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## Friendship matters: a research agenda for aphasia

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### ABSTRACT

*Background:* Social isolation and loneliness are often present after aphasia and lead to negative health, social, and physical outcomes. Maintaining social connections after aphasia has been identified as an important target for intervention, but is not regularly addressed in aphasia intervention. While many persons with aphasia maintain relationships with immediate family members after brain injury, there are considerable changes to the substance and quantity of friendship networks early on in the recovery period.

*Aims:* The aims of this article are to examine the literature on the topic of friendship within and across disciplines and to propose a research agenda for supporting the maintenance of friendships in persons living with aphasia.

*Main Contribution:* The benefits of friendship to quality of life and wellbeing are well documented. Persons living with aphasia are at high risk for social isolation and reduction of friendship network due to multiple factors including reduced language capacity and social participation, costs and benefits associated with sustaining friendships, and changing social roles and identities. This article identifies 1) prospective research variables that may influence the creation, maintenance, and dissolution of friendship networks, 2) requirements of friendship research based upon these variables, 3) descriptions of interventions designed to improve existing and new friendships, and 4) potential outcome measures for capturing friendship changes and general well-being. We also highlight the link between reducing social isolation and loneliness by targeting friendship at an early stage in the recovery process and recommend a detailed plan for preventing the loss of friendship networks for people with aphasia.

*Conclusions:* Strategic research and development of interventions targeting the maintenance of existing friendships is necessary to support the reduction of social isolation in persons with aphasia. The authors propose a research agenda which includes co-design of research projects and interventions for friendship maintenance as one means of addressing the issue of social isolation in persons with aphasia.

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## Introduction

“When you can’t talk and when you’ve had a stroke – um – you lose a lot of your friends (crying silently)” Brown et al., 2013, p.168.

Having a stroke is sudden and leads to significant life changes including social isolation and depression (Haun et al., 2008). Social isolation and social connectedness have been identified as significant health factors which may also influence well-being (Haun et al., 2008). Post stroke, individuals with aphasia have higher rates of depression than individuals post stroke without aphasia (Kauhanen et al., 2000). People with aphasia report feeling lonely (Nätterlund, 2010; Nyström, 2006) and feelings of loneliness can appear to create a distance with others (Nyström, 2006). The impact of social isolation and loneliness, critical components to participation, have negative health, social and physical implications. These impacts are comparable or higher than risks of smoking cigarettes or obesity (Gerst-Emerson & Jayawardhana, 2015).

Dalemans et al. (2010) succinctly state that “in order to participate you need to interact” (p. 538) and interaction requires language, a tool that aphasia damages. This places individuals with aphasia at a disadvantage for participating and having social connection. Even though aphasia challenges a person’s ability to maintain a strong social network in the months following a stroke, social isolation and loneliness are not regularly addressed in aphasia intervention, (Northcott et al., 2016). Yet, a key recommendation in a white paper on the “state of aphasia” included improving attention to life participation and social inclusion across the continuum of care in aphasia (Simmons-Mackie, 2018).

One way to address social isolation in aphasia is through the maintenance of friendship networks. Friendship is an essential ingredient contributing to feeling socially connected and increased quality of life and physical health (Simmons-Mackie, 2018). Friendship is an integral and highly rewarding part of the human condition. The bonds of mutual affection between friends can form in a variety of contexts and feelings of intimacy may vary depending on the strength of an interpersonal connection (Argyle & Henderson, 1984).

Though friendship is a complex and multifaceted phenomenon, the preponderance of evidence demonstrates an association between participation in friendships and general quality of life (Friedman & Rizzolo, 2018). Being in the presence of friends (as opposed to being with family or alone) often creates feelings of happiness (Larson & Bradney, 1988), or even joy (Argyle, 1987). People who have regular contact with friends or who are connected to larger numbers of friends tend to evince better health outcomes than people who are more isolated (Van der Horst & Coffe, 2012).

A variety of factors that commonly exist within the lives of people with communication impairments such as aphasia may jeopardize friendships. People with aphasia report that relationships with friends and family are viewed as having great value in life (Nätterlund, 2010), however often find it difficult to engage in the deep and detailed conversations that foster connection (Brown et al., 2013). Further, people with aphasia may feel the mutuality and reciprocity that characterizes healthy, enjoyable relationships cannot be maintained (Byng et al., 1997). A scoping review of literature on the experience of relationships for people with aphasia (including friends) revealed themes related to difficulties with timing in conversations with friends, as people with aphasia were often interrupted and not given enough time to contribute during interactions

(Ford et al., 2018). For these reasons, people with aphasia are at high risk for losing friendships (Northcott & Hilari, 2011; Vickers, 2010). Given the negative psychosocial effects of major, life-long health conditions such as aphasia (Le Dorze & Brassard, 1995), the well-being and related benefits of a sufficiently large and active social network could play an important role in helping people with aphasia adjust to living with a lifelong communication disability. Finding ways to support and foster friendships between people with and without aphasia will likely contribute to overall quality of life for our clients and help them and their families participate more fully across many domains of living.

