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“The most important thing is having patience, both of us.” Successful conversations from the perspective of people with aphasia and their primary conversation partners

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ABSTRACT

Purpose: Improving conversation between a person with aphasia (PWA) and their primary conversation partner (PCP) is a goal of aphasia therapy. However, there are few outcome measurements available that enable conversation success to be measured from the perspective of the target population. This study sought to define the construct of “conversation success” from the perspective of PWA and PCP in the development of a patient-reported outcome measure (PROM) of dyadic conversation.

Methods: PWA ($n = 20$) and their PCP ($n = 19$) participated in online focus groups using the nominal group technique. Participants responded to the question, “What makes your conversations successful with your communication partner?” and ranked the three most important items in terms of personal preference. Qualitative content analysis was used to analyse priorities across groups.

Results: In eight focus groups, 39 participants generated 190 items describing successful conversation. Five themes were identified: (1) working it out together, (2) having patience, (3) being familiar with your conversation partner, (4) considering the conversation environment, and (5) having a positive attitude and mindset.

Conclusions: The participants conceptualised successful conversation in terms of behaviours, strategies, and feelings. These results will inform the development of a PROM for dyadic conversation in aphasia.

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Aphasia; conversation; patient-reported outcomes; couples; dyads

> IMPLICATIONS FOR REHABILITATION

- Aphasia impacts how successful conversations can be for the person with aphasia and their conversation partner.
- Dyads with the lived experience of aphasia have strengthened the evidence regarding communication and coping strategies that facilitate successful conversations.
- Clinicians providing conversation therapies and communication partner training should focus more directly on coping strategies, attitudes, and mindsets and address the impact of aphasia on conversation and relationships.

Introduction

Conversation therapies and communication partner training (CPT) programs are critical components of aphasia therapy. The impact of aphasia on a couple or dyad’s ability to have successful conversations is well documented [1–4]. Measuring the success of such interventions is, however, challenging. The absence of outcome measurement instruments for conversation therapies, including CPT, is a recognised gap in both aphasia research and clinical practice [5–8]. Importantly, there is currently no way to measure this construct from the perspective of the target population, people with aphasia (PWA) and their primary conversation partners (PCPs) [9]. This research aims to define the construct of conversation success from the perspective of PWA and PCP, to develop a patient-reported outcome measure (PROM) for dyadic

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conversation. In this research program, we use the term dyad to describe two people (in a couple or close family member relationship) who are conversation partners.

Conversation is an essential tool for socialisation and is the “backbone of relationships” [10]. Conversation also has social rules and differences that can be observed across different cultures and languages [11]. Successful interactions depend on conversation skills to initiate social contact and enable the sharing of opinions and feelings [12]. Personal lives and social networks are shaped positively and negatively through conversations, which most often occur with our PCP (spouse, partner, or close family members) [13]. Couples and dyads communicate in various ways, including through verbal and non-verbal communication, and can develop positive and negative communication patterns within their relationships [14]. Couple therapy studies show that positive communication patterns within a relationship, for example, engagement and active listening skills, correlate to long-term relationship success [15,16]. Therefore, successful communication and conversations are vital to successful relationships, in particular, couple and close family relationships. Aphasia, however, disrupts conversations, which may negatively impact relationships [17].

Research has highlighted the challenges PWA face when conversing, including difficulty initiating topics, asking questions, and expressing everyday information [18–20]. PWA also report negative feelings such as frustration and helplessness when conversation breaks down, which can lead to disengagement from their conversation partners [21,22]. Furthermore, PCP acknowledge that conversation is more difficult for them when a family member has aphasia, and they change their behaviours in conversational situations [4,23]. Often, these changes in behaviour are positive and facilitate communication success for the dyad [4]; however, some of these behaviours can reduce participation in conversation for a PWA [23]. For example, PCPs can speak for the PWA or spend too much time on conversation repair strategies such as verification, redirection of the topic, clarification and assistance in word finding [24,25]. In some instances, these behaviours may contribute to family members or spouses having an overall negative perception of the person with aphasia (PWA) that can influence feelings of incompetence within the dyad’s relationship [3,6].

Aphasia has extensive and ongoing consequences for families, particularly the significant other of PWA. The International Classification of Functioning, Disability, and Health (ICF) describes these consequences as third-party disability, defined as “...disability and functioning of family members...due to the health condition of the significant others” [26]. Spouses and family members of PWA have reported negative consequences such as depression, social isolation, and frustration [27]. PCPs have also reported reduced social networks [28–30] and difficulty communicating with the PWA [28,31]. The provision of therapy that targets the dyad and assists with more effective and successful conversations is valuable in remediating these psychosocial consequences of aphasia [8,32,33].

Increasing conversation participation is a top priority identified by PWA, PCPs, aphasia researchers, and clinicians [9,34–36]. Furthermore, improving the communication and conversation skills of PWA and PCPs may reduce the risk of isolation and improve conversations in the home and community [37–39]. Aphasia therapies targeting couple or dyadic conversations have proven beneficial and fall under the umbrella of CPT [1,8,33,40]. The three key aims of CPT are (1) to establish explicit knowledge of aphasia in order to promote behavioural change, (2) to affect behaviour through explicit or implicit learning modelling coaching, and (3) to address feelings/attitudes about aphasia and communication [5].

