Both individuals and their family members can be significantly and long-lasting, with most cases of aphasia persisting for the remainder of an individual’s life. The chronic nature of aphasia has led some authors to suggest that, rather than focusing on healing the pathology of aphasia, interventions should aim to enable individuals to live successfully despite their communication disability (e.g., Holland, 2007a, b). Holland (2007b) has advocated the need for a greater emphasis in intervention programmes on interpersonal strengths of people with aphasia and their families to assist them in developing a fulfilling way of life. The concept of living successfully with aphasia has emerged as one alternative to more traditional ‘deficit’ models in aphasiology. Research focusing on living successfully with aphasia does not aim to ignore or minimize the potentially devastating effects of aphasia. Instead, it encourages the identification of potential positive factors, processes, and personal strengths that may inform clinical interventions for enabling individuals to live with aphasia.
In 2006, a special issue of *Topics in Stroke Rehabilitation* first examined the concept of living successfully with aphasia (Holland, 2006a). Four exploratory studies provided suggestions for living successfully with aphasia based on case study examples from interviews of individuals with aphasia (Boles, 2006; Cruice, Worrall, & Hickson, 2006a; Holland, 2006b) and examination of already published written accounts authored or co-authored by people with aphasia (Hinckley, 2006). Salient features of living successfully with aphasia identified across all four studies included social relationships and support, and autonomy or independence. Findings from individual studies also highlighted, among other factors, the importance of involvement in personally meaningful activities (Cruice et al., 2006a); renegotiating self-identity and setting new future goals (Hinckley, 2006); and the influence of personal characteristics, time post-stroke, and good physical and psychological health (Holland, 2006b).

These studies were not designed to be in-depth examinations of the topic, but instead to illustrate the significance of the topic and highlight the need for additional research. Authors of the studies called for further investigation of the phenomenon, including the development of better methods of documenting and measuring concepts related to living successfully with aphasia. One of the main criticisms of the studies was the selection of participants based on researcher-defined criteria of living successfully with aphasia, with the criteria not made explicit. Previous research examining the concepts of successful ageing in gerontology and consumer-driven “non-tragic” models of disability highlight the potential for large discrepancies between researcher or health professional and individuals’ definitions of successful living.

In order to expand on this preliminary research and address potential methodological differences, Brown, Worrall, Davidson, and Howe (2010a, b, 2011) recently published the findings of three separate studies describing the perspectives of individuals with aphasia, speech-language pathologists, and family members on the meaning of living successfully with aphasia. All three participant groups provided unique and valuable contributions to inform the concept of living successfully with aphasia. However, in order to best inform clinical practice this study sought to integrate findings across the participant groups.

Evidence suggests disparities between current speech-language pathology services and client values and priorities in a number of areas (e.g., Law et al., 2009), including availability and accessibility of information and therapy (Parr, Byng, & Gilpin, 1997), goal setting and goals of therapy (Worrall, Brown, Cruice, Davidson, Hersh, Howe, et al., 2010), and the way therapy is ended (Hersh, 2009). Only through continued reflection on how current practices align with clients’ values and priorities can improvements be made to the provision of client-centred care. By synthesizing findings on living successfully with aphasia across individuals with aphasia, family members, and speech-language pathologists, areas of commonality and discrepancy between the groups can be examined in greater detail to illuminate clinical implications.

While findings across the three studies on living successfully with aphasia were discussed in the context of the literature reviews and discussions of each study, the impetus for the current paper arose from the need for a more detailed, rigorous examination that qualitatively integrated the perspectives of the three participant groups. Congruencies noted between the main themes across the three studies suggested shared or similar perceptions across the three participant groups on a broad level. However, it was also noted by the authors that many of the sub-themes identified provided evidence of potential conflicts or tensions between participants in describing components of living successfully with aphasia. The rich and detailed qualitative data made it difficult to adequately describe findings from across the three studies in narrative discussions or literature reviews.

In recent years many authors have identified an increasing need for improved methods of synthesizing qualitative research, based on the argument that the true potential of qualitative research to inform practice and policy can not be achieved unless findings from individual studies can be meaningfully linked (e.g., Noblit & Hare, 1988; Paterson, Thorne, Canam, & Jillings, 2001; Sandelowski & Barroso 2007; Sandelowski, Docherty, & Emden, 1997). Qualitative meta-synthesis or meta-analysis involves the interpretative integration of findings from completed qualitative studies (Sandelowski & Barroso 2007). One means of synthesizing qualitative research is integrating findings from multiple studies within a research programme by the same authors (e.g., McCormick, Rodney, & Varcoe 2003; Sandelowski et al., 1997; Varcoe, Rodney, & McCormick, 2003). Sandelowski (1995) provides an example of using this approach (in the context of a program of research on infertility) to reformulate multiple study findings at a higher level of abstraction, with an explicit focus on contrasting two distinct groups of participants. This study shares the same aim of synthesizing findings across different groups of participants in order to discuss the ramifications of areas of congruency and discrepancy for informing clinical practice.

Analysis of data from multiple studies by the same authors offers the advantage of those authors having a closer relationship with the data, thereby giving the potential for a more fine-grained, detailed analysis, and a better ability to maintain the integrity of the original individual studies (McCormick et al., 2003). It also avoids some of the methodological difficulties of qualitative meta-analysis in determining topical
and methodological similarity between studies (Sandelowski et al., 1997). Although this approach may suggest methodological parallels to triangulation, it differs because it aims to create a richer, interpretative integration of findings, identifying areas of convergence and divergence, rather than using multiple sources of data to confirm or validate commonalities (McCormick et al., 2003).