Ford et al. (2018) propose that as clinicians, we must begin to understand how people with aphasia maintain friendships over time and this begins by asking both people with aphasia and their friends about their relationships. Additionally, Le Dorze et al. (2014) challenge clinicians to strategically target therapy services to support satisfying relationships. Despite this, there are no clear intervention guidelines available for clinicians to support people living with aphasia in maintaining existing friendships. Subsequently, this paper proposes a strategic research agenda to develop therapeutic interventions that target the maintenance of existing friendship networks. The overarching aim of this proposed agenda is rooted in improving social inclusion, quality of life, and the lived experiences of people with aphasia.

### **A proposed framework for friendship research in aphasia**

Although the benefits of friendship are well documented and include improvements in physical and psychological well-being, a paucity of research has addressed friendships in older adults (Blieszner et al., 2019). Even less attention has been directed toward exploring friendships of older people with disabilities. Although most stroke survivors experience a drastic decline in contact with friends (Northcott et al., 2016), having aphasia seems to exacerbate this decline. Stroke survivors with aphasia are more likely to experience considerable changes to the substance of friendships and lose entire networks of friends when compared to stroke survivors without aphasia (Northcott & Hilari, 2011). Maintaining friendships after aphasia is important to people with aphasia and their families and has been identified as an important outcome of aphasia intervention (Brown et al., 2013). However, several unexplored research questions remain about friendship in aphasia.

In the following sections we identify 1) prospective research variables that may influence the creation, maintenance, and dissolution of friendship networks, 2) requirements of friendship research based upon these variables, 3) descriptions of interventions designed to improve existing and new friendships, and 4) potential outcome measures for capturing friendship changes and general well-being. By identifying these factors through a proposed research agenda, our goal is two-fold: 1) To highlight the link between reducing social isolation and loneliness by targeting friendships at an early stage in the recovery process and 2) to focus energies on maintaining existing friendships, not necessarily developing new friendships in people with aphasia. While aphasia certainly does not discriminate by age, this particular paper will focus primarily on friendships in older adults.

## Factors influencing friendship networks

There are several variables that must be considered for research questions aimed at sustaining friendships after aphasia, the most obvious of which includes structural dimensions of friendships such as network size and frequency of contact. For older adults without disabilities, it is generally agreed upon that both the size of friendship networks and frequency of contact with friends decrease as people age (Wrzus et al., 2013). Social convoy theory (Kahn & Antonucci, 1980) maintains that there are different levels of relationships across a person's social network and relationships with people in the innermost circle (e.g., spouses) are stable throughout life, but relationships in the periphery of the convoy (e.g., friends) are less stable and susceptible to external circumstances such as life-changing events (Wrzus et al., 2012).

Aphasia is certainly a life-changing event that carries with it shifts in communication abilities, social roles and identity, independence, and psychological well-being. While older people do have a reduction of friendship networks in terms of size and frequency of contact, the occurrence of aphasia disproportionately impacts this trend. In two separate studies comparing the social relationships of older people without aphasia to those with aphasia, findings have indicated that people with aphasia had a lower total number of friends, decreased communication exchanges with friends, and decreased frequency of contact with friends (Davidson et al., 2008; Hilari & Northcott, 2017). Other studies investigating friendships after aphasia detail similar findings (Cruice et al., 2006) and have helped to raise awareness of the loss of social networks that so often occur after aphasia.

Other variables influencing friendship networks are less recognized in the aphasia literature. Features of friend networks such as external, internal, and personal characteristics are inextricably tied to factors like size of network and closeness. These features must also be considered as potential research variables. For instance, nonnormative life events such as the death of a relative or relocation are considered external factors that can have profound effects on social relationships (e.g., Blieszner & Adams, 1998). Internal factors may include a person with aphasia's premorbid positive attitude, motivation, or social skills and are associated with differences in friendship ties in older adults. For example, theory of mind skills such as understanding others and being motivated to use social skills has been shown to influence friendship outcomes (Lecce et al., 2017).

