

Rigorous Qualitative Research Involving Data Collected Remotely From People With Communication Disorders: Experience From a Telerehabilitation Trial

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Abstract

Diverse challenges arise with research involving people with communication disorders while using remote methods for data collection. Ethical and methodological issues related to the inclusion of people with communication disorders in research, specifically qualitative research, are magnified by communication challenges specific to remote communication. Avenues are discussed to ensure that remote data collection processes can include people with a communication disorder, while limiting negative impacts on the validity of the data.

Keywords

communication impairment, post-stroke aphasia, remote services, research accessibility, speech and language pathology

Introduction

Communication disorders are characterized by an impairment in the ability to speak, understand, read, or write.¹ They can be developmental in origin (stuttering, autism spectrum disorder, learning disability) or acquired, as in the case of stroke, traumatic brain injury or neurodegenerative diseases such as multiple sclerosis, Parkinson's disease, amyotrophic lateral sclerosis, or dementia. In Canada, over 440,000 people are estimated to be living with a communication disorder.¹ For instance, 64% of stroke survivors are reported to have a communication disorder, whether it is aphasia, dysarthria, or both.² Therefore, individuals with aphasia or dysarthria represent a significant proportion of the population receiving rehabilitation services and for this reason must be adequately represented in the field of post-stroke research.³

The inclusion of people with communication disorders in research involves certain ethical and methodological challenges, which too often lead to their exclusion, both to protect them and to simplify the research process, which is often already complex. People living with aphasia are particularly likely to be excluded because of possible impairments in understanding that can exist in addition to the expressive disorder—unlike people with dysarthria, who can understand spoken or written language as well as before the stroke.⁴ In addition to the ethical questions concerning the capacity to provide informed consent,⁵⁻⁷ questions about the validity of data collected from people with aphasia have also been raised,

especially in qualitative approaches using the interview as a means of data collection.⁸ As a result, this population is missing from many research projects when they should be included.⁹ For example, Brady et al.¹⁰ identified that in a Cochrane review of information provided to patients after stroke, of the 14 RCTs listed, only one had included people with aphasia.¹⁰

In the current context of the COVID-19 health crisis, these concerns must be considered within a new paradigm, that of social distancing. Since the beginning of the pandemic, social distancing has led researchers who would have previously offered in-person interviews to rely strongly on online encounters for data collection. Any research project involving human subjects is, at least in part, based on effective communication between participants and investigators, even if only to ensure informed consent. Some research designs,

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particularly those adopting qualitative approaches involving interviewing, rely very heavily on effective communication. This also applies to projects using questionnaires, which require participants to be able to understand the questions—either orally or in writing—and to provide adequate answers. Thus, effective communication is key in human research. However, by changing the mode of communication from in-person to virtual, new challenges can be expected to arise in ensuring the quality of the data collected, especially for people with communication impairments.

The Problem

Context, Methodology, and Reflexivity

This paper is the result of a reflective process and methodological adjustments by the authors, who are currently conducting a telehealth project in rehabilitation.¹¹ The aim of the study is to assess patient adherence to a stroke rehabilitation intervention according to whether it is offered at a rehabilitation center or at a distance using telehealth means. The study population consists of male and female adults who have had a stroke event (haemorrhagic or ischemic) are considered to be safe for home discharge by the acute/in-patient care team; have a relative or informal caregiver who is present in the home should physical rehabilitation treatments be required; and can speak French or English. Patients with severe cognitive decline prior to the stroke event (as per clinical judgment of the stroke unit team) are not excluded. The individuals recruited represent the full diversity of post-stroke profiles, including those with communication disorders such as aphasia, dysarthria, and apraxia of speech. As 330 participants will be recruited and 40% of stroke survivors have aphasia,² we aim to contact 130 people with aphasia during the recruitment process. However, because they are more likely to refuse research participation than stroke survivors, we do not have a fixed goal of recruiting 130 people with aphasia. Once participants are recruited, they are contacted at least five times throughout their rehabilitation for interviews that can last up to 45 minutes. For participants communicating without any barriers, during these interviews a research team member goes through various forms with the participant over the phone. However, this process is not suitable for people with communication disorders, especially those with aphasia. For these participants, one of the team members and first author of this paper, a speech-language pathologist (SLP) by training with several years of clinical and research experience in aphasia, adapted the recruitment and collection procedures so that people with aphasia could participate as ethically and optimally as possible, while minimizing the risk of attrition due to the barriers that communication disorders can present in research involvement. In addition to drawing on her experience working with people with aphasia, she also took care to follow the guidelines for accessible communication from Communication Disabilities Access Canada (CDAC)⁵⁷ to adapt each form, whether to

collect informed consent or research data. She also trained other research team members and wrote a booklet to help them assist people with aphasia to complete administrative or research documents. These measures are in compliance with the Canadian Tri Council Policy Statement 2, article 4⁵⁶, on appropriate inclusion and inappropriate exclusion of participants from research.