Synthesis or meta-analysis of qualitative data remains controversial, with some contending that it is epistemologically inappropriate to attempt to integrate qualitative findings that are by their very nature ideographic and highly contextualized, and thus should not be generalized (see Sandelowski & Barroso, 2007). Researchers have expressed concerns regarding the potential loss of the integrity and uniqueness of the human experience, which give qualitative studies their value (Sandelowski et al., 1997). However, we support the opinions of Sandelowski et al. (1997), Noblit and Hare (1988), and McCormick et al. (2003), who argue that while qualitative studies cannot be generalized according to positivist definitions of generalizability, they can lead to naturalistic generalizations, which extend understanding of particulars. Qualitative meta-analysis is not grounded in a positivist paradigm, in which synthesis is based on comparability and concerned with accumulative knowledge, and determining a “greater truth” or causal relationships. Rather, qualitative meta-analysis falls under an interpretivist or constructivist paradigm, in which explanations of social phenomenon or experiences are sought based on the unique perspectives of individuals. The aim of qualitative meta-analysis under a constructivist paradigm is to use an inductive and interpretative approach to account for similarities and differences around the perspectives of individuals on an experience and enable new reconstructions of meaning through broader, richer data sets.

By examining the perspectives of individuals with aphasia, speech-language pathologists, and family members on the topic of living successfully with aphasia through qualitative meta-analysis, both overarching commonalities and more subtle differences between the groups can be analysed in greater detail. It is hoped that this will afford a richer understanding of the concept of living successfully with aphasia as a basis for informing clinical practices. The aim of this research was, therefore, to synthesize the perspectives of individuals with aphasia, speech-language pathologists, and family members in exploring the concept of living successfully with aphasia through qualitative meta-analysis.

Method

Qualitative meta-analysis approach

Qualitative meta-synthesis or meta-analysis involves the interpretative integration of findings from completed qualitative studies (Sandelowski & Barroso 2007). It is achieved through an inductive, iterative process of systematically “translating” or re-interpreting and transforming concepts from an individual study into another (Noblit & Hare, 1988), in order to reformulate multiple study findings at a higher level of abstraction (Sandelowski, 1995).

Noblit and Hare’s (1988) seven-step process was one of the earliest, ground-breaking methods for successful qualitative meta-analysis (McCormick et al., 2003). Table I provides details of how each of the steps was applied in the current study. Initially, researchers read and reread the original study findings in order to become familiar with the texts. Themes and sub-themes from each study were listed and juxtaposed to identify themes that were conceptually similar. These themes and sub-themes were then compared and contrasted in greater detail across the three studies, by returning to the original data to verify, contradict, or extend interpretations. Based on these comparisons new overarching themes were created to account for the areas of congruency and disparity across the participant groups. An iterative approach was utilized, in which emerging overarching themes were checked and rechecked against the original studies’ findings to ensure the integrity of data from the original studies had been maintained. Overarching themes arising from the meta-analysis process were described through a narrative account that highlighted the congruencies and discrepancies of data across the participant groups. Venn diagrams were constructed as a means of visually displaying the overlapping relationships between the three participant groups for each overarching theme (Sandelowski & Barroso, 2007).

Description of the original studies

Three studies conducted as part of a doctoral research program informed the qualitative meta-analysis. Ethical clearance for the studies was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland. Each study aimed to explore the concept of living successfully with aphasia from the perspective of a different participant group: Study 1, 25 individuals with aphasia; Study 2, 25 speech-language pathologists; and Study 3, 24 family members. Speech-language pathologists were recruited independently of the participating individuals with aphasia (i.e., were not treating clinicians of the participants with aphasia) because many of the participants with aphasia had ceased speech-language pathology services. Family member participants were nominated by the participating individuals with aphasia. Data were collected for all three participant groups through semi-structured, in-depth interviews. Interview transcripts were analysed using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003, 2004; Smith, Jarman, & Osborn, 1999). IPA uses a bottom-up,
may have influenced their interpretations of data to their own biases, as speech-language pathologists (Lincoln & Guba, 1985). The authors acknowledge the need to compare and contrast the qualitative findings from the three participant groups in the parent study in a more rigorous, detailed manner. Three studies reporting results from each of the participant groups were included in the analysis.

Researchers read and reread reports from the original studies. Themes and sub-themes from each of the three studies were listed, with themes that were conceptually similar juxtaposed. Themes and sub-themes were compared and contrasted across the three studies, with the researchers returning to the original data to verify, contradict, or extend interpretations. Based on the translation of themes and sub-themes in Phase 5, new overarching themes were identified that encapsulated data across the participant groups. Narrative accounts were written describing each overarching theme. Findings were discussed in relation to existing literature in order to draw clinical implications based on the data.

Table I. Steps in the meta-analysis process.