Finally, personal characteristics including gender, race, socioeconomic status, education, culture, geographic region and so forth also likely play a role in creating or maintaining friendships. Several studies have examined the intersections of personal characteristics and their impact on friendship networks. Findings include variations in friend networks that are influenced by socioeconomic status, power within a community, and religion (Adams & Torr, 1998). Gender and level of education also appear to play a role in how friendships are sustained. Women and men provide different types of supports to their friends and individuals with more education provide more help to friends (Kahn et al., 2011). Furthermore, while some factors related to friendship networks appear to be cross-cultural, there are important differences in the composition and prevalence of friendship networks that may be related to differences in cultural equality and hierarchy, ethnic homogeneity, life expectancy, and marital status (Fiori et al., 2008).

Studies thus far have not explicitly investigated the impact of personal characteristics on preserving friendships after aphasia. However, in their study of protective factors, Northcott and Hilari (2011) found that the availability of a friend (including mobility and physical health) and distance to a person with aphasia were both strong protective factors for maintaining friendships after aphasia. In a separate longitudinal study on factors predicting strong social networks, Northcott et al. (2016) found ethnicity to be a significant predictor of social network functioning post stroke. It is likely that other factors such as attitude, motivation, theory of mind, gender, status and power, among others, also play an important role in friendship maintenance. These factors may be predictive of the types of friends that continue relationships with a person with aphasia after stroke. They also may be prognostic indicators for friends most likely to benefit from programs aimed at friendship maintenance.

*Styles of friendship.* Not all friendships are alike or serve similar purposes. The definition of “friendship” may vary from person to person, even within the same culture. Matthews (1986, 1995) proposed a model of three distinct friendship styles based upon a qualitative study of 63 older adults in the U.S: 1) the discerning friendship style, 2) the independent friendship style, and 3) the acquisitive friendship style. The discerning friendship style included persons who only had a select number of deeply committed friendships. The independent friendship style also had a limited number of friends, but did not establish long-lasting friendships and let life circumstances regulate relationships. Individuals in the acquisitive friendship style set out to make new friends throughout their lives and enjoyed both long-standing and distant relationships. Importance differences were noted between the groups in relation to number of friends, commitment level, replaceability, and closeness. Not all individuals value similar types of friendship, and beliefs about friendship often determine how one will seek out or maintain relationships with friends. Differences in friendship style have rarely been explored in the aphasia literature. Research in aphasia should consider pre-morbid friendship styles and values with the understanding that these preferences will impact the types of friendships that may be targeted in programs aimed at friendship maintenance.

*Considerations for the digital world.* Factors influencing friendship have also changed due to our digital world and the growing use of technology and social networking sites. Social media usage in older adults more than tripled over the span of five years (Perrin, 2015) and has allowed adults to maintain and develop relationships in new ways. Social networking websites such as Facebook have become increasingly popular for older adults as a way of maintaining contact with family and friends and as a means of self-expression (Valentine 2011). In fact, significant correlations have been found between Facebook usage and perceived social satisfaction in older adults (Bell et al., 2013). Many people with aphasia use the Internet for entertainment and social purposes (Finch & Hill, 2014). Several social media websites allow activities that require minimal demands on language, such as photo sharing or clicking a “like” button, to interact with people (Menger et al., 2016). Virtual environments are also now being explored and may enable people with aphasia to make social connections and reduce feelings of isolation (Amaya et al., 2018). In light of the COVID-19 pandemic, several aphasia groups have been successful in transferring services online and there are initial, anecdotal reports that suggest virtual groups to be as beneficial for some people with aphasia as face-to-face services. Thus, the Internet is a powerful tool that can facilitate remote social connections when communication,

physical, and other everyday challenges make it difficult for persons with aphasia to maintain face-to-face connections with friends. For these reasons, future research should consider factors related to friendship in digital contexts, especially barriers and facilitators that may be unique to developing and maintaining friendships in this environment.

### Potential causes of friendship loss

Several theories from other disciplines explore why friendships in older people may dissolve. These theories can provide a valuable starting point for aphasiologists interested in conducting friendship research, especially if researchers are considering developing programs to target the maintenance of friendship networks. Social exchange theory (e.g., Roberto, 1989) suggests that social interactions involve costs and benefits that people assess as they establish and sustain relationships. According to this theory, equity and reciprocity during social exchanges are important components of sustaining relationships. Due to the devastating loss of language that occurs in aphasia, especially early on, friends may consider relationships with people with aphasia as too costly, inequitable, or lacking opportunities for reciprocity.

*Emotional energy.* Older people can have dwindling amounts of emotional energy. Socioemotional selectivity theory is rooted in the belief that older adults adapt to this change by reserving their emotional energy for relationships that are most important to them (Carstensen et al., 1999). The dissolution of friendships after aphasia may include friends prioritizing other relationships over friendships with people with aphasia so that they can reserve their dwindling emotional energy for more perceived meaningful connections. Friendships are voluntary and require more maintenance and effort than family relationships (Roberts & Dunbar, 2011).

