

Family-Centered Care in Aphasia

Assessment of Third-Party Disability in Family Members With the Family Aphasia Measure of Life Impact

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More than 50 years of research has demonstrated the profound effect that aphasia has on people with the condition and their family members. In the International Classification of Functioning, Disability and Health, the World Health Organization described the impact of an individual's health condition on a significant other as "third-party disability." Recent research has described how third-party disability can occur in family members of people with aphasia post-stroke. Despite the extensive history and ongoing relevance of these findings, family-centered rehabilitation has been slow to integrate into clinical practice and policy. The aims of this article are (1) to provide an overview of third-party disability in family members of people with aphasia; (2) to consider how third-party disability can be addressed through family-centered care and to identify some of the barriers to family-centered care; and (3) to describe The Family Aphasia Measure of Life Impact (FAML), a tool for measuring third-party functioning and disability in family members of people with aphasia, identifying family rehabilitation needs, and measuring outcomes of family-centered care. **Key words:** *aphasia, caregiver burden, family-centered care, family members, FAML, ICF, rehabilitation, stroke, third-party disability, third-party functioning*

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FIVE DECADES of research have demonstrated the extensive and enduring consequences that aphasia has upon those with the condition and their family members. Secondary to aphasia, family members experience changes to their emotional functioning, communication, relationships, recreational activities and social lives, work, education, caregiving and domestic duties, and finances (Grawburg, Howe, Worrall, & Scarinci, 2013a). For example, family members may

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leave their jobs (Herrmann, Britz, Bartels, & Wallesch, 1995), no longer have time to see friends (Nätterlund, 2009), have difficulty communicating with the person with aphasia (Paul & Sanders, 2010), and lose income (Grawburg, Howe, Worrall, & Scarinci, 2013b), all as a result of having a significant other with aphasia. Communication problems that occur secondary to aphasia are central to relationship changes (Le Dorze, Tremblay, & Croteau, 2009) and, in some cases, marriages break up because of aphasia (O'Halloran, Carragher, & Foster, 2017). Family members of people with aphasia may also develop health conditions, such as depression or anxiety (Grawburg, Howe, Worrall, & Scarinci, 2014; McGurk, Kneebone, & Pit ten Cate, 2011). Indeed, depression is more likely to occur in family members of people with aphasia than in family members of people with stroke without aphasia (Artes & Hoops, 1976; Bakas, Kroenke, Plue, Perkins, & Williams, 2006).

Although family members are often included in aphasia rehabilitation as caregivers (e.g., they may be provided with education and communication training), their own needs are not routinely assessed and they are infrequently included in rehabilitation as patients who require support, information, and care for their mental, emotional, and physical health (Howe et al., 2012; Visser-Meily, Post, Riphagen, & Lindeman, 2004). Although education and communication training serve as a starting point for the inclusion of family members in rehabilitation, additional services specific to family members' needs are required. In this article, we focus on the rehabilitation needs of family members as patients themselves, not only as caregivers or communication partners.

The aims of this article are to (1) provide an overview of third-party disability in family members of people with aphasia; (2) consider how third-party disability can be addressed through family-centered care and to identify some of the barriers to family-centered care; and (3) describe The Family Aphasia Measure of Life Impact: An assessment of Third-Party Functioning and Disability (FAMLI). The

FAMLI is a tool for measuring third-party functioning and disability in family members of people with aphasia, identifying family rehabilitation needs, and measuring outcomes of family-centered care.

THIRD-PARTY DISABILITY

In the International Classification of Functioning, Disability and Health (ICF), third-party disability is described as "... disability and functioning of family members ... due to the health condition of significant others" (WHO, 2001, p. 251). Third-party disability is used to describe negative changes experienced by family members as a result of a significant other's health condition, whereas positive or neutral changes to their functioning are called third-party functioning (Grawburg, Howe, Worrall, & Scarinci, 2012).