<table>
<thead>
<tr>
<th>Phase 1: Getting started</th>
<th>How step was applied for this study</th>
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<tr>
<td>Identify an intellectual interest that qualitative research might inform</td>
<td>The need to compare and contrast the qualitative findings from the three participant groups in the parent study in a more rigorous, detailed manner.</td>
</tr>
<tr>
<td>Phase 2: Deciding what is relevant to the initial interest: Decide what studies or accounts are relevant, based on the intended audience, what is credible and interesting, what accounts are available, etc.</td>
<td>Three studies reporting results from each of the participant groups were included in the analysis.</td>
</tr>
<tr>
<td>Phase 3: Reading the studies: Repeatedly read accounts and note interpretative metaphors*</td>
<td>Researchers read and reread reports from the original studies.</td>
</tr>
<tr>
<td>Phase 4: Determining how the studies are related: Determine the relationships between the studies by creating a list of the key metaphors*, phrases, ideas, or concepts for each study and juxtaposing them with those of the other studies.</td>
<td>Themes and sub-themes from each of the three studies were listed, with themes that were conceptually similar juxtaposed.</td>
</tr>
<tr>
<td>Phase 5: Translating the studies into one another: Translate the studies by treating accounts as analogies: “One programme is like another except …”. An adequate translation maintains the integrity of the central metaphors or concepts of each account, while identifying similarities and differences between different accounts.</td>
<td>Themes and sub-themes were compared and contrasted across the three studies, with the researchers returning to the original data to verify, contradict, or extend interpretations.</td>
</tr>
<tr>
<td>Phase 6: Synthesizing translations: Compare translations to identify concepts that transcend individual accounts and can be used to produce a second level of interpretation.</td>
<td>Based on the translation of themes and sub-themes in Phase 5, new overarching themes were identified that encapsulated data across the participant groups.</td>
</tr>
<tr>
<td>Phase 7: Expressing the synthesis</td>
<td>Narrative accounts were written describing each overarching theme. Findings were discussed in relation to existing literature in order to draw clinical implications based on the data.</td>
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*metaphors are defined by Noblit and Hare (1988) as “referring to what others may call the themes, perspectives, organizers, and/or concepts revealed by qualitative studies” (p. 14).

iterative process to identify themes of importance from a text. Conceptually related clusters of themes were grouped hierarchically as themes and sub-themes. Table II describes the participant characteristics and main findings from each study. For further details readers are referred to the original publications (see Brown et al., 2010a, b, 2011).

Rigour

To increase the rigour or trustworthiness of the meta-analysis procedures, a process of peer debriefing was utilized, whereby co-authors examined and discussed emergent translations of themes to challenge analyses, to probe potential areas of bias, and to ensure the reasonableness of interpretations made (Lincoln & Guba, 1985). The authors acknowledge their own biases, as speech-language pathologists may have influenced their interpretations of data collected.

Results and discussion

The qualitative meta-analysis process identified seven overarching themes that encapsulated data across the three participant groups. These were:

1. Participation;
2. Meaningful Relationships;
3. Support;
4. Communication;
5. Positivity;
6. Independence; and
7. Living successfully with aphasia as a journey over time.

Themes are described in detail below, highlighting the congruencies and discrepancies observed across the participant groups. Findings from each theme are discussed in relation to the literature in order to suggest clinical implications arising from the data.

Participation: Living successfully with aphasia occurs through participation in meaningful activities

All three participant groups placed a strong emphasis on the importance of participation in meaningful activities for living successfully with aphasia. Hobbies or leisure activities were most prominently mentioned, but activities centred around the home, travel, work, volunteer work, and vocational training or study were also referred to. Findings from all three participant groups indicated the value of resuming activities from pre-stroke life, adapting activities, and developing new hobbies or interests (see Figure 1).

In the context of describing participation, participants referred to a wide range of activities, focusing on those activities that were most enjoyable and meaningful to individuals. This includes activities that were communication-based (for example reading newspapers and books or using a computer to email family) as well as many activities that were not...
Table II. Description of the original studies informing the meta-analysis.

<table>
<thead>
<tr>
<th>Study</th>
<th>Study 1: Individuals with aphasia. Snapshots of success: An insider perspective on living successfully with aphasia (Brown et al., 2010b)</th>
<th>Study 2: Speech-Language Pathologists. Exploring speech-language pathologists’ perspectives about living successfully with aphasia (Brown et al., 2010a)</th>
<th>Study 3: Family Members. Living successfully with aphasia: Family members share their views (Brown et al., 2011)</th>
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<tr>
<td>Participant characteristics</td>
<td>A total of 25 individuals with aphasia participated in the study. All individuals were 2 years or more post-onset, had aphasia as a result of stroke, and were living in the community. Participants were recruited through community-based groups or clinics, and 12 females and 13 males, aged 38–86 years (mean age 63.2 ± 12.2) participated in the research. Individuals with a range of aphasia severities were included in the sample.</td>
<td>Speech-language pathologist participants were recruited through special interest groups for speech-language pathologists working with adult caseloads in Australia. All participants had a current caseload including clients with aphasia, but were sampled for variation in years of experience and differing work environments across the continuum of care. One male and 24 females participated.</td>
<td>Family members were nominated by the participating individuals with aphasia. Each individual with aphasia was asked to identify their closest family member. A total of 24 family members (nine males and 15 females) took part in the study. Of these, 21 lived with the person with aphasia, while three did not. Participants were predominantly spouses of individuals with aphasia, but parents, siblings, and children were also represented.</td>
</tr>
<tr>
<td>Main findings</td>
<td>Analysis of participant transcripts revealed that the concept of living successfully with aphasia is complex and highly individualized. Four core themes related to living successfully with aphasia emerged from the data: doing things; meaningful relationships; striving for a positive way of life; and communication.</td>
<td>Through the analysis of speech-language pathologist participant transcripts, the following themes emerged as components of living successfully with aphasia: participation and community engagement; communication; meaningful relationships; independence; acceptance and embrace of aphasia; self-esteem; happiness; and purpose or meaningfulness. A wide variety of factors were perceived to influence individuals’ abilities to live successfully with aphasia. These included support, acceptance, and understanding; personal factors; and speech-language pathology services.</td>
<td>Seven themes were identified from analysis of family member participant transcripts. The themes relating to living successfully with aphasia were: getting involved in life; support for the person with aphasia; communication; family members’ own needs; putting life in perspective; focusing on and celebrating strengths and improvements; and experiences with services.</td>
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(for example gardening, photography, or wood-carving). Participants perceived that restrictions in activities occurred as a result of both communication and physical impairments. It was interesting to note that speech-language pathologists recognized the value of participation in non-communication-based activities in order to provide individuals with aphasia opportunities to participate successfully without reliance on their communication skills. Although this was not mentioned explicitly as a focus by participants with aphasia, many did identify activities that could be characterized as non-communication based.