*Complementary traits.* Friendships are often formed and maintained among people who are similar to one another or have complementary traits. As friendships develop, factors such as shared interests, values, and goals play a major role in the likelihood that a relationship will be maintained (Weber & Schafer, 2019). Often the diagnosis of aphasia brings significant changes to identity, life interests and objectives, and physical and social abilities. Previous goals and activities shared among friends may no longer be possible due to disabilities or energy levels. Friends may believe that aphasia has made their friend a different person entirely and that they no longer have much in common. People with aphasia have discussed experiences where they have been labeled as disabled, with low intelligence, diminished, and pitied by friends (Fotiadou et al., 2014), which likely contributes to dissolving relationships.

*Context.* There are also data to support that friendship type in older adults is heavily tied to the context in which friendships are formed and maintained (Adams & Torr, 1998). Friendships tend to form with individuals who live nearby or are easily accessible through a shared activity. Because many older adults no longer maintain workplace relationships, they are likely to develop or maintain friendships through other activities such as religious groups, retirement communities, or shared hobbies (e.g., Piercy & Cheek, 2004). These shared activities may be more important in friendship maintenance than the other factors discussed above such as personal characteristics or friendship styles. People with aphasia are at a significant disadvantage for maintaining friendships since there is often a reduction of participation in social groups after aphasia, yet these are the very contexts

in which friendship is most supported. When friendships are preserved after aphasia, a contributing factor to maintaining the relationship may involve participating in a shared activity. In Parr's (2007) study of social exclusion in severe aphasia, the few instances that detailed people with aphasia interacting with friends all centered around a hobby or activity that was a part of life prior to aphasia (e.g., choir, bowling).

*Communication.* Byng et al. (1997) seminal work exploring an insider perspective of the day-to-day, lived experience of aphasia highlights the effect of communication problems on maintaining friendships. People with aphasia reported that delays in speaking and responding led to friends dominating conversations and determining the direction of the conversation topic. Brown et al. (2013) also describe stories of people with aphasia who mourned the type of deep, detailed conversations that they had with friends prior to aphasia and that changes in the ability to converse with friends was a source of emotional distress. Similar experiences regarding communication challenges and friendship have been noted by adults who use augmentative and alternative communication (AAC) devices. In her study of factors contributing to successful friendships, Therrien (2019) found that skill in using AAC to overcome communication breakdown was an important factor in positive interactions with friends and slow speeds and delays tended to interfere with friendship formation and maintenance. Adult AAC users have pointed out that their need to communicate through a third party can hinder the development of friendships (Cooper et al., 2009), an experience that may be echoed by people with aphasia. Other communication challenges have been reported in the AAC literature including inefficiency of AAC systems (Higginbotham & Wilkins, 1999), poorly trained communication partners (Kent-Walsh & McNaughton, 2005), and stigma associated with using an AAC device (Parette & Scherer, 2004), all of which can create barriers to interactions with friends. These studies demonstrate that communication difficulties occurring as a result of aphasia and/or AAC use can have a rapid, deleterious impact on friendships.

## Requirements of friendship research

*Successful exemplars.* While recent studies have begun to reveal the consequences of aphasia on friendship, the topic remains largely unexplored when compared with literature from other fields detailing theories and factors related to friendship maintenance and dissolution. Several areas of friendship research should be prioritized. The first involves an exploration of variables that may be most susceptible to friendship maintenance and dissolution after aphasia. For example, in the friendships that have been maintained after aphasia, what factors might contribute to preservation? Are there pre-morbid characteristics of both a person with aphasia and his/her friend (e.g., social skills, propinquity) that are important for friendship maintenance? Understanding these variables would allow researchers and clinicians to select candidacy for friendship interventions and inform the development of friendship programs that may target internal characteristics that are more malleable such as theory of mind skills.

*Viewpoints of persons with aphasia.* The second area of inquiry includes understanding the viewpoints of persons with aphasia and their friends in terms of the types of friendships most important to maintain, the benefits and challenges to preserving existing friendships in the early stages of aphasia, and the immediate perceptions of aphasia and identity as described by friends. Systematically examining friendship from the perspective

of people with aphasia and their friends will ensure that our research agenda aligns with consumer-driven approaches to aphasiology (such as the Life Participation Approach to Aphasia) (LPAA Project Group (In alphabetical order: Chapey, R., Duchan, J., Elman, R.J., Garcia, L., Kagan, A., Lyon J. & Simmons-Mackie, N.), 2008) and the evidence-based practise framework which requires clinicians to consider client values and perspectives when developing and implementing interventions (Rycroft-Malone et al., 2004).