Conversation therapies for aphasia, including CPT, can be delivered through generic training targeting health workers and volunteers [41,42] or individualised training, which can be one-to-one, working just with the PWA or the communication partner [8]. Conversation therapy and CPT can also target the dyad or couple [2,37,43,44]. These different delivery models may impact how conversation therapy outcomes are measured. The optimal way of measuring conversational success in couples has not been established, and the concept of conversation success has not been clearly defined [45]. It is therefore unsurprising that there are challenges in selecting an outcome measurement instrument that aligns with the goals of conversation therapy and CPT, particularly one that can measure unobservable changes occurring within the dyadic relationship [5,46]. Furthermore, in the field of aphasia, traditional approaches to measuring communication, which usually involve monologues, naming tasks and picture descriptions, do not reflect everyday interactions. These methods limit clinicians’ ability to assess communication success in real-life situations and contexts [47–49].

The development of PROMs has been identified as a priority for aphasia rehabilitation [50], as has the development of psychometrically robust measures of couple conversation success [5,9,49]. PROMs enable meaningful outcomes to be captured based on the self-ratings of people with lived experience [51]. This is important, as the person with lived experience is best qualified to judge whether a treatment has been effective for them [52]. Many underlying feelings and emotions in a conversation or communication exchange are subjective, reflecting that people with lived experience can best judge whether a conversation is successful [53]. PROMs can measure less observable features of a condition, such as feelings and emotions [54]. For this reason, they are valuable because they are person-centred and collect essential data on people's health or rehabilitation experiences [55]. PROMs are also able to capture the lived experience of different cultures and communities, and the need for more Indigenous-specific outcome measures to address healthcare inequalities has been raised [56]. The aim of the current study was to define conversation success from the perspective of the target population, PWA and PCPs, as the first step in the development of a PROM of successful dyadic conversation.

Methods

This study represents step 1 in the PROM development approach outlined by de Vet et al. [57]: the following six steps are recommended:

1. Defining the construct intended to be measured,
2. Choosing a measurement method,
3. Selecting and formulating items,
4. Choosing scoring methods,
5. Pilot testing, and
6. Field testing.

Step 1 involves “Defining the construct intended to be measured” (i.e., successful dyadic conversation). This was in part informed by our previous scoping review, which explored how communication and conversation have been measured in treatment studies with couples with and without aphasia [45]. Construct definition should also include the perspective of the target population. The current study used the nominal group technique (NGT) within online focus groups with people with lived experience of aphasia. NGT uses small-group discussions to generate and rank ideas [58]. The method uses structured turn-taking, which allows for the efficient generation of ideas and balanced contributions [58,59]. NGT is suitable for PWA as time is taken to give each person a turn, allowing equal participation and the use of appropriate communication strategies [35,60].

Ethical approval was obtained through the University of Queensland Human Research Ethics Committee A (2019/HE002639) and the New Zealand Ethics Committee, Te Roopu Rapu o te Tika (2022-44).

Establishment of stakeholder advisory group

PROM development requires the engagement and oversight of the target population at every stage of development. A stakeholder advisory group was established to ensure that lived experiences and knowledge could guide the research process. Using principles of consumer and community involvement (CCI) engagement [61], a group was established comprising two expert speech-language therapists experienced in CPT, two couples with aphasia (one couple who were Māori), and a member with expert experience in co-design research and CCI. To provide guidance and support regarding cultural safety, a Kaumatua (cultural advisor) was a vital member of the group. This advisor shared his experience of stroke and aphasia and provided advice on ways to ensure cultural safety for participants. The stakeholder advisory group had terms of reference to guide its aim and purpose.

Cultural considerations, the Aotearoa/New Zealand context

This research was conducted in Aotearoa New Zealand, where Te Tiriti o Waitangi (1840) (Treaty of Waitangi) acknowledges the partnership of the indigenous people and the British “crown” head of state. Research conducted in Aotearoa/New Zealand needs to consider Te Tiriti and the impact research will have on Māori iwi (tribes), hapu (communities), and whānau (families). The *Te Ara Tika* guidelines [62] are a kaupapa Māori ethical framework based upon applying Tikanga (traditional Māori practices) and Western ethical principles and support researchers in implementing te Tiriti into research practices. The knowledge and implementation of the Te Ara Tika framework incorporates the elements of whakapapa (relationships), mana (justice and equity), tika (research design), and manaakitanga (cultural and social responsibility). The engagement of participants who identified as Māori in the research required cultural considerations to ensure that they were acknowledged as equal partners in the research process [63] and also to consider the importance of Māori data sovereignty¹ [64].

Māori members of the stakeholder advisory group provided advice on appropriate cultural practice choices. The first author ensured that participants in this study who identified as Māori, the indigenous people of Aotearoa/New Zealand, were provided with a culturally safe environment to participate in the research. In the first meeting, this was achieved by asking the participants about their cultural needs and taking time for relationship-building through “whakawhanaungatanga” (making connections) and providing the researcher’s background and information about whakapapa (history and connections). The meeting was structured to incorporate a Te Ao Māori view, such as the offer of karakia (prayers), whakatauki (proverbs) to open and close the meeting, and including some relevant te reo Māori words and concepts such as “kōrero” (to speak or converse), which assisted in creating an environment where people can express their ideas freely and without judgement.

