Changes of Lived Experience in Persons with Aphasia Subsequent to the COVID-19 Outbreak

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Abstract

COVID-19 has notable effects on the lived experiences of people with aphasia (PWA) (Kong, 2021) and their caregivers (Kong, 2021). More specifically, on their experience associated with speech therapy (Chu et al., 2020), including both face-to-face and teletherapy sessions. This narrative study provides a summary of such experiences in the pre- and post-COVID outbreak in Hong Kong using the inductive approach (Thomas, 2006). Interviews were conducted with PWA and caregivers, who were recruited using convenience sampling (Andrade, 2020). Staff in close relation with PWA, or speech therapists (STs), were recruited using snowball sampling (Naderifar et al., 2017) and interviewed. Each interview lasted 45 minutes to 1 hour and was analysed using the method of content analysis (Bengtsson, 2016). Major themes including (I) Sociopsychological impacts of COVID-19 on PWA, (II) Impacts of COVID-19 on speech therapy, and (III) Perception of teletherapy and telepractice were identified. These thematic phrases will be used to produce materials that will be disseminated to the public in the final stage of the project, aiming to raise the understanding and assistance towards PWA in Hong Kong.

Keywords: People with aphasia (PWA), COVID-19, speech therapy, teletherapy, telepractice caregivers, speech therapists (STs)

Introduction

Aphasia refers to the difficulty in producing or understanding speech, which could occur due to brain tissue damage, such as a stroke (*What Is Aphasia? — Types, Causes and Treatment*, 2017). PWA may improve their language abilities by participating in speech therapy (Brady et al., 2016), which can be held individually, under the presence of caregiver(s) (The Hong Kong Association of Speech Therapists, 2021), and group therapy (Brumfitt & Sheeran, 1997).

COVID-19 is a respiratory disease induced by SARS-CoV-2, a virus belonging to the coronavirus family, and is transmitted through droplets (Castillo-Allendes et al., 2021). Since December 2019, it has spread worldwide rampantly, resulting in an ongoing global pandemic (*Coronavirus Disease (COVID-19) Pandemic*, 2023). In January 2020, Hong Kong confirmed its first COVID-19 case, marking the gradual start of preventive measures that are among the strictest in the world (*Hong Kong Covid Stringency Index, December, 2022 - Data, Chart | TheGlobalEconomy.com*, n.d.), including compulsory mask wearing and social distancing measures (OT&P Healthcare, n.d.). These measures have resulted in mask-wearing in face-to-face speech therapy sessions and the introduction of telepractice, which was previously not well established (Fong et al., 2021), therefore impacting the experience of PWA, caregivers and speech therapists (STs) in their speech therapy sessions.

Despite the challenges faced by these stakeholders in contemporary times, the issue itself does not receive much public attention in Hong Kong. According to the only corresponding local organisation, Aphasia HK, there has been no establishment of any self-help groups catering

specifically to PWA in Hong Kong (Aphasia HK, 2022). Limited progress is present on the number of studies investigating the social and psychological challenges experienced by aphasic patients during the ongoing pandemic (Kong, 2022). By studying the lived experiences of PWA and related stakeholders qualitatively, the research work aimed to address the existing literature gap. Another goal is to produce qualitative data for the concluding stage of the project, which is characterised by the dissemination of the generated knowledge to the public. Following rigorous future refinement and selection of the qualitative data from this section of the project, the research findings will be summarised and shared to the public in the form of educational and promotional leaflets, together with posts and short videos on social media. It is hoped that the public dissemination of knowledge could enhance the awareness and understanding towards aphasia and PWA and contribute to the betterment of services for PWA and their related stakeholders.