There was a general consensus across the three participants groups that participation in activities enabled individuals with aphasia to gain a sense of independence and to foster pleasure and well-being. Participation was also valued because it provided:

- A sense of purpose or usefulness (identified in data from participants with aphasia and speech-language pathologists);
- Stimulation for the brain (identified in data from participants with aphasia and family members);
- A sense of normality (identified in data from family members); and
- A sense of ability and achievement (identified in data from participants with aphasia).

These findings reinforce previous research emphasizing the importance of participation for individuals with aphasia. Cruice, Hill, Worrall, and Hickson (2010) found that “activities” were the most influential factor affecting quality-of-life according to individuals with aphasia. Other studies discussing the negative impacts of reduced or restricted activities have also highlighted the significance of participation (e.g., Cruice et al., 2003; Hilari, Wiggins, Roy, Byng, & Smith, 2003; Le Dorze & Brassard, 1995).

The wide variety of activities identified by participants suggests a need for speech-language pathologists to explore in detail the interaction between...
aphasia and participation in everyday activities, on a client-by-client basis. Findings provide support for interventions that focus on meaningful communicative activities for clients, as well as considering the availability of opportunities for clients to participate in activities that are non-communication based. Participants also illuminated the many different underlying reasons why participation in activities is valued so highly, suggesting that the variation in the meaning individuals assign to activities should also be considered in clinical practice. The two most frequently mentioned reasons for valuing participation were to gain a sense of independence and to foster pleasure or well-being. The importance of independence for living successfully with aphasia is also prominent in previous research (Boles, 2006; Cruice et al., 2006a; Hinckley, 2006; Holland, 2006b) and as a main theme in its own right within this study. Findings indicate that clinicians should therefore work with clients to identify activities that have the greatest impact on their independence as initial targets for interventions addressing participation.

**Meaningful relationships: Living successfully with aphasia occurs in the context of meaningful relationships**

Another common theme across data from the three participant groups was meaningful relationships (see Figure 2). Comments from participants emphasized the importance of social companionship, connectedness, and positive interactions with others as core components of living successfully with aphasia. Parr, Byng, and Gilpin (1997) describe language as the “currency” of relationships (p. 44). Findings from this study illustrate the significant impact aphasia has on relationships, but also reinforce the idea that living successfully with aphasia can only occur within the context of love, acceptance, friendship, and support from others. In particular, participants emphasized the value of relationships with family, friends, and other people with stroke and aphasia.

In terms of friendship, both participants with aphasia and speech-language pathologists described the difficulties individuals with aphasia face in maintaining friendships following their strokes. For participants with aphasia, loss of friendship was often perceived to be associated with a lack of understanding and acceptance from friends: “Friends … they didn’t know about aphasia … the misunderstanding of what it was … it’s very upsetting”. Many expressed a desire to meet more friends and also reported they did not see existing friends as often as they would like. Speech-language pathologists also believed that changes in friendship can occur as a result of friends’ reactions, but suggested that, in addition, changes in friendship may arise because of social withdrawal by those with aphasia: “they don’t have the confidence to see their friends”. While acknowledging that aphasia often has a negative impact on friendships, both participants with aphasia and speech-language pathologists expressed their views that friendships that continued post-stroke, as well as the development of new friendships, contributed positively to individuals’ abilities to live successfully with aphasia. Family members and participants with aphasia also expressed their beliefs that individuals with aphasia needed to be proactive in going out and meeting new people.

Social isolation or reductions in social networks, and a desire for increased social interaction are commonly reported sequelae of aphasia (Cruice, Worrall, & Hickson, 2006b; Davidson, Howe, Worrall, Hickson, & Togher, 2008; Hilari & Northcott, 2006; Le Dorze & Brassard, 1995). Social relationships and support was identified as a salient theme to living successfully with aphasia across the four exploratory studies on this topic (Boles, 2006; Cruice et al., 2006a; Hinckley, 2006; Holland, 2006b), and this
study provides further collaboration of the importance of social relationships to individuals with aphasia. Findings from this study indicate that one reason that individuals may lose friends is because of a lack of understanding about aphasia. As Davidson et al. (2008) advocate, future research is required to extend our understanding of changes in friendship following the onset of aphasia, and to develop community interventions and training programmes for friends of individuals with aphasia.

All three participant groups identified other stroke and aphasia survivors as a valuable source of new friendships, acceptance, and support for individuals with aphasia. Comments from participants suggested that strong bonds form between peers with stroke and aphasia, based on the inherent nature of their understanding of each other through the mutual experience of stroke and aphasia. Participants with aphasia described how they valued new friendships and the opportunity to relax and have fun with other stroke and aphasia survivors. One participant with aphasia commented, “When you’ve had something wrong with you … you need to get friends who have the same problem … this is one thing that we’ve all got in common”. Family members and speech-language pathologists likewise commented on the role of peers in providing friendship and support, but also suggested aphasia groups played an important role in empowering individuals by providing them with opportunities to contribute to society and help others. For example, family members described how involvement in aphasia groups had enabled their family member with aphasia to be “part of a process for improvement” and to “pass experiences … on”. Offering encouragement and support to others within their aphasia groups, becoming active members of support organizations, and being advocates in the community for aphasia were also identified by speech-language pathologists as providing individuals with a purpose or meaningfulness in life. Previous research has reported improvements in both communication and psychosocial adjustment as a result of group treatment of aphasia (Elman & Bernstein-Ellis 1999a, b), and these findings suggest group interventions that facilitate peer support should remain a priority.