The implementation of these adaptations to fit the needs of people with communication impairments has raised a series of questions and challenges. Furthermore, along the way, the research team opted for online encounters for data collection, as did many others over the course of 2020, to ensure continuity of the project during the pandemic. The authors held regular statutory meetings during which adaptations, recruitment, and collection issues were discussed and addressed based on their research experience. For example, the topics discussed included the pointing issues, the limited non-verbal communication or the difficulty to support communication by writing, strategies commonly used to support communication with people living with aphasia. The decision to follow a remote data collection process only was also an opportunity to reflect on the methodological means to ensure the validity and the ethicality of data collected remotely from people with a communication disorder. These means are presented below.

Rehabilitation Research and Communication Impairment

The importance of examining life experiences from the perspective of the insider has been increasingly recognized.¹³ These kinds of research projects, focusing on processes and issues related to health and illness, have largely been qualitative, relying primarily on in-depth, open-ended interviews. Given the communication barriers that people with aphasia face, obtaining their perspective can be challenging, and researchers often consider interviewing them as being close to impossible and, therefore, do not attempt it. Considering the large proportion of individuals with post-stroke communication disorders, excluding them on the basis of communication impairment leads to potential clinical repercussions for this population, as their issues remain unknown, creating “evidence-biased care” as Jones et al ingeniously put it recently.¹⁴ While there are ethical issues in including people with communication disabilities—such as ensuring that they can express their desire to withdraw from the project despite their expressive difficulties—there are also ethical issues in excluding them. Systematic exclusions based on disability, that is, communication impairment, are discriminatory. Therefore, it is necessary to protect people with communication disabilities not by excluding them, but by adapting the research process so that it is communicatively accessible at all stages of the project. With this in mind, many authors have provided guidelines and tools to include people living with a

communication disorder in research, whether quantitative or qualitative.¹⁵⁻¹⁷ Most of the proposed strategies are based on the principle that the competence of people with a communication disorder is masked by language difficulties, and that collaboration between the researcher and the participant will reveal that competence and provide access to what the participant has to say about the topic being explored. To ensure this, Luck and Rose¹⁶ encourage researchers to assist by “altering questioning style, offering ideas to participants, and using supportive conversation techniques,” even if it means offering words to the participant when he or she is facing anomia or significant difficulties in producing the target word. When doing so, Luck and Rose recommend that the interaction should be video-recorded and transcribed so that a judgment can be made on interviewer bias. To read more on how to do qualitative research with people who have aphasia, see Wilson and Kim.¹⁸

While these strategies address the ethical issues related to the inclusion of people with communication disorders in research and allow them to be heard, they also raise other methodological questions. More specifically, investigators may be expected to adopt a neutral attitude during data collection in order to guarantee objective results—from a positivist perspective. This is reflected in the credibility and trustworthiness criteria of qualitative research, and refers to confirmability, that is, the ability of the researcher to report the participants’ responses only, not the researcher’s views.^{19,20} That said, following Luck and Rose’s suggestion of offering ideas to participants with aphasia, for example, increases the risk of the investigator influencing the responses provided. Yet, from an epistemological perspective, it is accepted in qualitative research that the researcher and the participant influence each other.²¹ This does not mean that it is impossible to strive for trustworthiness in qualitative findings, but rather that one must be aware of this influence and find ways to account for it in the process of data collection and analysis. To this end, researchers are encouraged to engage in scientific triangulation and critical reflexivity.^{22,23}

Triangulation is a validation strategy that can be applied to different aspects of research, the most well-known of which is data triangulation (including different data sources), but it also refers to triangulation of methods, investigators, or even theories, which involves analyzing data from different approaches.²⁴ The value of triangulation is that it adds to the validity of the research by ensuring its authenticity.²⁵ Howe et al.^{26,27} proposed a textbook case of triangulation with their project combining observation and interviews of people with aphasia to better understand the environmental factors influencing their community participation. This triangulation approach revealed that some of the factors influencing the participation of people with aphasia outside the home that had been identified in field observations did not emerge in home interviews, and vice versa. Reflexivity is an instrumental approach where the “processes of knowledge production

become the subject of investigation.”²⁸ By reflecting on and providing insights about how—as researchers—we think and act, reflexivity aids the interpretation of results.