Methodology

Setting

This experiential learning project was part of research work by Dr. Anthony Kong entitled ‘Changes of Lived Experience in Persons with Aphasia Subsequent to the COVID-19 Outbreak’ (A. P. H. Kong, 2021). This section of the qualitative study aimed to identify and contrast the main themes of changes in experiences on receiving speech therapy and daily life among PWA. The increasing number of confirmed COVID-19 cases led to the official announcement of the pandemic being an ‘emergency’ by the Hong Kong government (OT&P Healthcare, n.d.-b). Other measures included traffic reduction from the People’s Republic of China, border control, the closure of schools and recreational facilities. These were followed by stricter measures, including mandatory closure of certain shops and mandatory mask-wearing, and gathering restrictions (OT&P Healthcare, n.d.-c). This project under the Laidlaw research period was carried out between July and September 2023, approximately 3 years after the onset of the coronavirus in Hong Kong (OT&P Healthcare, n.d.-d). Following the stoppage of isolation measures for infected persons in January 2023, preceding the lifting of the mask mandate by the HKSAR government in March 2023 (*Mask-wearing Requirement to Be Lifted*, 2023), and the relaxation of travel requirements (*Latest Travel Requirements for Hong Kong | Hong Kong Tourism Board*, n.d.), Hong Kong citizens have been gradually returning to normalcy. Some student clinicians and interviewees did not wear masks during the interviews. Qualitative interviews were conducted by student clinicians from the University of Hong Kong (HKU) to collect their personal information and lived experiences.

Interviewees

4 people with aphasia (PWA) of ages 57-74 were sampled with the assistance of staff from the Hong Kong Stroke Association, which provides speech therapy sessions and activities for members who have experienced a stroke, with some being PWA. 2 caregivers, aged 65 and 74, were also interviewed simultaneously. Convenience sampling (Etikan et al., 2016) was utilised, resulting in the recruitment of some who experienced stroke or received speech therapy, but do not suffer from aphasia. Through the recruitment of non-aphasic participants who have received speech therapy, the research team could contrast the lived experiences of aphasic and non-aphasic clients receiving speech therapy following the outbreak of the pandemic. STs, who were referred to by Dr. Kong Pak Hin, were also interviewed. The participants were categorised into three groups, namely PWA, caregivers, and staff, each receiving a distinct set of questions developed prior to the interviews. The interviewees without aphasia and were clients of speech therapy received the same set of questions as the interviewed PWA.

Procedure

Before the collection of qualitative data, approval was sought from the Human Research Ethics Committee (HREC) at HKU (HREC Reference Number: EA220100). PWA and their caregivers were then recruited from the Hong Kong Stroke Association. Promotional posters were sent to the organisation for interviewee recruitment. Access to the sampling population of speech therapists was achieved by snowball sampling (Naderifar et al., 2017b). Most importantly, before the start of each interview, interviewees were asked to sign an informed consent form that clearly seeks their preferences on the usage of the produced qualitative data, including identification, face and voice shown in the video recording. Consent on video

recording was also sought. In addition, their right to discontinue the study at any time without any consequences was stated. Verbal clarifications were also provided by student clinicians administering the interviews. Most importantly, to ensure the privacy of participants, additional privacy remarks, such as face blurring, and voice processing in the final videos, were also carefully recorded on Excel by the research team. Semi-structured interviews (SSIs) (Mashuri et al., 2022) lasting 45 minutes to 1 hour were conducted individually, except some PWA being interviewed with their caregivers.

Data Collection

All interviews were conducted in Cantonese as it is the mother-tongue of the participants and students administering the interviews. Interviews with STs included terms in English, such as ‘teletherapy’ and ‘telepractice.’ The interviews were conducted by 1-3 student clinicians. In interviews with 2-3 interviewers, 1 was responsible for audio and/or video recording, and 1-2 took on tasks including asking questions and charting. All interviews, under the informed consent of respondents, were audio recorded to reduce recall bias (Lam et al., 2022). Video recording was performed based on the preference of interviewees. Participants were either interviewed individually, or in some interviews with PWA, together with their caregivers. Each interview lasted for around 45 minutes to 1 hour. The interviews with PWA and/or their caregivers were all conducted in one of the activity rooms at the Hong Kong Stroke Association in San Po Kong. Interviews with STs were conducted either physically in various locations, such as the Aphasia Research and Therapy (ART) Lab in the University of Hong Kong (HKU), or via online means. The choice of venue was based on the preference of the interviewed STs. The 3 sets of pre-written questions were used to guide the interviews. For PWA, the interviews covered the following areas: (1) Delivery of speech therapy before COVID, (2) Delivery of speech