Finally, meaningful relationships with family were identified as perhaps the most highly valued relationships for individuals with aphasia. Findings from across the three participant groups indicated the importance of individuals maintaining positive relationships with family. For example, family members described the need for couples with aphasia to work as a “united front” and have “love and respect”. Comments from participants with aphasia illustrated the importance of social occasions with family, keeping in touch with family interstate and overseas, and family members being “always there” and accepting individuals with aphasia for who they were despite their changed communication.

While positive aspects of relationships with family were illuminated, findings also emphasized the impact that aphasia can have on family roles and relationships. Speech-language pathologists and individuals with aphasia both identified the need for individuals with aphasia to actively contribute to family life or maintain relationship roles (for example, the role of parent or spouse) in order to be living successfully with aphasia. For some family members, aphasia was perceived to have had little impact on their relationships; for others, it had resulted in large changes. In particular, many family members, especially spouses, described changes to communication within their relationship and expressed a desire for more effective communication with the individual with aphasia: “I would like to be able to have more conversation with him too. It’s more or less just answering or asking questions. Not sitting down and having a proper conversation”. Changes in family roles as a consequence of aphasia were described as resulting primarily from family members assuming greater responsibilities within the relationship and becoming carers or a support person for the individual with aphasia. Support for the individual with aphasia was described as a core component of living successfully with aphasia across the three participant groups. The prominence placed on support led to its emergence as a separate, but related theme to meaningful relationships. The complexities of support in the context of changing family roles and relationships are discussed further below.

Support: Living successfully with aphasia necessitates support for individuals and for family members

Support within the context of meaningful relationships emerged strongly as an additional theme for living successfully with aphasia (see Figure 3):

Support you … is a big thing. [participant with aphasia]

I truly believe that a supportive environment is imperative to living successfully with aphasia … the most important is supportive family. [speech-language pathologist]

Support, support, support. [family member]

Family members were perceived to be the main providers of support for individuals with aphasia, with recognition also given to the role of support from friends and aphasia or stroke groups. Many congruencies were observed in descriptions of support as a key feature of living successfully with aphasia across the participant groups. Similarities were also noted in the types of support described. These included: practical support (e.g., with chores around the house), emotional support (e.g., encouragement and companionship), support to participate in activities, and support with communication.

Family member participants provided a unique perspective in highlighting their own requirement for
support as carers: “For the carer, being able to do the hard yards ... sometimes that gets really tough ... it’s having a support network for the carer. So that they can go and talk it out ... having an ear to listen”. In describing their own needs, family members referred to how their own lives had changed as a result of their role as the primary support person for the individual with aphasia. For example, participants described their desire for their family member with aphasia to share the burden of family roles, responsibilities, and decision-making; the restrictions placed on their own participation in activities as a result of aphasia; and their need to put their own priorities first and have time to themselves. Comments reflected how difficulties in communicating with the individual with aphasia had altered family roles and relationships. Thus, at the same time as playing a key role in providing support, family members felt under-supported themselves and in some cases felt unable to communicate effectively with their aphasic family member.

Data from participants with aphasia and family members also alluded to the complexities of finding a balance between support and independence or autonomy, within the context of family relationships and roles. For some participants with aphasia, distinction was made between support, which was welcomed, and sympathy or pity, which was not: “You need support. You don’t need pity. You don’t need someone, oh I’m so sorry. That doesn’t get you anywhere”. There was also an emphasis from participants with aphasia on family and friends treating them no differently than before their stroke.

Similarly, family members acknowledged the importance of not over-protecting their family members or treating them differently under the guise of providing them with support: “We don’t mollycoddle”, “They’re still the same person they were ... treat them as normal people”. For many family member participants, however, there was evident tension in determining the appropriate level of support to provide to their family member, especially in the early stages post-stroke. One family member commented, “You want to do it for them—what they can’t do”. Others voiced their struggle in balancing their desire for their family member to achieve independence or autonomy and worries about safety (for example, how their family member would cope living alone, going out alone, or in an emergency). Concerns about safety were particularly noted in family members who didn’t live with the person with aphasia, were parents of individuals with aphasia, or whose family member with aphasia had additional health concerns such as seizures.

These findings emphasized the complexities of the support needs of both the individual with aphasia and family members in the context of family relationships and roles. There is a clear role indicated for speech-language pathologists to provide interventions ensuring clients with aphasia and family members have access to adequate support networks. Speech-language pathologist participants made three references to support in describing aspects of their services perceived to facilitate successful living: the importance of a supportive clinician–client relationship, the need to provide some form of ongoing support to clients after discharge, and the importance of providing education and information to individuals and their family members. Overall, family members did not feature prominently in speech-language pathologists’ comments about support provision.

Previous research has advocated for the increased involvement of family members in the rehabilitation process (e.g., Avent, Glista, Wallace, Jackson, Nishioka, & Yip, 2005; Holland, 2007a; Michallet, Le Dorze, & Teatreault, 2001; Worrall et al., 2010). Results from this study indicate the need for interventions that acknowledge the multiple roles family members may play:

1. Family members as support persons for the individual with aphasia. As this study has indicated, family members play a significant role in supporting the individual with aphasia. Family members may be a valuable resource within the rehabilitation process because they know their family member better than anyone else, can provide important background information (Worrall et al., 2010), and will assist in the recovery of their family member outside of the
therapy room. As Holland (2002) advocates, services must therefore “honor family members’ expertise” and allow them meaningful involvement as partners in the rehabilitation process (p. 174).