Additionally, focusing on the lived experiences and perceptions of people with aphasia and their friends will promote the development of more effective programs. As underscored by Byng et al. (1997), people with aphasia lose friends early on after diagnosis, often during the rehabilitation period, before they or their friends develop skills for how to communicate with one another. If the goal of aphasia intervention is to preserve existing relationships, it is of great importance that future research investigate the perspectives of people with aphasia and their friends during the early stages of recovery, before social networks begin to dissolve. Gaining an insider perspective on these issues will improve our understanding of barriers and facilitators to maintaining friendship and the wants and needs of people receiving speech and language services.

*Changes over time.* A third area of investigation includes an appreciation for how friendship changes over time. When friendships are successful and sustained, how do friends and people with aphasia navigate relationship changes and communication challenges due to aphasia? Do views of aphasia and definitions of friendship change over time? Understanding factors related to changes in friendship may raise awareness of the positive aspects of maintaining relationships with people with aphasia. This may also help prepare friends to cope with the inevitable communication and social challenges that are present after aphasia.

*Integration into the healthcare system.* As research into the work of aphasia friendships develops, it is critical to embed any prevention strategies or intervention into current healthcare systems where people with aphasia usually find themselves at the time of their aphasia onset. For example, it is a priority for most healthcare systems to limit falls for patients across a variety of diagnoses (Rowen & Goodwin, 2017). As such, physical therapists bill for skilled interventions to prevent falls. Signs are positioned around the patient's room indicating fall precautions, and in some cases, alarms alert staff when a person attempts to get out of bed without assistance. Limiting falls is a priority within the healthcare system, and as such, administration, third party payers, skilled therapists, direct care staff are all invested in patients not falling in the hospital (Moncada & Mire, 2017). The whole system is on board and falls, though still a problem, have been steadily decreasing (LeLaurin & Shorr, 2019).

Speech-language pathologists are uniquely positioned to provide skilled intervention for friendship for people with aphasia. Within a life participation approach, speech-language pathologists could bill a third-party payer for an evidence-based intervention to target friendship even now under current procedural terminology (CPT) code 92,507, treatment of speech, language, voice, *communication*, and/or auditory processing disorder; individual. For example, a client will initiate contact using supported conversation techniques with at least 1 friend weekly in a chosen modality (email, phone, video chat), is a skilled treatment goal; however, systematic change is required to implement such practises. Unless the healthcare system adopts these prevention strategies and interventions as a priority, uptake will be stunted, slow, or not at all. We recommend research of

aphasia friendship prevention and intervention methods within learning healthcare systems to allow for the implementation of these interventions as systematically as possible (Britto et al., 2018).

### **Current interventions to address social isolation – new friendships**

*Peer befriending.* There are two broad categories of interventions that might address social isolation through friendship. The first of which includes the goal of facilitating *new friendships* after brain injury and aphasia. Peer befriending is a widely used approach for supporting new friendships across a range of populations including those with mental illness or dementia (e.g., Bradshaw & Haddock, 1998). Peer befriending typically involves volunteers engaging in a “supportive and unidirectional relationship that aims to alleviate loneliness and provide social support through the provision of one-to-one regular companionship by volunteers” (Siette et al., 2017, p. 1). For the past several years, the United Kingdom (UK) based charity Aphasia Re-Connect (formerly Connect) has offered a peer befriending program to persons with aphasia who are in the later stages of recovery. More recently, researchers from the UK were funded by The Stroke Association to examine the clinical benefits and cost-effectiveness of a randomised controlled trial aiming to refine the peer befriending scheme developed at Aphasia Re-Connect (Hilari et al., 2019). The program aims to train volunteers with chronic aphasia to be peer-befrienders of persons newly diagnosed with aphasia to increase social networks and improve psychological and social well-being.

*Group treatment.* Another important avenue for addressing social isolation in aphasia is group treatment. Groups may offer the opportunity to participate in a wide variety of activities. In communication focused groups, members might practise communication by engaging in casual conversation or discussing the news and current events (Bernstein-Ellis & Elman, 2007). In some settings, groups form book clubs and members talk about a common book that everyone reads (Elman & Bernstein-Ellis, 2006; Knollman-Porter & Julian, 2019). Aphasia group treatments which revolve around hobbies such as photography (Levin et al., 2007) or choral singing (Zumbansen et al., 2017) have also been described in the literature.

Persons with aphasia have reported positive outcomes following speech-language therapy group treatment including making new friends and developing a genuine camaraderie for others that share similar experiences (Elman & Bernstein-Ellis, 1999). In a study of the perceived benefits of participating in aphasia groups, persons with aphasia have discussed the importance of the group in helping them develop new friendships and providing social contact outside of family members (Rotherham et al., 2015).