Participants, eligibility, and recruitment

The study involved two participant groups: (1) PWA and (2) PCP. Participants in both groups were over 18 years of age and had sufficient English skills pre-stroke to participate in an interactive group. PWA were eligible to participate if they met the following inclusion criteria: they were at least three months post-stroke and had a diagnosis of aphasia secondary to stroke. The aphasia diagnosis was confirmed through speech-language therapy assessment, including the Western Aphasia Battery-Revised (WAB-R) [65] and for those who had scores at or near the cut-off score, the use of self-report of the ongoing impact of aphasia on their conversations was considered relevant. PWA needed to be able to participate in a group setting using the English language. The use of te reo Māori (Māori language) was also accepted for words or concepts and was translated by the lead author or through discussion with the Māori participants. PWA were excluded if they had a history of dementia, traumatic brain injury, or degenerative neurological conditions. PCPs were eligible to participate if an eligible PWA identified them as their PCP. This person could be their spouse, partner, family member, or close friend. Participants needed to be able to participate in English without an interpreter. If participants used te reo Māori, the first author could clarify, interpret, and translate these terms as required.

Recruitment and sampling

Recruitment occurred in Christchurch and Auckland, New Zealand, through established local community aphasia groups and aphasia networks such as university programs. Information about the study and informed consent were provided via aphasia-friendly information sheets and a face-to-face explanation of the study in person or online. Communication support was provided to PWA so they could understand the study and provide informed consent. All participants in the study consented to participate.

Participants were purposively sampled to achieve variation in age, gender, and employment status (both participant groups). Age was included to capture participants who are still working or not able to work after the onset of aphasia. In addition, PWAs were sampled to achieve variation in aphasia severity (WAB-R), type of aphasia, and time post-onset of aphasia. The first author, a qualified speech-language

therapist, administered the WAB-R. Most assessments were conducted in the person's home. Assessments for two participants who lived in another region were conducted online.

Nominal question procedure

The nominal question: "What makes your conversations successful with your communication partner?" was developed and piloted with the stakeholder advisory group. All participants received the nominal question in writing before attending their focus group meeting to allow additional time for understanding the question and reflection. The nominal question was presented to PWA in multiple modalities and using supported conversation techniques [41]. The research facilitator used communication strategies to assist participants with aphasia, e.g., using pictograms, placing one question per page, bolding the key concepts in the question, using a large font, visualising the answering possibilities in words and pictures, reducing the question length, and excluding negatives in the question [60]. Focus groups were conducted between October 2021 and August 2022. All groups were conducted online over Zoom due to COVID-19 restrictions. Groups were video recorded and transcribed verbatim to ensure the accuracy of data collection.

The first author facilitated all the focus groups using a standard process [58]: (1) presentation of the nominal question; (2) generation of ideas through supported communication techniques; (3) round-robin feedback from group members with ideas recorded on the virtual whiteboard; (4) group discussion of each idea to allow for clarification and evaluation; and (5) individual voting on top three ideas.

Data analysis

Data analysis comprised two stages. First, a within-group analysis, where the prioritised ideas from each group were scored and summed to present the results quantitatively [59]. Votes were summed, i.e., the most important idea scored 3 points, the second most important scored 2 points, and the third item scored 1 point. Voting frequency was also factored into the calculation. For example, if an item scored a three by three participants, this was calculated as 3×3 for a total of 9. The scores were then summed to provide a list of items prioritised for each participant group.

Second, the focus group data sets for each participant group, which included the ranked items and the total list of ideas collated within each group, were analysed using inductive descriptive content analysis [66]. This analysis involves grouping similar ideas to form codes, and then codes are grouped into categories. The resulting categories were grouped into themes.

Reflexivity and rigour

In qualitative research, a researcher's background and own biases can influence the research process [67]. The first author is an experienced speech-language therapist with a background in aphasia rehabilitation and previous qualitative research. She was responsible for designing the research protocol, recruiting participants, conducting the focus groups and qualitative analyses. The co-authors are also speech-language therapists and experienced aphasia researchers. Authors SW and KS were involved in the research protocol design, data collection, and analysis. They reviewed the ranking and inductive content analysis [67]. Authors KH and CC contributed to the research protocol and provided critical review of the manuscript.

The first author maintained a reflexive journal and other documentation throughout the research process. Data analysis was reviewed, and agreement was reached through consensus between the first author and two other authors regarding the codes and categories of items to enhance the credibility of the research findings following the process described by McMillan et al. [59]. Rigour was maximised through the process of member checking [68], whereby all PWA and PCPs were invited to participate in meetings online, where the preliminary findings were presented to the participants. These meetings allowed participants to review the results, ensuring that the data reflected their contribution to the focus groups. Following advice from the stakeholder advisory group, the findings were presented to the PWA in an aphasia-friendly format. The first author recorded and facilitated the member check sessions, and any additional comments about the results were transcribed and

analysed, following the steps of qualitative content analysis described above. Feedback was sought from participants and from the stakeholder advisory group as to the best way to disseminate the research findings.

Results

Twenty PWA participated; the majority were male ($n = 14$; 70%), aged 35–83 years. The aphasia quotient (AQ) from the WAB-R ranged from 24 to 98, representing all aphasia severities (very severe $n = 1$, severe $n = 3$, moderate $n = 3$, and mild $n = 13$). Although ethnicity was not a sampling variable, it is of note for consideration of cultural factors and Māori data sovereignty that 18 participants identified as New Zealand European and two identified as Māori (see Table 1 for further demographic information).