(2) **Family members as clients with their own unique support needs.** Data from this study suggest a number of gaps in service provision for family members, and this is congruent with a substantial literature documenting the needs and wants of family members of individuals with aphasia (e.g., Avent et al., 2005; Denman, 1998; Le Dorze & Signori, 2010; Michallet et al., 2001, 2003). There is a need for services to recognize family members as potential recipients of care themselves. Intervention programmes for family members (for example, family group therapy) are gaining momentum (e.g., Fox, Poulsen, Clark Bawden, & Packard, 2004), and further research is needed in this area.

(3) **Family members as members of a relationship dyad.** One of the findings from this study that is also supported by other literature (e.g., Le Dorze & Brassard, 1995; Michallet et al., 2003) is the ongoing difficulty family members experience in communicating with the person with aphasia and the impact this has on their relationship. There is therefore a clearly indicated need for interventions focusing on communication within the context of spousal or other family member dyads. Communication partner training (e.g., Boles, 1997; Booth & Perkins, 1999; Cunningham & Ward, 2003; Fox, Armstrong, & Boles, 2009; Hopper, Holland, & Rewega, 2002; Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001) may be one suitable method of addressing this need more effectively.

**Communication: Communication plays an integral role for living successfully with aphasia across all areas of life**

Communication was another overarching theme identified across data from all three participant groups. While all three groups emphasized the importance of communication for living successfully with aphasia, there were some notable differences in the way each participant group described communication, and in the different aspects of communication that were most strongly emphasized (see Figure 4).

For speech-language pathologists, individuals perceived to be living successfully with aphasia were described as “good communicators”, defined by participants as being communicators who were able to get their messages across using all available modalities and through the successful use of multiple strategies. Individuals with aphasia also identified the use of communication strategies as being important for living successfully with aphasia. However, in contrast to speech-language pathologists, individuals with aphasia placed a strong emphasis on verbal communication (“talking” or “speaking”). Family members also more commonly referred to verbal communication over other aspects of communication. It was interesting to note that when participants with aphasia did describe communication strategy use, they referred to strategies that had been self-developed through personal experience over time, rather than strategies that had been introduced by speech-language pathologists.

For all three participant groups, comments referring to communication illustrated the integral role it plays across all areas of life, with the richest data to demonstrate this point coming from the individual accounts of participants with aphasia. Examples of how communication interacts with the themes of participation, meaningful relationships, and support have already been provided in descriptions of these themes above. In particular, interactional components of communication and the impact of aphasia on relationships were strongly emphasized. For example, speech-language pathologists described the importance of personal and social communication over and above basic functional communication that conveys needs and wants. Family members expressed a strong desire for conversation with the person with aphasia. For individuals with aphasia, the impact of aphasia on friendships was one particularly prominent aspect of communication in participant transcripts.

![Figure 4. Findings across participant groups for the theme of communication: People with aphasia (PWA), speech-language pathologists (SLPs) and family.](image-url)
Finally, speech-language pathologists also suggested that enjoyment of and confidence with communication were important aspects for living successfully with aphasia. Family members also referred to self-confidence in their accounts of living successfully with aphasia, but applied the term more broadly to individuals’ confidence in themselves, rather than with respect to communication only. These aspects of communication were not noted in the data of participants with aphasia.

Descriptions of communication for living successfully with aphasia arising from this study reinforce the need for holistic aphasia management approaches that address communication in the broader context of an individual’s everyday life. For example, in line with frameworks such as the International Classification of Health, Functioning and Disability (ICF) (World Health Organization, 2001; see also McLeod, 2008) and the Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen, et al., 2008). The emphasis placed on verbal communication by individuals with aphasia and their families may present a challenge to speech-language pathologists in the establishment of joint aims in the therapeutic relationship. Speech-language pathologists may play an important role in providing education about other modalities of communication and encouraging and supporting people with aphasia and their families to use them. The importance of considering interactional components of communication or communication in the context of relationships was also emphasized.

**Positivity: A positive approach is needed for individuals and families to live successfully with aphasia**

A positive approach was also perceived to be important for living successfully with aphasia. This theme did not emerge strongly in the data of speech-language pathologists, although the need for a positive approach in therapy was described by some participants. In contrast, for individuals with aphasia and family members, this theme featured more prominently, with a strong emphasis on the necessity of a positive attitude and a focus on improvements and strengths for living successfully with aphasia (see Figure 5).

Individuals with aphasia described living successfully with aphasia in terms of focusing on the improvements they had made, and how far they had progressed (across all areas of their lives, but in particular in communication skills) since when they first had their stroke. One participant stated, “When I had my stroke—2 years [ago]—I can see how far I’ve come … a gauge … I had no voice and couldn’t speak. Two years—I can talk properly”. Family members expressed similar views, and further highlighted the fact that celebrating early successes was important to provide confidence, hope, and a foundation on which to build further successes.