therapy during outbreak of COVID, and (3) Telepractice (if applicable), and (4) Changes in life during COVID. Caregivers, on the other hand, were asked to provide personal information of the PWA preceding their own. Respondents in this group were then asked to describe (1) Impacts of 1st COVID outbreak, (2) Impacts of 2nd COVID outbreak, (3) Comparison between face-to-face and telepractice, and (4) Other impacts brought by COVID, with sections (1) and (2) designed to repeat and confirm the answers of PWA. This is to enhance understanding and ensure the accuracy of responses provided by the PWA. In some interviews, the technique of probing (Robinson, 2023), in the form of both close- and open-ended questions, was utilised to elicit clarifications from interviewees. As for STs, questions were raised according to this order: (1) Impacts and changes during COVID outbeak, (2) Impacts and changes after COVID outbreak, (3) Perception of teletherapy. Before the qualitative study, all student clinicians have been equipped with the communication skills necessary to interact with PWA.

Data Analysis

All interviews were audio-recorded with the informed consent of interviewees, with some video recorded simultaneously after agreement. Together with the collected consent forms (in both hard and soft copies) and notes made during the interviews the recordings made were organised by student clinicians in a respective folder of each interviewee on OneDrive. To achieve familiarisation, the recordings were played several times before and during content analysis. The main points of each response were summarised and conceptualised into a few keywords and themes using the inductive approach (Elo & Kyngäs, 2008), and were recorded in a table using Excel. Each of the interviews was analysed by one student clinician separately. Regular online meetings were held within the team to conduct discussions on the collected data.

Limitations

A higher tendency in disobeying pragmatic rules may also be imposed by narratives (Kong et al., 2023), which may contribute to discomfort of PWA participating in the study. To ease expression by PWA, they may opt to write (Ford, 2019) using the pen and paper prepared before the start of each interview with PWA. Secondly, although probing could contribute to the richness of collected qualitative data by increasing the number of responses (Robinson, 2023b), it is concurrently associated with bias from prompting the respondent towards a certain answer (Bergelson et al., 2022). There is also a possibility that some respondents were subject to the effect of social desirability under the presence of another individual, i.e., the student clinician(s) (Grimm, 2010a). Before the commencement of each interview, participants were reminded of confidentiality and anonymity (Grimm, 2010b). To further reduce these biases, the student clinician(s) avoided the use of leading questions, phrases previously unused by the interviewee, and refrained from suppositions and judgements (Cairns-Lee et al., 2021) to lower demand effects (Grimm, 2010c).

Results

Theme I. Sociopsychological impacts of COVID-19 on PWA

Subtheme 1. Disruption to social life

Both PWA and non-aphasic clients of speech therapy have shown a decline in social activities during the first phase of COVID-19 (January-July 2020). Before the first phase, social activities mentioned by PWA included dining with friends and relatives, hiking, karaoke, and the participation of activities organised by the Hong Kong Stroke Association. Many have expressed a great reduction in social activities, which was further explained by the suspension of services and activities by the aforementioned organisation, and the lowered frequency of meeting friends and relatives. Some have expressed that they have sustained social contact with their friends and family via digital means, including the usage of WhatsApp and video conferencing.

Subtheme 2. Impacts of COVID-19 on psychological well-being

Those who associated COVID-19 and worrying have referred the source of their worries to the fear of infection. Pressure, on the other hand, was linked to the ambiguity of the duration of the pandemic, and the fear of infecting their family members. The suspension of visits in nursing homes, and the death of loved ones has also contributed to the psychological discomfort of an interviewee with aphasia. However, some PWA have expressed their personality trait, or 'being optimistic,' has contributed to little or no worry following the outbreak of the COVID-19 pandemic.

Theme II. Impacts of COVID-19 on speech therapy

Subtheme 1. Disruption to face-to-face speech therapy sessions

Before the lift of the mask mandate, clients of speech therapy and STs were required to wear masks when delivering face-to-face sessions. Given that the mask would cover the mouth, both clients and STs have said that mask-wearing has made observing lip movements unfeasible. In the case of PWA, difficulties were imposed on observing the movements associated with speech production. In addition, most clients and STs have experienced cancellation of in-person speech therapy sessions due to the closure of the service-providing centre, or the disabled access of STs to venues such as schools and nursing homes. Most respondents said that they have currently resumed back to in-person sessions.