Twenty PCP were recruited; however, one withdrew, resulting in 19 PCP participants. Fifteen were long-term partners or spouses of the PWA, three were parents, and one was a sibling. Participants ranged from 46 to 86 years; 13 PCPs were retired, five were working, and one was not working. Sixteen of the PCPs identified as New Zealand European, and three identified as Māori.

Eight focus groups were conducted: four with each participant group. The focus groups with PWA generated 99 items, of which 36 were prioritised. The PCP group generated 92 items; again, 36 items were prioritised (see Table 2 for the top 20 ranked items). The top-ranked items for PWA were: first equal, *my conversation partner knows me* (score 10) and *give me time and patience* (score 10). The item ranked as second-most important was *having a quiet environment* (score 8), and the item ranked as third-most important was *patience – both of us* (score 7). For the PCP focus groups, the item ranked as most important was *having patience* (score 22). There were two items ranked as second-most important: *be patient and listen* (score 8) and *time of day* (score 8), and the third-most important item was *don't interrupt, let them finish* (score 7).

Member-check meetings

Two member-check meetings were attended by $n = 10$ PWA and $n = 7$ PCPs. Participants agreed with the qualitative analysis and reported that it represented focus group discussions. Some categories that were highlighted as particularly important included: having patience, reducing frustrations, having a sense of humour, and familiarity. Participants raised concerns about the use of the term “multimodal communication,” reporting that it was not easily understood. Alternatives were suggested, including “nonverbal communication” or “using a variety of communication methods.”

Table 1. Purposeful sampling matrix for participants.

Sampling variables	Age	Gender	Employment status	Aphasia severity-WAB-R AQ	Aphasia type	Time post onset of aphasia	Relationship to PWA
PWAs $n = 20$	<65 $n = 9$	Men $n = 14$	Retired $n = 11$	Mild $n = 13$	Anomia $n = 8$	<12 months $n = 1$	
	>65 $n = 11$	Women $n = 6$	Working $n = 2$	Moderate $n = 3$	Fluent $n = 4$	1–5 years $n = 9$	
		Non-binary $n = 0$	Non-working/ volunteering $n = 7$	Severe $n = 3$	Non-fluent $n = 8$	5–20 years $n = 10$	
				Very severe $n = 1$			
			WAB AQ range: 24.6–98				
PCPs $n = 19$	<65 $n = 11$	Men $n = 5$	Retired $n = 13$	NA	NA	As above	Spouse/partner $n = 15$
	>65 $n = 8$	Women $n = 14$	Working $n = 5$				Sibling $n = 1$
		Non-binary $n = 0$	Non-working/ volunteering $n = 1$				Parent $n = 3$

WAB-R AQ: Western Aphasia Battery-Revised Aphasia Quotient; NA: not applicable.

Table 2. Top 20 ranked items for PWA and PCP.

PWA ideas generated across focus groups	Ranking order	Sum of scores for each idea	PCP ideas generated across focus groups	Ranking order	Sum of scores for each idea
My conversation partner knows me	1=	10	Having patience	1	22
Give me time-patience	1=	10	Be patient and listen	2=	8
Quiet environment	2	8	Time of day	2=	8
Patience, both of us	3	7	Don't interrupt, let them finish	3	7
PCP knows my aphasia	4	6	Clarify the topic	4	6
Being understood	5	6	Gestures, charades, pen, and paper	5	5
PCP asks questions to clarify	6	6	Reduce background noise	6	5
Write it down	7	6	Giving them time	7	3
Humour	8	5	Establishing the topic	8	3
Partner gives space and time to speak and contribute to the conversation	9	4	Humour	9	3
One on one	10	4	Recognise intelligence	10	3
Feeling included	11	4	Empower-do things that support confidence	11	3
Focus on the message	12	3	Let PWA drive the conversation	12	3
Body language	13	3	Relaxed environment (keep it simple)	13	3
Avoid conflict	14	3	Self-awareness	14	3
PCP understands me	15	3	Patience, give time	15	3
Laugh and relax	16	3	Ask opinions on relevant life matters	16	2
Show phone or items in room	17	3	Be face-to-face so your partner can read your lips	17	2
Conversation is better when not tired	18	3	Knowledge of aphasia	18	2
Less distractions	19	2	Talk about topics of interest	19	2
Relaxed environment	20	2	Love and laughter	20	2

Qualitative content analysis

For each participant group, analyses produced the same five themes: (1) working it out together, (2) having patience, (3) familiarity, (4) considering the communication environment, and (5) having a positive mindset. Within these themes, 15 categories were identified from the PWA, and 20 categories were identified from PCP. Themes are described below.

Theme 1: "Working it out together" facilitates successful conversation

Theme 1 reflects the dyadic nature of a conversation and the need for both communication partners to work together to support the conversation. Participants reported using a range of communication strategies to overcome potential conversation breakdowns. PWA shared specific communication strategies that worked well to repair any conversation breakdown. The use of specific verbal techniques to clarify the topic of conversation, ask questions, and initiate topics were discussed, as well as various means of nonverbal communication, such as using technology, gestures and pointing, and written keywords. For example, one participant stated, "I show them on my phone or things in the room" (PWA17, AQ 93.4).

