28.09.22; accepted 21.10.22; published 02.12.22.

Please cite as:
Pigott JS, Armstrong M, Chesterman E, Read J, Nimmons D, Walters K, Davies N, Schrag A
Remote Consultations for People With Parkinson Disease and Cognitive Impairment: Interview Study With Patients, Caregivers, and Health Care Professionals
JMIR Neurotech 2022;1(1):e39974
URL: https://neuro.jmir.org/2022/1/e39974
doi:10.2196/39974
PMID:

©Jennifer Sarah Pigott, Megan Armstrong, Elizabeth Chesterman, Joy Read, Danielle Nimmons, Kate Walters, Nathan Davies, Anette Schrag. Originally published in JMIR Neurotechnology (https://neuro.jmir.org), 02.12.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Neurotechnology, is properly cited. The complete bibliographic information, a link to the original publication on https://neuro.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org

XSL•FO
RenderX