While a small number of speech-language pathologists acknowledged the need to be positive and focus on strengths and improvements in therapy, individuals with aphasia and family members reported conflicting experiences of being offered hope through services. The way information was provided by health professionals was described as a key factor influencing individuals or family members’ abilities to maintain a positive outlook. For example, one individual with aphasia contrasted the discouraging manner in which his doctor provided information to the more positive manner of his speech-language pathologist: “Talk positive. Like that stupid doctor says … can’t do this, can’t do that … always talk negative … [Speech-language pathologists] they talk the other way. Maybe. You may have. It may happen”. Another family member participant provided an example of how their hope had been taken away by comments from a speech-language pathologist: “One of them said … you’re wasting your money … she’s never going to improve”. Therapy tasks offered also had the potential to provide encouragement (“The speech therapy session … Because I learn every day. Words and how to get over it and go ahead [participant with aphasia]”) or discouragement (“After my encounter with the drill [therapy drills] I was not impressed … a lot of it was just totally inappropriate … soul destroying [family member]”).

These comments reinforce the need for services to focus on providing hope and positivity to individuals and their families, while highlighting the fact that current services are not always meeting this goal. Findings from this research support a previous study of what individuals with aphasia and their family members want from speech-language pathology services, which likewise emphasized hope in the rehabilitation process (Worrall et al., 2010). In the general population a positive outlook is perceived as a key component of quality-of-life (Bowling & Gabriel, 2007), health (Miller & Iris, 2002), and successful ageing (Knight & Ricciardelli, 2003) in older adults.

In addition to focusing on positivity and improvements, all three participant groups made reference to the contribution of personal strengths towards living successfully with aphasia. Traits described...
Independence and autonomy: Feelings of independence and autonomy are important for living successfully with aphasia

Independence and autonomy was another theme emerging from the meta-analysis of data across the three participant groups (see Figure 6). For participants with aphasia, independence was primarily described in terms of their ability to do everyday activities by themselves. Independence was sought across activities in all areas of their lives, encompassing both activities that would be impacted on greatly by aphasia (e.g., ordering in restaurants or looking up bus timetables to catch a bus), and those with little reliance on communication (e.g., putting on make-up). Living independently in one's own home also emerged as a theme for participants with aphasia.

Speech-language pathologists likewise recognized the significance of independence in everyday activities and living in one's own home. However, they described autonomy of decision-making or control over their own lives as perhaps the most important aspect of independence for individuals with aphasia.

Comments from speech-language pathologists strongly emphasized issues of empowerment and ownership of life decisions for living successfully with aphasia, in particular in the key areas of relationship, financial, legal, and health-related matters. In contrast, only one participant with aphasia commented on the importance of being involved in decision-making in the context of family decisions.

Another area identified by speech-language pathologists that was not mentioned by individuals with aphasia was the importance of independence in communication (for example, individuals with aphasia not being reliant on another person answering questions for them). These differences between results of individuals with aphasia and speech-language pathologists may have resulted from individuals with aphasia being unable to express more complex ideas such as autonomy in decision-making or because legal or social issues of independent living did not happen to be important to the specific participants with aphasia in this study. For family members, there was not a strong emphasis on independence as a component of living successfully with aphasia, although family members' own needs (such as a desire for time to themselves) may reflect a lack of independence on the part of their family member.

The importance of clinicians working with individuals with aphasia to address issues of independence in everyday activities has already been discussed under the theme of participation. Findings from speech-language pathologists indicate that clinicians may also perceive themselves to have a role influencing the independence of their clients through advocating for their decision-making capacity and ability to live independently where appropriate. This finding is supported by Ferguson, Duffield, and Worall (2010), who found that speech-language pathologists are currently playing active roles when decision-making for clients with aphasia may fall easily into the scope of practice for speech-language pathologists (for example, ensuring information provided to clients is aphasia-friendly or accessible so that they can make informed decisions about their care), other aspects may not be so clearly defined. Further research is indicated to explore further the role of speech-language pathologists in facilitating independence for individuals through advocacy, and to develop guidelines of practice for speech-language pathologists in these areas.

Living successfully with aphasia as a journey over time: Accepting, moving forward, and living through the ups and downs

Lastly, the metaphor of living successfully with aphasia as a journey over time emerged as a new theme during the meta-analysis process (see Figure 7).
Commonalities arising from the translation of themes and sub-themes from each of the original studies into one another gained prominence when considered across the three participant groups. They were grouped under the new theme of living successfully with aphasia as a journey over time, which encompasses participants’ perspectives that:

- Living successfully with aphasia takes time;
- Living successfully with aphasia is not a smooth journey, and for many the journey is ongoing;
- Acceptance and moving forward are key points along the journey; and
- The journey of each individual or family will be different.

All three participant groups emphasized that living successfully with aphasia takes time. One speech-language pathologist stated, “I think that it’s a journey. It takes a long time for people—up to 2, 3, 4, 5 years to move through the phases and then come out the other side”. For some participants with aphasia there was a perception that things gradually improved with time, while others advocated taking a day-by-day approach. Individual stories illustrated that in some instances the journey of living successfully with aphasia encompassed large life changes occurring over long time periods. For example, after the onset of his aphasia, one individual had initially gone through a deep depression and contemplated committing suicide, but at the time of the research rated himself as living “very successfully” with aphasia. His story demonstrated how the journey of living successfully with aphasia can take place over many years.

The journey metaphor also encapsulated participants’ perceptions that living successfully with aphasia is not a smooth journey, and that, for many, the journey is ongoing. Comments from both participants with aphasia and family members highlighted the fact that for some there is no clearly defined endpoint to the journey of living successfully with aphasia, because they are continually striving for further improvements. One family member said, “You accept it … doesn’t mean that you just want to leave it as it is. You always want to try and master it and get on top of it better than you are, but at the same time you realize that you just have to be content”. A large number of participants with aphasia still hoped for or wanted to regain functioning and expressed the desire for complete recovery of their “speech”, despite conceding in many cases that they knew this may not be possible. Many also framed their concepts of living successfully in terms of things they missed from the past or desired for the future. They therefore continued to strive for further improvements or changes to their lives, and were not satisfied with their current status. For many, the journey of living successfully with aphasia day-to-day was not smooth, but rather “a roller-coaster ride” [family member], or a journey of “ups and downs” [participant with aphasia], and steps forward and backwards: “you take three forward and then you drop back two” [participant with aphasia].