PCPs also identified communication strategies used with their family member with aphasia. They discussed ways to find and clarify the topic, such as asking questions. PCPs discussed adapting their verbal communication to assist with understanding, such as using a slower speech rate and ensuring the PWA could see their face and lips. Similar to PWA, they identified specific strategies, including gestures, writing, and technology. These strategies were described as needing to be ready for use in any context; "I have learnt to have a pen and paper wherever we go- I can draw a picture, and he is starting to read single words now.... even on the beach, can use a stick..." (PCP8, under 65 years).

Theme 2: "Having patience" facilitates successful conversations

Theme 2 describes the importance of patience from both PWA and PCPs. Patience was described as a necessary response to the feelings of frustration that both conversation partners experienced due to

aphasia. PWA discussed patience as something the dyad needed to cope with frustration and regular conversation breakdowns. PWA identified strategies for the PCP, including coming back to it later, listening with patience and allowing time to communicate. Many PWA explained that having extra time to get their message across reduced their stress and frustrations. Deciding to come back to it later helped move the conversation forward, and the hope that the ideas might come easier later. PWA described having time to speak and not being interrupted as important communication strategies for their PCPs, which showed their patience: “I have time to speak and contribute to the conversation; easier to contribute because I have more time and strategies” (PWA16, AQ 96.7).

PCPs emphasised their role in helping to manage the frustration experienced by the PWA, and strategies included being patient and listening, giving time, and not interrupting. “The very first thing is an extreme amount of patience; you can feel frustrated, and this can transfer onto that person” (PCP4, over 65 years). During the member check process, PCPs generated additional less observable coping strategies, including “biting one’s tongue” or remembering to “just breathe.” PCPs reported that they were very aware of the need to allow time for the PWA to communicate their message. “You must listen to the person who has aphasia- listen, don’t interrupt, and ask few questions” (PCP9, over 65 years).

Theme 3: “Familiarity with your conversation partner” facilitates successful conversations

Theme 3 describes the role of familiarity in successful conversations that comes from having a close or long-term relationship and knowledge of the person and their life. For many participants, this involved knowledge of routines, roles, preferences, and understanding aphasia.

PWA described that familiarity with their PCP made conversations more manageable and reduced the burden. This involved the PCPs making accommodations for aphasia and reducing the communication burden, resulting in a supportive communication environment. One participant explained, “Oh... she understands what I’m trying to say and ... I feel sometimes I don’t get my words out correctly...” (PWA18, AQ 92.8). Likewise, PCPs also felt that knowledge of aphasia and how it impacted the PWA helped immensely in using appropriate strategies and understanding the needs of the PWA.

PWA acknowledged that shared knowledge and backgrounds enabled humour and a sense of closeness: “familiarity – knowing each other, sense of humour.... just close” (PWA20, AQ 94). From the perspective of the PCPs, familiarity with the PWA meant that the PCPs had a shared history and understood the PWA well. Knowledge of preferences, personalities, interests, and routines facilitated successful conversations by reducing the need to discover new information. For example, PCP16 (under 65 years) shared, “I can sort of guess what he is getting at, depending on what has happened in the day – so having the knowledge of what has gone on in his day that he wants to tell me about.”

Having shared experiences such as holidays and shared interests also contributed to easier conversations and the ability to be on the same page; “We’ve just been to, um, to, um and for a four-day holiday. And, uh, it’s been really super just recounting to each other the the, uh the the funny, the funny things” (PWA18). PCPs also discussed that shared hobbies and interests support successful conversations. The shared experiences meant that the PWA did not have to explain in detail what happened and that participation in the activities could be enjoyed through body language, laughter and gestures. This was exemplified by PCP4 (over 65 years), who stated, “Knowing each other’s routine and having a long relationship helps – reliance on each other. We can converse and talk about those ideas. Always done everything together – e.g. going fishing – many common things that we do – have gotten back to since stroke.”

Theme 4: “Considering the communication environment” facilitates successful conversations

Theme 4 describes the communication context and physical environment’s central role in successful conversations. Many participants noted that the conversation environment impacted the ability of the PWA to understand. Busy and noisy environments were described as a cause of stress when trying to converse.

PWA discussed their awareness of modifications to reduce distractions and make the environment quieter and more suitable for a conversation. The PCPs also reflected on how the environment could impact the success of conversations and emphasised the importance of reducing distractions and avoiding noisy environments. Being one-on-one, therefore, was described as a way to ensure successful

conversations. “One-on-one is easier, helps me focus” (PWA15, AQ 31). PCPs also described the need to be physically situated at the same level as the PWA (e.g., both sitting down) and be aware of any other physical disability, such as hemianopia, which can impact where one positions oneself for a successful conversation. Both participant groups identified coping strategies such as humour and being easy-going. One PWA described, “We laugh and relax” (PWA12, AQ 85.8).

PCPs raised awareness of the timing of the conversation in relation to fatigue. One participant stated, “It’s hopeless having a conversation when he is tired; it does not work. We all get so frustrated, so that’s really important to not have conversations when he is tired” (PCP14, under 65 years). PCPs also identified the need to give the PWA their full attention, for example, “I stop what I am doing, and give him my attention, give him time, especially at the beginning – giving him my full attention, pausing and letting him know I am really listening to him” (PCP12, over 65 years).

Theme 5: “Having a positive mindset” facilitates successful conversations

Theme 5 centres on the benefit of a positive mindset to support conversation success. PWA described positive feelings and emotions, such as being understood, included, relieved, and having fun through humour, which were associated with happiness and success. One PWA raised the feeling of mutual respect between conversation partners as necessary for making a conversation successful, stating, “Mutual respect of a conversation partner makes conversation relaxed and easier” (PWA16, AQ 96.7).