### **Current interventions to address social isolation – maintaining existing friendships**

The second category of intervention is more closely aligned with the goals of this article and involves preventing the loss of *existing friendships* after brain injury and aphasia. While there are clear benefits to forming new friendships with others, many persons with aphasia are equally, if not more so, interested in maintaining old friends that knew them before their brain injury. As previously discussed, peer befriending and other models

aimed at creating new friendships may be unidirectional in nature, with a volunteer providing the majority of support. Pound (2011) points out that established friendships are voluntary and bi-directional, and that sustaining friendship requires a certain amount of reciprocity between a dyad. Well-established friendships provide different types of benefits when compared to new friendships. Sharing memories and telling stories together are likely infrequent activities in newly formed friendships but have been shown to be important for perpetuating long-term friendships (Elder & Clipp, 1988). Sharing memories and telling stories also contribute to positive identity formation (Rawlins, 2009).

While there are some programs developed at community-based aphasia centers that are focused on preventing the loss of friendships, there are no current published interventions that aim to address social isolation for people with aphasia through the maintenance of existing friendship networks. However, there are programs developed for older adults without aphasia that have outlined essential components to consider when developing interventions for sustaining friendships after aphasia. It is likely that elements of these programs could be incorporated into interventions developed for friends of people with aphasia to help sustain and improve relationships after the onset of aphasia.

*Key features of effective friendship programs.* Stevens and Albrecht (1995) have long suggested that self-efficacy, positive frame of mind, and reevaluation counseling are key features of effective friendship programs. In a series of studies, Stevens and colleagues (Martina et al., 2012; Stevens, 2001; Stevens et al., 2006) have shown that techniques based upon these theoretical frameworks result in positive outcomes for improving existing friendships, the ability to express opinions, and skills related to taking initiative in making contact with others. Stevens et al. (2006) also report a significant reduction in loneliness one year after older women participated in their friendship enrichment program. The authors discuss techniques such as clarifying needs, desires, and expectations in friendship, analyzing current relationship networks, and formulating goals and strategies to improve existing friendships as contributing to the success of friendship programs. These critical ingredients may be considered for interventions aimed at reducing loneliness after aphasia through the maintenance of friendship networks.

*Theory of mind principles.* Others have proposed that friendship programs for older adults incorporate theory of mind principles. Lecce et al. (2017) found that theory of mind, the ability to perceive another's thoughts and feelings, was significantly associated with friendships for older adults, but not relationships with relatives, and that there is a significant relationship between theory of mind skills and social motivation. The authors suggest that to have good, supportive friendships, older people need to possess both theory of mind skills and be motivated to use these skills for social purposes. Other studies have shown that it is possible to increase theory of mind in healthy older adults (e.g., Lecce et al., 2015). Theory of mind may be an integral part of training programs aimed at sustaining friendships in older adults with aphasia. It is possible that current partner training programs developed for routine communication partners such as spouses (e.g., Better Conversations with Aphasia; Beeke et al., 2013) may be adapted to include theory of mind and other social skills. Although these papers provide an excellent starting point, we propose a specific, systematic agenda to further study some of these unexplored questions.

## Potential outcomes of a systematic friendship research agenda in aphasia

Potential outcomes of the implementation of a systematic research agenda of friendship for people with aphasia are many. These potential outcomes have probable impacts on the physiological and psychosocial health and well-being of people with aphasia. As the following outcomes are speculative due to the call for this new line of research, they are rooted in prior literature and will be described below.

*Acquisition of specific skills.* As described above, loss of friends by people with aphasia requires simultaneous attention to critical ingredients and the recognition of the nuances of human relationships. Any friendship prevention or intervention program may result in the acquisition of specific skills tied to that intervention. For example, part of the Helping Older People Experience Success – Individually Tailored (HOPES-I; Pratt et al., 2008, 2017) intervention designed to support friendship and other aspects of self-management for adults with serious mental illness includes a communication module. Within Module 2, *Communicating Effectively*, key aspects to consider include starting a conversation, maintaining a conversation by asking questions, maintaining a conversation by giving factual information, sticking with a topic of conversation, appropriate self-disclosure, appropriate disclosure in conversation, and ending a conversation smoothly and putting it all together. These factors are likely considered in many aphasia group interventions at present (Attard et al., 2018); however, Module 4 considers *Making and Keeping Friends*.

Within this module building a foundation for friendship and finding common interests, meeting new people, giving and receiving compliments, learning about another person, making plans with a friend, negotiating a compromise, reconnecting with old friends, and responding to requests are targeted. Outcomes measures used to examine progress toward friendship goals included the *Social Skills Performance Assessment* (Patterson et al., 2001), a role-play test examining specific skills, and the *Scale to Assess Negative Symptoms* (Andreasen, 1984) as a measure of friendship skills and social connectedness. If an intervention such as HOPES-I is studied and/or modified for people with aphasia, acquisition of these friendship specific skills to support friendship maintenance is a probable outcome.