To summarize, research involving people with communication disorders is not only possible but critical, although it requires adaptations in terms of access to communication and methodology. Let us now add a layer to the problem: collecting research data using telecommunication.

Healthcare and Research Involving Data Collected Remotely

The ongoing health crisis since March 2020 led researchers worldwide to react and to implement and expand remote services, which were already being used in many countries and areas where geographic distribution across the territory had always complicated face-to-face service. For example, Weidner and Lowman published a systematic literature review in 2020 that identified telehealth services for screening, assessment, and treatment in speech-language pathology for the adult population between 2014 and 2019, that is, before the COVID-19 pandemic. Their review included 31 studies and confirmed that telehealth provides reliable assessments and that the intervention is valid in terms of feasibility and benefits for patients, including people with communication impairments like aphasia.²⁹

By leading a large number of research teams to turn to remote data collection methods, the health crisis has made a major contribution to the production of methodological data on this subject, which had already begun to emerge in recent decades. Already in 2005, questions of the relevance and usefulness of the telephone compared to face-to-face interviews and mailed questionnaires were raised.³⁰ Compared to face-to-face interviews, there was concern that telephone interviewing could lead to slightly shorter responses and the exchange of less information. A little later, in 2012, Irvine and al. confirmed in their systematic comparison of interviews conducted by telephone or face-to-face that the former tended to be shorter, and suggested that this was because interviewees provided less detail in their responses.³¹ However, the same year, Trier-Bieniek claimed that interviews conducted over the phone could lead to more honest exchanges.³² According to the author, this was the result of increased familiarity with virtual communication and a sense (even if false) of anonymity.

With the rise of technological developments in communication, the same types of questions have been raised about studies using instant messaging and email in addition to face-to-face and telephone interviews in qualitative designs.³³ According to the authors, using these four means of data collection can allow for qualitative interviews to be conducted with a comparable success, provided that the research team adapts its collection process to each medium (in particular by proposing shorter meetings by telephone than in

person) and by leaving the choice of data collection modality up to the participant, when possible.

Recently, video conferencing started to be studied as a method of data collection in qualitative research. In their paper on the topic, Gray et al.³⁴ reported that not only did the quality of video conferencing interviews not differ from that of face-to-face ones, but that online interviewees were more open and expressive. However, this applies to participants who can use communication technology easily. Without referring directly to people with communication impairments, de Villiers et al.³⁵ warned that facial expressions and body language facilitate communication in face-to-face interviews, while Pocock et al.³⁶ highlighted the ethical challenges tied to virtual methodologies, including Internet-user population bias and underrepresentation of the other.

In addition to their validity and reliability in terms of assessment and intervention, remote services have many advantages compared with face-to-face service. The most commonly cited are the time saved, increased flexibility, and decreased logistical concerns related to transportation.³⁷⁻³⁹ Although the use of remote services in healthcare and research has surged as a result of constraints such as severely limited direct contact with participants, their many advantages and benefits suggest that interest in remote services will continue even after the pandemic wanes, including for individuals with communication impairments.

Communication Impairments and Remote Methods of Communication

Although remote services are not new tools for speech and language therapists in countries where geographical distance complicates face-to-face therapy, such as Australia or Canada,⁴⁰ they present specific challenges for people with communication impairments due to the nature of these disorders and the means by which services are administered. First, the particularities of relying on telephone calls, visual calls, or online forms with participants who have a communication disorder may further complicate the difficulties typically encountered. Indeed, it has been observed, for example, that remote services in healthcare are associated with a tendency to fatigue in patients, in addition to challenges achieving joint attention.⁴¹ Joint attention, which Butterworth defines as “looking where someone else is looking,”⁴² is a basis for communication that is effectively absent from any communication system that is not in person, since it is impossible to know with certainty what the person is looking at, even with visual calls.