Having a positive mindset also included proactively managing the impact of aphasia. PWA often talked of the ways they manage frustrations or fatigue to ensure they can communicate or converse more successfully. PWA realised they were more successful when rested and used proactive strategies to ensure this happened, e.g., “Take a break have a rest” (PWA 4, AQ 86.6).

PCPs emphasised the importance of the couple’s attitudes, focusing on strengths and keeping positive. PCPs often framed how they created successful conversations by building confidence and independence and acknowledging intelligence. The positive mindset carried through with the ideas expressed by PCPs, acknowledging past life roles and being a team, was essential for supporting the PWA in feeling successful about themselves. For example, one PCP stated, “...he used to be a school principal, so it’s very important to make sure he still feels he has a role and he is valued” (PCP12, over 65 years).

PCPs also reflected on ways to cope with the impact of aphasia that is within their control. They felt they needed to be more self-aware of their feelings and attitudes and consider proactive ways to manage frustrations caused by aphasia when the conversation would break down. They discussed how keeping things “light-hearted” and having a sense of humour was important in facilitating successful conversations.

Tables 3 and 4 summarise the themes, categories, and items from the participant groups.

Discussion

This study aimed to identify how PWA and their PCP conceptualise the construct of successful conversation. PWA and PCP discussed *successful conversation* in the context of five themes: *Working it out together*, *Having patience*, *Having familiarity*, *Considering the conversation environment*, and *Having a positive mindset*. The themes were the same for both participant groups, reflecting the shared experience of conversations.

Many of the top-ranked items were well-known communication strategies for supporting conversations in aphasia [41,69,70]. The top-ranked items for participants with aphasia, such as (1) giving me time and patience and (2) having a quiet environment, reflect communication strategies regularly included in published conversation partner training programs [41,70,71]. The PWA identified other nonverbal strategies that are well-documented in past CPT systematic reviews [34,39], such as using gestures, writing things down and using technology to support conversations. Items and strategies not typically included in CPT and conversation therapies were also identified. For example, participants with aphasia ranked the item *my conversation partner knows me* highly, highlighting the importance of having a PCP who understands their background, routines, beliefs, and values. This theme of *Having familiarity* includes the consideration of common ground and context, which is not overtly considered or measured in aphasia

Table 3. Themes, categories, and items from the perspective of PWA.

Themes	Categories	Items ^a
Theme 1: “Working it out together” facilitates successful conversations	Identifying and clarifying the topic.	I repeat the topic if they don't understand. Choose topics of interest to the person. PCP asks questions to clarify. PCP repeats the information to help me understand. PCP focuses on the message and works it out.
	Using a variety of communication supports.	Body language. Write it down. Working it out together. Looking at each other (lip-read). Use technology to support (maps, contacts, to identify places and people) Use of gestures/charades/iPad. Showing photos (on the phone) or items in the room.
Theme 2: “Having patience” facilitates successful conversations	Having patience-both of us.	<i>My partner is very patient, both of us are. (Ranked 3)</i> Be patient (not to get frustrated) PCP listens with patience.
	Allowing time to communicate.	Time to speak and contribute to the conversation. <i>Give me time-patience. (Ranked 1=)</i> Time to talk/listen. Time to get my thoughts and ideas out. Easier to contribute because I have more time and strategies. Don't finish my sentence – I want to give my ideas and opinions. Come back to it later. <i>My PCP knows me. (Ranked 1=)</i> My PCP understands me. Being on the same wave length. 1:1 is easier because of familiarity. Familiarity – knowing each other and our sense of humour . Familiarity with my PCP.
Theme 3: “Having familiarity with the conversation partner” facilitates successful conversations	My PCP knows me.	<i>My conversation partner knows my aphasia. (Ranked 4)</i> My conversation partner understands my aphasia.
	My PCP knows my aphasia.	Having similar backgrounds and families. Socialising with other old friends. Common interests help conversation topics – recounting shared experiences.
	Having shared experiences and interests.	Spending time and talking with grandchildren. Fewer distractions. Quiet, not too noisy. <i>A quiet environment. (Ranked 2)</i> Turn off the TV and other distractions. Have each other's attention. Laugh and relax. Creating a relaxed environment. One-on-one is easier, I can concentrate more easily. One-on-one is easier because of familiarity.
Theme 4: “Considering the communication environment” facilitates successful conversations	Go to a quiet space.	Mutual respect of a conversation partner makes conversation relaxed and easier. <i>Being understood. (Ranked 5)</i> Feeling included Feeling relieved
	Being relaxed.	Having a sense of humour Laugh and relax
	Being one-on-one.	Coming back to it later Taking a break My conversation partner calms me down Avoiding conflict Accepting imperfection Acknowledging that it is difficult
Theme 5: “Having a positive mindset” facilitates successful conversations	Having mutual respect.	Rest Conversation is better when not tired Having shorter conversations when fatigued
	Experiencing positive feelings	
	Having a sense of humour	
	Managing frustrations constructively	
	Managing fatigue	

^aTop 5 ranked items.

conversation therapy and CPT [39,40]. Nevertheless, having familiarity is an important finding that benefits the conversation as the PCP can fill in the gaps and understand what the PWA may think or feel about a topic. Acknowledging how familiarity and common ground facilitate successful conversations is a useful addition to dyadic conversation interventions and outcome measures in aphasia.