Subtheme 2. Sudden transition to teletherapy and telepractice

Under closure and disabled access of STs to service-providing facilities, some speech therapy sessions have switched to online mode. As mentioned by most respondents, the majority were conducted using Zoom. According to most STs, teletherapy and telepractice were not common in Hong Kong before the pandemic, rendering the conversion of the mode of delivery fast paced. Most STs had limited training beforehand, with only ‘a few hours of online training’ and have been ‘learning throughout the process.’ Interviewees who were clients of teletherapy mentioned that they have also been gradually adjusting themselves to the use of online conferencing, with the majority requiring assistance from their caregivers or children. Most non-aphasic clients expressed that they require swallowing practice, which is difficult to observe and guide without in-person contact. Both PWA and non-aphasic clients have expressed that they are now familiar with the operations of teletherapy and telepractice.

Subtheme 3. Impacts on home practice

Most respondents said that home practices after the COVID-19 outbreak during the first phase, in the form of online apps and worksheets, have remained similar to before the pandemic started. Those who have delivered home practise themselves said that home practice is mainly dependent on self-discipline.

Theme III. Perception towards teletherapy and telepractice

Subtheme 1. Teletherapy and telepractice as alternatives

Most speech therapy clients have expressed that they prefer face-to-face sessions.This is agreed upon by the STs. Teletherapy and telepractice, as said by the majority of interviewees, is considered an alternative to in-person speech therapy, and 'better than none' when face-to-face sessions are not possible. Nevertheless, as commented by a ST, teletherapy and telepractice could be beneficial to clients who may be more reserved, or in sessions where long travelling time would be incurred when delivered in-person. The ST also said when mask wearing is needed, regardless of mandated by law or desired by parents of children, conducting speech therapy and practice online was also considered helpful in sessions where observing mouth movements were needed. As the seriousness of the pandemic declined, the majority expressed that they seldom engage in teletherapy and telepractice in recent times.

Subtheme 2. Constraints and limitations of teletherapy and telepractice

(i) Technical issues

Most respondents have said that they have experienced connection issues relating to Wi-Fi connection, resulting in some disturbances listening to the instructions from STs. Some

who have received group teletherapy said that they fear disrupting the progress of the group when requesting the ST to repeat during a connection delay.

(ii) Limited assistance from STs

Given that content is being delivered online, interview participants said assistance provided by STs is limited. Most said that assistance is usually limited to solving technical issues, with STs providing guidance on 'which buttons to click' on the Zoom interface. This idea was also expressed by some STs.

(iii) Importance of cooperation between caregivers and STs

As expressed by some STs, in cases where clients practise swallowing, STs may have to assist in the delivery of food to the mouth. In teletherapy, as said by some interviewed STs, caregivers such as domestic helpers or family members may assist with the delivery of such content by attending the teletherapy sessions with the client, therefore requiring the communication between caregivers and STs. Some STs also mentioned that some of their clients, including children and the elderly, may not have adequate knowledge on setting up the necessary equipment for teletherapy and telepractice, and often needed assistance from their parents or caregivers. The need for caregiver assistance was highlighted by one of the interviewed STs, who said that some elderly at nursing homes were deprived of access to teletherapy due to the lack of cooperation by caregiving staff.

Conclusion

Within the Laidlaw research period, interviewee recruitment, qualitative interviews with speech therapy clients, including both PWA and non-aphasic patients, and STs were conducted. Following the preliminary stage of content analysis, changes in the lives of PWA, and stakeholder experiences with face-to-face speech therapy and teletherapy were summarised into themes and subthemes. These findings suggest that COVID-19, together with measures introduced during the pandemic, has negatively impacted in-person speech therapy sessions, and concurrently, led to the emergence of teletherapy and telepractice in Hong Kong, which had posed both benefits and constraints on the population (Banerjee & Chaudhury, 2010). For the betterment of speech therapy services for PWA, more resources, i.e., hardware and personnel, could be allocated. However, considering this qualitative study was based on a small sample of the population, more studies would be required for a more accurate understanding.

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