For all three participant groups, acceptance was identified as a key point on the journey. Speech-language pathologists described their perception that for individuals with aphasia, acceptance was a process that required time, with individuals making a transition from initial thoughts of catastrophe or denial, then moving through stages of grieving, before reaching a point of acceptance. For many participants with aphasia, accepting that they were not going to return to their pre-stroke level of functioning presented a significant challenge, yet they acknowledged it was a necessary step for living successfully with aphasia. One individual commented, “And I know it’ll never be the same as what I was before I had the stroke … And as I say I hate to accept it, but I’ve got to accept it”. Changes that individuals with aphasia had to learn to accept included their impaired communication, as well as specific inabilities following their stroke (for example, not being able to drive or an inability to return to work). Family member perspectives highlighted that it is not only the individual with aphasia that needs to accept aphasia and its related lifestyle changes, but also family members.

Following on from acceptance, all three participant groups also made reference to the importance of moving forward with life. For family members, this was reflected in comments about re-assessment of life priorities following the onset of aphasia: “It’s given us … time to sit back, take a look, and realize what we want to do with our lives”. In some instances this had led to positive life changes for family members; for example, one participant changing her working pattern to spend more time with her partner following his stroke. Nearly all family member participants proffered the advice to “just keep going ahead”, while participants with aphasia also espoused a mindset of “moving ahead” and “getting on with life” by focusing on the future rather than the past, and by trying new things or adapting activities in order to move forward with life. Speech-language
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For all three participant groups, the idea of moving forward was strongly linked to individuals getting involved in activities and not letting aphasia prevent them from “living”. One speech-language pathologist described those living successfully with aphasia as individuals who “learn to deal with their impairment and their disability and then … embrace life again … leading a full life and still doing things that they enjoy despite their impairment”. All three groups also highlighted the importance of happiness as a measure of moving forward and living successfully, although again it was stressed that there would always be ups and downs, and that living successfully with aphasia did not mean being happy 100% of the time. For speech-language pathologist participants, high self-esteem was considered another indicator of moving forward: “Though they may have low times, [those living successfully with aphasia] have quite high self-esteem. And can feel comfortable with who they are now”. Finally, data across the participant groups illustrated that the journey of living successfully with aphasia is highly individualized, as reflected in the complexities and multifaceted nature of participant responses. As one speech-language pathologist stated, “I think it really is different for each person, and it depends on what they want and what they need”.

These findings are consistent with other literature suggesting that living successfully with aphasia takes time, with individuals’ longer term goals and priorities emerging as they come to terms with the chronicity of aphasia (Holland, 2007b; Worrall et al., 2010). Speech-language pathologist participants in this study criticized system or service policies that dictated the amount and timing of services their clients were receiving, arguing that services should be allocated based on clients’ perceptions of need and readiness. One commented, “There’s so little invested in chronic aphasia”; with another asking “why can’t they decide on [treatment] intervals themselves? Why do we have to decide?” Hersh (2009) found that many individuals with aphasia upon discharge from therapy still believe they would have benefitted from continued services. Taking into consideration the chronicity of aphasia, findings indicate a need for speech-language pathologists to advocate for ongoing services for clients. As Holland (2002) advocates, the ongoing needs and changing goals of individuals over time “should mandate continual management” (p. 109). The individualized nature of the journey of living successfully with aphasia also highlights the importance of speech-language pathologists routinely gathering information from the person with aphasia and his or her family to compare it to their own views about important issues for living successfully with aphasia for the individual client over time.

Conclusion

This qualitative meta-analysis study aimed to synthesize the perspectives of individuals with aphasia, speech-language pathologists, and family members on the meaning of living successfully with aphasia. Throughout the results clinical implications for each theme were discussed in detail. Key implications arising from the study included:

- The need for a holistic, client-centred approach that considers communication in the broader context of an individual’s daily life, with emphasis on participation, meaningful relationships, support, and independence and autonomy;
- A call for greater involvement of family members in the rehabilitation process and services that cater for family members’ needs alongside those of the individual with aphasia;
- The need for positivity and hope in rehabilitation services; and
- Services that acknowledge the chronicity of aphasia by addressing individuals’ changing needs over time.

One limitation of this study was that the speech-language pathologist participants were not the treating clinicians of the participating individuals with aphasia and their family members, and so specific congruencies or discrepancies within individual therapist–client relationships could not be explored. Future research may include more detailed examination of issues arising from the seven themes discussed in this study. For example, future research could explore how the theme is currently being addressed by speech-language pathologists in clinical practice, evaluate the effectiveness of current interventions, or develop and trial new intervention guidelines. One finding from this study was the evident changes in the needs of individuals with aphasia and their families for living successfully with aphasia over time. All participants with aphasia informing this study were at least 2 years post-onset. Longitudinal research that statistically models factors associated with living successfully with aphasia over time may add another valuable layer to current knowledge on the topic. Perspectives from all three participant groups provided unique and valuable contributions to inform the concept of living successfully with aphasia in this study. By working in partnership with individuals with aphasia and their families, speech-language pathologists, along with other healthcare professionals, are challenged to continue to improve services and assist clients on their journey of living successfully with aphasia.

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References