In our experience, communications that are not in person hinder the dynamics of interactions in multiple ways by filtering out key components of communication:

- The simplest eye contact is systematically disrupted even when both interlocutors use a video camera, since

when looking at a person our eyes are drawn to his or her picture on the screen and not to the camera, which results in a lowered gaze when the camera is positioned above the screen. Thus, it is impossible to look someone straight in the eye;

- People are also limited in what they can point to. Indeed, if the object of the pointing is not behind or very close to the participant, it is necessary to bring the object into the frame of the screen or to redirect the camera;
- Non-verbal communication—on which people with aphasia depend heavily⁴³—is highly restricted. One sees only the upper body and often solely the face—and a very small one at that—of the person speaking or listening, whereas communication is also conveyed by the entire posture, such as by lowering the shoulders and tapping the foot nervously. Even with the largest screens, the portion of the person that one can see is much smaller than in face-to-face interactions, making it harder to read non-verbal information;
- “Reading the room”—which according to the⁴⁴ is the ability “to be or become aware of the opinions and attitudes of a group of people that you are talking to” based on instinctive analysis of micro elements of verbal and non-verbal communication—seems impossible in this context. The shared room does not even exist;
- For written support of communication, it is necessary to use screen sharing with cursor pointing, which is doable but not always as easy as sketching on paper. This is summarized by Goldberg et al.⁴⁵ as a “reduced quality of visual cues and stimuli than that available in traditional settings.”⁴⁵ This runs directly counter to strategies identified by people with aphasia as distinguishing “good” from “bad” speakers. Indeed, people with aphasia feel that their interactions are facilitated when the person they are talking to uses shared materials (e.g., paper/pencil on the table between them) to write or draw;⁴⁶
- Finally, the use of remote vs face-to-face interactions also raises questions concerning the establishment of a relationship of trust between interlocutors,³⁷ which is necessary in research, where the sensitivity of the data collected depends on it.⁴⁷

To be clear, the authors of this paper do not intend to state that people with aphasia cannot or should not participate in virtual activities. They already do, and results show that telepractice, even in groups, can be significantly beneficial to them.^{48,49} However, we do believe that, with this population, face-to-face interviews should not always be dismissed when virtual options are accessible. In addition, in our experience, certain recommendations are useful when the choice to collect data through virtual means is made.

Recommendations for Conducting Rigorous Research using Remote Methods for Data Collection with People who have Communication Disorders

Research in rehabilitation involving people with a communication disorder and based on data collected remotely presents a number of barriers, which the authors believe can be overcome if one considers and addresses them when designing research projects. Although the steps to be taken are highly dependent on the nature of the scientific project to be adapted, we propose a list of considerations based on the theoretical frame depicted in Figure 1. These considerations were developed through synthesizing the key literature in this field along with trial-and-errors adaptations by the authors in their experience with remote data collection.

Given the large proportion of people with a communication disorder and the ethical importance of including these people in an increasing number of rehabilitation research projects, these recommendations should apply to any research in rehabilitation where data is collected remotely:

- * In line with patient and public involvement (PPI) which, by including the experience of service users aims to include more relevant knowledge, include patient partners with a communication disorder as early as possible in the project development process (for more about PPI in health research, see.⁵⁰ By doing so, people who have a communication disorder can advise the team on how best to ensure communicative accessibility in the recruitment and data collection stages. However, the inclusion of patient partners with communication disorders may also present challenges;⁵¹
- * Ensure that investigators are trained by qualified speech-language pathologists on how to support

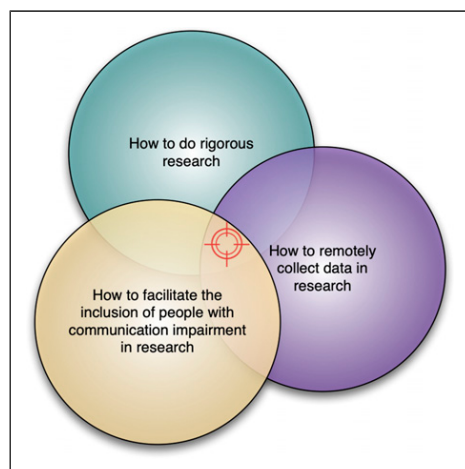










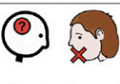


Figure 1. Methodological and ethical targets for rigorous research involving data collected remotely from people with communication disorders.

communication for people with communication disorders, especially in a virtual setting. This could help prevent their experience from resembling that of healthcare professionals, who have reported thinking of themselves as ill-equipped and untrained to assess and treat this population compared with patients without communication disorders;⁵²