*Satisfaction with friendship(s).* A friendship satisfaction measure streamlined by Jones (1991), adapted from Stokes (1985) is a common way to measure friendship satisfaction. Examples of questions are: How satisfied are you with the assistance you get from your friends in daily activities such as helping you with chores are giving you information? How satisfied are you with the emotional support you receive from your friends such as feeling cared about, discussing personal problems? How satisfied are you with the socializing you do with your friends? Although these questions are brief and may appear simple, it is suspected that perceived improvement on these questions from the person with aphasia would result in purposeful information to support friendship maintenance.

*Friendship structures.* As discussed above, a key piece to consider in friendship research is the structure of said relationships. Examples of one's friendship structure may include having a residential partner, non-resident family, family network size, family contact frequency, number, and frequency and duration of contacts. In addition to family, those same variables could be assessed in terms of friends and participation in group activities (Windsor et al., 2016). The quality of those structures is another potential outcome of an aphasia friendship research agenda. This may include frequency of positive and negative

exchanges in both friend and family domains (Windsor et al., 2016). Using these variables, Windsor and colleagues found that older adults with more diverse friendship networks had better mental health than those with more restricted friendship networks. The number of positive exchanges was also highly associated with better mental health and is likely a key ingredient to a successful aphasia friendship maintenance.

*Quality of friendships.* The *McGill Friendship Measure* (Mendelson & Aboud, 1999) was used as a measure of friendship quality in a small sample of adults with traumatic brain injury (TBI) and their informant friends. Interestingly, adults within the small sample each had at least one friendship that they rated as high quality (Flynn et al., 2018). The authors point to the possibility of the long-term nature of the friendships as half of the sample had their relationship for more than 10 years and in some cases, prior to their TBI. This provides further evidence toward our call to an agenda to prevent friendship loss in people with aphasia. It also posits the benefits of maintaining longer, more well-established relationships after the onset of aphasia.

*Maintenance of friend(s) over time.* The importance of people with aphasia maintaining their relationships over time cannot be overstated. The *Friendship Maintenance Scale* (Oswald et al., 2004) assesses a person's engagement in specific friendship maintenance behaviours across four dimensions positivity, supportiveness, openness, and interaction. Unfortunately, the trajectory of a sample of people status-post TBI describe their friendships as, "going downhill" with four overlapping phases including *losing contact*, *being misunderstood*, *wanting to share* and *hanging on* (Douglas, 2019). Again, the rehabilitation process is considered to play a potential critical role to support established friendships.

*Well-being and quality of life.* Finally, there is a well-established relationship between friendship and overall well-being and quality of life (QOL; Chopik, 2017). Instances of increased depression, anxiety and loneliness have been associated with social isolation and feelings of social disconnectedness (Santini et al., 2020). Preventing these negative consequences by focusing on the maintenance of prior friendships in people with aphasia is a worthy endeavor.

In addition to the positive psychosocial aspects of friendships, there is accumulating evidence concerning the negative impacts of social isolation. Social isolation has been connected to decreased gait speed and increased difficulty in activities of daily living (Shankar et al., 2017). Cardiovascular disease, stroke and diabetes have been associated with social isolation in older adults (Alun & Murphy, 2019; Valtorta et al., 2016). Along the same lines, social isolation in older adults has been linked to rehospitalisation and even death (M. Douglas et al., 2020; Liotta et al., 2018; Tanskanen & Anttila, 2016). Although it could be argued that these would be distal outcomes of an aphasia friendship maintenance intervention, these significant negative consequences are worth deeply contemplating.

## Research agenda

As a first step toward preventing the loss of friendship networks for people with aphasia, we propose a comprehensive research agenda to address friendship maintenance in aphasia. A key element of this agenda includes multi-stakeholder involvement from the initial development stages of research interests and questions. A reference group has been formed to advise and provide feedback on this program of research that aims to

prevent social isolation through the maintenance of friendship networks. Members include persons with aphasia, partners of persons with aphasia, SLPs with experience working with people with aphasia in acute care and community-based programs, and researchers with expertise in friendship research in aphasia. As a result of these discussions and a review of existing friendship research in aphasia, the following aims will be addressed in the initial stages of the research agenda:

- (1) What interventions exist within our field and across other fields that address friendship maintenance in aging adults and those with communication impairments?

A first step in increasing our understanding of the specific characteristics and impact of friendship programs is to critically review friendship interventions within and across disciplines. Conceptual components of interventions likely differ across interventions and are grounded in various theories on the development and maintenance of social relationships. A scoping review of these interventions will help to determine elements and outcomes of existing programs that may be applicable to people living with aphasia.