Along with the more familiar communication strategies, this research identified important coping strategies for facilitating successful conversations in aphasia. The top 4 ranked items for PCP were (1)

Having patience, (2=) *Considering the time of day*, (2=) *Being patient and listening*, and (3) *Not interrupting and letting them finish*. Listening and not interrupting are well documented in aphasia couple therapy programs [2,8]. Past CPT programs have included knowing a person's routines and taking opportunities for conversations at any time of day as important for conversation success [40]. However, the consideration of the timing of the conversation in relation to managing fatigue has not been documented in past CPT programs, yet it was an essential consideration for many PCPs in the current study. Strategies for fatigue management are part of recommended best practice stroke rehabilitation guidance, and the links between fatigue, depression, and anxiety are documented [72]. However, excluding PWA from previous post-stroke fatigue studies leaves a gap in this data, and the need to include PWA in future post-stroke fatigue research is highlighted [72]. The current study provides some preliminary insight into the impact of post-stroke fatigue on communication and conversation and how managing the fatigue affects family members and dyads.

Another critical finding discussed in all four focus groups with PCPs was having patience. Having patience was vital in acknowledging the frustration that aphasia causes and was an essential mechanism for reducing frustrations for both communication partners. This notion is not a construct measured by current outcome measurement instruments [45]; however, it was such a dominant theme in the focus groups as vital for successful conversations and having patience is the foundation leading to other strategies PCPs employed. In our study, participants identified that patience leads to staying calm and listening, coming back to it later, not interrupting, and trying the wide range of identified communication strategies. For this reason, we identified the item and theme of *Having patience* as a coping mechanism.

For the PCPs, this consciousness of coping was also evident in the categories of *Managing frustrations constructively*, *Having self-awareness*, *Building confidence*, *Building independence*, *Considering life roles*, *Having patience*, and *Acknowledging intelligence*. PWA also contributed similar categories: *Experiencing positive feelings*, *Managing fatigue*, *Managing frustrations constructively*, *Being relaxed*, and *Having patience*. Traditionally, CPT programs and conversation outcome measures have not directly addressed the impact of attitudes and feelings for dyads affected by aphasia [5]. Supported conversation for aphasia [41] strongly emphasises acknowledging the competence of the PWA and has also devised a way to measure this through the Measure of Supported Conversation scales [73]. However, the range and depth of the coping mechanisms resulting from this current qualitative research will enable these more qualitative aspects of successful conversation to be overtly measured via the new PROM.

The role of coping strategies

A wide range of communication strategies were identified based on the lived experiences of PWA and PCPs. Furthermore, coping strategies were identified that reflect the impact of a person's attitude, feelings, and the mindset they bring to a conversation and their relationship. The inclusion of personal coping strategies to enable participation in PWA is reinforced in a communication participation approach based on the WHO ICF model developed by Baylor and Darling-White [74]. The model places communication participation at the centre of three domains: (1) communication skills – impairment and activity, (2) the communication environment – social and physical, and (3) personal perspectives – preferences and coping mechanisms. These three domains form the basis of treatment and interact with each other to ensure treatment success. The current research findings, which have identified the importance of having a positive mindset and attitude and supporting a person's self-efficacy and self-esteem in conversation, support Baylor and Darling-White's approach and provide another model to consider when delivering conversation therapy for couples and CPT programs.

Communication participation is also promoted in a conversation therapy approach designed to promote self-repair and increase self-efficacy in dyadic conversation for PWA [75]. The theme of *Having patience* demonstrates that PCPs are aware of the benefits of allowing time for the PWA to find their words and contribute to the conversation and the knock-on effect on their confidence and self-efficacy for ongoing conversational success. The treatment approach described by Leaman and Archer [75] uses clinician-rated conversational analysis and coding methods. Their findings show the importance of

Table 4. Themes, categories, and items from the perspective of PCP.