- * Develop a reflective practice in the research process, including about how communication impairment and remotely collected data are compatible and how the research team overcomes the challenges encountered;⁵³
- * Triangulation is one useful way to support credibility in qualitative research, and there are various options to consider. For example, filmed observation could be considered to supplement the data and to allow for triangulation since it does not rely solely on verbal data and allows people with communication disorders to use non-verbal information;¹⁶
- * While recruiting participants, ensure that all those involved have access to quality equipment (e.g., screens of appropriate size, relatively recent computers, tablets or cell phones and a recent version of the telecommunication platform, strong signal for internet connection). For example, in the telehealth project this paper originated from, the budget included equipment for people who did not already own it. This is a recommendation many authors provided concerning remote data collection,^{35,37,48,49} but it needs to be stressed when including people living with communication disorders. Pocock et al.³⁶ also advise assessing the technological capabilities of participants and, if needed, offer training;
- * Knowing that telecommunication interactions can be more demanding, whether by telephone, instant messaging, or teleconference,^{31,54} offer more breaks than you would in a face-to-face setting and schedule shorter sessions, even if it means holding more of them. Because this recommendation applies to any type of participant whose data is collected remotely, it is all the more relevant when it comes to people with a communication disorder. This recommendation can be adjusted according to the severity of the communication disorder and the related fatigue of the participant. For example, people with severe aphasia can be cognitively drained from a 30-minute interview. Therefore, sessions need to be adapted to the participant's characteristics.
- * During these remote sessions, suggest ways to facilitate joint attention and pointing, including screen sharing. This can also provide visual support for the information provided to participants or for the statements of the questionnaires. From our experience, a relative or caretaker can also act as a facilitator by writing or drawing in front of the participant what the investigator would have written or drawn in a traditional setting. The

Box 1. An example of a form adapted to be aphasia-friendly.

	Personal history of mental health	
1  	Before your stroke , did you ever receive treatment or consult a health professional for a problem with depression ? Including post-partum depression for women	
No	<input type="checkbox"/>	
Yes	<input type="checkbox"/>	
I don't know / I don't want to answer	<input type="checkbox"/>	
2  	Have you ever received treatment or consulted a health professional for any other problem related to your emotions or your mental health ? ex : anxiety, attention deficit, alcohol or drug use?	
No	<input type="checkbox"/>	
Yes	<input type="checkbox"/>	
I don't know / I don't want to answer	<input type="checkbox"/>	

challenge here is to ensure the caretaker does not replace the participant's responses with his or her own, as they can have different perspectives⁸ and have been reported as having a tendency to speak for the person with aphasia.⁵⁵ From our experience, although caretakers can act as facilitators when available, clarification of their role is often needed. Furthermore, not having a caretaker available does not mean that an interview is not possible if the investigator is a trained speech and language therapist or has been carefully trained for the task.

- * Adapt all questionnaires or interview guides in terms of communication by making them aphasia-friendly⁵⁷ and sharing them on the screen at the time they are proposed. Have the answers written by the investigator on the shared screen so that the participant can confirm or deny them if necessary. A document camera might help with this task. **Box 1** shows an example of the adaptations we made to a form originally offered by phone to participants without a communication disorder, used here as a communication support via shared screen during video conferencing with participants with aphasia. This collection process not only allows the participant to follow the questions on the form while the investigator asks them, but also allows the investigator to confirm the participant's response by pointing to what was understood.

- * Build rapport between participants and investigators by making personal connections and showing interest in what interests them, which is as relevant for people with communication disabilities as any other participant. This should help bypass the barriers met when communication is not in person.

If readers are interested in other practical resources to adapt their project to the COVID-19 situation when conducting research with people with aphasia, they are referred to the website of the international Collaboration of Aphasia Trialists (CATs) (www.aphasiatrials.org).

Conclusions

The ongoing health crisis since 2020 has led to an explosion in the use and an enhancement of remote services over more than a year. Given the reported benefits, effectiveness, and validity of remote methods in research, they should in all likelihood outlast the resolution of the pandemic and continue to be offered widely to post-stroke and other communication disorder populations. In this context, it is important to ensure that rehabilitation research considers the communication challenges these populations face in this communication configuration, particularly for projects seeking

participants' perspectives. The recommendations listed in this paper helped the authors overcome the challenges they faced while including people with communication disorders in a rehabilitation project involving data collected remotely. This list is a first step in this direction, until studies identify the best strategies to conduct research projects utilizing telecommunication that include people with communication disorders. To our knowledge, this has not yet been done.

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