- (2) Gain an understanding of the lived experiences of people living with aphasia, friends, and caregivers in terms of maintaining friendship networks.

While previous research has shed some light on the perspectives of people with aphasia about friendship, much of these data involve perceptions of newly developed relationships. Only a handful of studies have explored challenges associated with maintaining existing friendships and no known studies have involved the lived experiences of friends of people with aphasia. The available data suggests that many (if not most friendships) do not survive the first weeks and months after the onset of aphasia so a critical component of understanding friendship maintenance will include investigating the experiences of people with aphasia, friends, and family members early on in the recovery period. A focus on the acute stage will allow researchers to identify challenges that jeopardize the continued existence of relationships. Conversely, investigating dyads who successfully negotiate the onset of a communication disability may suggest factors that protect relationships between people with and without aphasia.

Quantitative approaches entailing the distribution of surveys or administering standardised instruments to PWA and their friends could yield relevant data from large numbers of participants. Correlational relationships between the various factors that help to prevent social isolation might be revealed in studies of this kind. Alongside broad-based investigations, researchers should also conduct in-depth studies in which they focus on a judiciously chosen, relatively small group of friendships which include a person with aphasia. We suggest that qualitative research paradigms provide data gathering and analysis approaches suitable to this purpose. Qualitative approaches would require researchers to gather data generated by persons with aphasia and their friends, which can take the form of texts such as interviews, diaries or observational fieldnotes. These data are then analysed inductively; by carefully and systematically interpreting (and re-interpreting) the data, researchers attempt to understand how participants understand their own experiences or worldviews.

In the proposed research line, we would use these and other similar approaches to better understand how people with aphasia, their family and friends define social connectedness and isolation. These approaches will allow key stakeholders to offer trenchant insights concerning why and how friendships change after the onset of aphasia.

(3) How do SLPs view their role in supporting friendships in persons with aphasia?

Once data are obtained on perceptions related to friendship and key components of interventions and their outcomes, it will be important to understand the views of SLPs who would be targeting friendship as a part of a plan of care. Again, we argue that a research endeavor which combines apposite elements from quantitative and qualitative paradigms will yield findings that are grounded and accurate. Because we are most interested in targeting friendships before they dissolve, the views of SLPs working in acute and subacute facilities will be most valuable in appreciating the requirements, practicality, feasibility, and suitability for targeting friendships early on in the recovery period. Indeed, an intervention has increased odds of being implemented in typical healthcare settings if implementing clinicians are involved in the intervention design (N. F. Douglas et al., 2015).

(4) Create and evaluate a program to address maintenance of existing friendship(s) in aphasia.

Findings from the scoping review and studies involving stakeholder perspectives will be combined to develop a friendship program in aphasia that aims to prevent social isolation by preserving friendship networks in the early stages of recovery. Friends will be the main participants in the program, but people with aphasia will also likely be involved in the program to some degree. By building a friendship program that is based upon the values and needs of stakeholders, we can ensure that the program design is person-centered and relevant, but also flexible and usable across a range of participants and clinical settings.

## **Caveats**

Interventions on preventing the loss of existing friendships are scant in the aphasia literature, likely because of the complexity that exists in the way friendships are defined and the dynamic nature of friendship maintenance and dissolution. Maintaining existing friendship networks after aphasia must be respected as an organic and highly individualised process, one that cannot be medicalised or “cured” with an intervention. It is not reasonable to assume a one-size-fits-all approach to supporting friendships in persons with aphasia and researchers must be careful not to medicalise friendship through prescriptive interventions.

Another limitation involves the ability to investigate friendships in the early stages of recovery from aphasia. Various obstacles may be faced in gaining information from people with aphasia, caregivers, and friends in the months following brain injury and also in delivering interventions geared towards maintaining friendship. The focus of care during this time is often on medical aspects of health and the word aphasia may be vague,

unfamiliar, or completely unknown. As mentioned, friendships start to change and deteriorate early on after aphasia so gaining these perspectives may be both practically and philosophically challenging.

## Conclusion

Having friendships is associated with a range of positive health outcomes and overall quality of life. While we know that social isolation is a common experience for people living with aphasia, very little research which focuses specifically on relationships between people with aphasia and their friends exists. A research endeavor which combines apposite elements from current literature and which uses quantitative and qualitative paradigms to understand the lived experiences of people with aphasia and their friends will yield findings that are grounded and applicable across many typical settings. Our ultimate goal is to use these findings to inform programs for preventing social isolation in persons living with aphasia. We believe that empowering people with aphasia to maintain and establish connections to old and new acquaintances will help promote participation in many life domains.

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The authors report no conflict of interest.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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