Themes	Categories	Items ^a
Theme 1: "Working it out together" facilitates successful conversations	Clarifying the topic	<i>Clarify the topic. (Ranked 4)</i> Repetition of what is said – reaffirm topic Clarification is important throughout the conversation Clarifying – checking who or what they are talking about Asking questions to narrow down the topic Cueing questions to work out the topic
	Finding the right topic	Establishing the topic Topic – common interests are better – find the right subject Talk about topics of interest I let her drive the conversation more-helps her focus on what the topic is. Find out some more information on the topic by using phone, emails, text
	Ensure they understand	Asking opinions on relevant life matters Being on the same level – both have understood equals success Make sure they understand Be aware they might not understand or might bluff Don't change topics rapidly – 1 topic at a time
	Use a variety of communication supports.	<i>Use gestures, charades, pen and paper (rank 5=)</i> Encourage PWA to use drawing/visuals/gesture Write some things down Use of technology to support conversation PWA shows on the phone – photos, emails to explain what they have been doing Use of online information, e.g., News to help have in-depth discussion
	Adapting your communication	Write numbers down, sports tactics, dates, etc. Speaking slowly Be face to face so partner can watch lips Getting close and making him concentrate Avoid asking too many questions to avoid brain fatigue Grouping words together Repeat what is said – reaffirm
Theme 2: "Having patience" facilitates successful conversations	Having patience	<i>Having patience. (Ranked 1)</i> <i>Be patient and listen. (Ranked 2=)</i> Don't dismiss when you don't understand
	Allowing time to communicate	<i>Don't interrupt. Let them finish. (Ranked 3)</i> Communication partner listening closely Let them have their say – make sure to include them Resist the urge to fill in the gap Giving them time to talk Giving them time to think Giving time to respond Patience, give time to communicate
Theme 3: "Having familiarity with the conversation partner" facilitates successful conversations	Having shared activities and interest	Spend time with grandchildren Shared common interests – can understand body language, give opinions, laugh
	Knowing the person	Knowing the person Person is still the same Long relationship – knowing each other Knowing a person makes it easier to be on the same page Shared memories and background – know what they are wanting to say Knowing each other's routine
Theme 4: "Considering the communication environment" facilitates successful conversations	Knowing about aphasia Consider the time of day	Knowledge of aphasia <i>Time of day, avoid when fatigued. (Ranked 2=)</i> Pick the right time, avoid when tired/stressed <i>Reduce background noise/Avoid noise/Limit distraction. (Ranked 5=)</i>
	Location	Relaxed environment – keep it simple Location of conversation – relaxed and quiet environment Café rather than home for a good conversation
	Give your full attention	Give full attention Getting close helps concentration Being aware of where to position self (e.g., consider hemianopia) Be face-to-face so your partner can watch your lips

(Continued)

Table 4. Continued.

Themes	Categories	Items ^a
Theme 5: "Having a positive mindset" facilitates successful conversations	Having a sense of humour	Act with love and laughter Having a sense of humour
	Managing frustrations constructively	Feeling a sense of achievement – (we got there – the strategies worked) Make sure they are not stressed She needs to know she is being heard Acknowledge good days and bad days Be calm and easy going
	Having self-awareness	Having self-awareness (Am I ok?) Acknowledge that the conversation has changed
	Building confidence	Empowering – doing things that support confidence Playing to strengths Build confidence at home and with family The more conversations she has, the more confidence she has
	Building independence	Show interest and willingness Help them build independence
	Acknowledging intelligence	Recognising and acknowledging intelligence Person is still the same
	Considering life roles	Acknowledge their previous role Giving a role

^aTop 5 ranked items.

clinicians' skills in developing and teaching dyads about conversation strategies. The combined use of PROMs and clinician-rated measures enables best-practice methods for capturing meaningful treatment outcomes. It is proposed that a new PROM for dyadic conversation in aphasia could be used in conjunction with clinician-rated measures, enabling an optimum way to obtain the outcomes of treatment success [9,50].

The relationship is important

Aphasia can negatively impact marital satisfaction [17,76] and cause third-party disability for significant others and family members of PWA [27] who are PCPs for many PWA. Past aphasia research has identified priorities for families and partners of PWA, including supporting familial relationships, having communication strategies and tools for addressing communication breakdown, as well as managing the impact on the marital relationship [35,76]. Therefore, the findings from this research, which emphasise the importance of self-efficacy and supporting positive interactions, provide further evidence for conversation therapies and CPT programs to focus more directly on coping strategies, attitudes and mindset and address the impact of aphasia on relationships.

Furthermore, the development of a PROM for dyadic conversation in aphasia, which includes a focus on measuring mindset and attitudes along with communication strategy training, will address the third identified target area from Saldert et al. [5], which is that CPT programs consider feelings/attitudes about aphasia and communication. The new measure would also address the identified gap that there is no PROM available to address dyadic communication and relationships for couples affected by aphasia, and would provide a way to measure the efficacy of CPT programs [9,77].

Limitations and future directions

In the current study, the research participants were predominantly identified as New Zealand Europeans (87%) and Māori (13%), giving some variation in cultural perspectives. The Māori members' involvement in the stakeholder advisory group enabled cultural insights essential for cultural guidance and fostering reciprocity in sharing the research outcomes with Māori networks in the future [63]. Balancing cultural responsiveness with evidence-based practice for speech-language therapy resources and outcome measures is an ongoing priority to address health inequities for minority groups and indigenous populations [78,79]. Cultural acceptability studies will enhance the PROM development process for ensuring the future application to different contexts and cultures.

The findings of this study will inform the items within a PROM for dyadic conversation in post-stroke aphasia. Similar research in related populations, such as those with primary progressive aphasia or traumatic brain injury, would be helpful to guide practice for conversational success in these populations.

Conclusions

This research provides the perspective of PWA and their PCPs about what makes a successful dyadic conversation based on their lived experience. Various verbal and nonverbal communication strategies have been identified that facilitate successful conversations for couples and close family members. New insights into dyadic coping mechanisms post-stroke and aphasia have been shared. These include maintaining a positive mindset and attitude and describing the conscious coping strategies that family dyads and couples use to support successful conversations and relationships. There is an identified gap in the field of aphasia for suitable outcome measurement instruments that not only measure everyday conversation for dyads and couples but also consider how to measure the impact of aphasia on relationship communication and long-term relationship satisfaction. The results generated in this research will contribute to an item bank for future PROM development to measure conversational success for dyads where one person has aphasia.

Note

1. Māori data sovereignty refers to the inherent rights and interests that Māori have in relation to the collection, ownership, and application of Māori data.

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Data availability statement

The data that supports the findings of this study are available by request of the first author.

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