Using the ICF framework, third-party disability is shown to occur when the Functioning and Disability of the person with the health condition acts as an Environmental Factor that interacts with the Functioning and Disability of the family member (Scarinci, Worrall, & Hickson, 2009). For example, the health condition of aphasia may cause Impairments, Activity Limitations, or Participation Restrictions for the person with the condition. For the family member, these changes are associated with the Environmental Factors of having a significant other with aphasia, which affects the family members' own Functioning and Disability.

Investigation into third-party disability has been conducted in many areas of communication disorders including aphasia (Grawburg et al., 2013b), hearing impairment (Scarinci et al., 2009), and dysphagia following head and neck cancer (Nund et al., 2016). New research is being conducted in regards to third-party disability in dysarthria secondary to Parkinson's disease (Mach, Baylor, & Yorkston, 2018) and the importance of third-party disability in dementia has been previously highlighted (Byrne & Orange, 2005).

THIRD-PARTY DISABILITY IN APHASIA

Third-party disability in aphasia was first examined through a qualitative study analyzed in the context of the ICF. Twenty family members (five spouses, 15 other relatives) of 11 people with aphasia participated in semi-structured interviews with findings analyzed through qualitative content analysis to form categories or codes, which were subsequently mapped to the ICF using established linking rules (Grawburg et al., 2013b; 2014).

The results of the qualitative content analysis revealed that family members were impacted by aphasia in most areas of their lives. Aphasia was associated with negative changes to family member's physical, mental, and emotional health (reported by 85% of participants); communication (85%); relationships (95%); recreational activities and social life (70%); paid work, volunteer work, and/or education (50%); domestic and caregiving responsibilities (90%), and; finances (30%; Grawburg et al., 2013b).

One family member discussed her depressed mood and lack of sleep,

I'm sure I must have some kind of depression. I'm certain about that. . . . I think all I need really is extra sleep. I went to the doctor and had a good talk to him and . . . he said, yes, you're in a depressing situation, which will make you feel depressed from time to time, but you probably, what you actually need is more and better sleep. (60-year-old daughter; Grawburg, 2014b)

This family member report was categorized as a physical change and subcategorized as tired.

Family members expressed guilt and embarrassment, which were categorized as emotional health, "After a few episodes, it was like, No, no, I'll go on my own. Because, [I was] scared of running into people you knew . . . feeling guilty . . . feeling guilty about . . . being embarrassed by your mother" (55-year-old daughter; Grawburg, 2014b). Family members also explained how their lives and friendships have changed,

. . . not just the aphasia, the whole stroke itself means that my life is inclined to revolve around what mum's (the person with aphasia) doing . . . [my] friends, they're still all there, of course, but we don't do the same things because, you know, when I have a day off, I've got these other things that I need to do. You know, I've got to take mum to physio . . . or go see a doctor . . . (60-year-old daughter; Grawburg, 2014b)

These types of changes were categorized as recreational and social life.

Most research codes were linked to the Functioning and Disability part of the ICF. Within the Functioning and Disability part, 32 codes were mapped to the Body Functions component, specifically to the domains of Mental functions and Functions of the digestive, metabolic, and endocrine systems. For example, the 51-year-old wife of a person with aphasia said, "I found my memory has got very bad in the last few years I think there's a lot of stress factors involved in that" (Grawburg, 2014b). Her statement was given the research code "memory got worse" and linked to the Mental functions domain and the ICF code b140 Attention function.

Eighty-five codes were mapped to eight domains within the Activities and Participation component: Learning and applying knowledge; General tasks and demands; Communication; Self-care; Domestic life; Interpersonal interactions and relationships; Major life areas; and Community, social and civic life. Only the Mobility domain was not linked to any research codes. The 48-year-old daughter of a woman with aphasia said,

. . . that was really hard because she couldn't really consent to anything. I think that . . . was one of the things that I found difficult to deal with . . . the fact that someone who's very private no longer had the power of speech to be able to say, Well actually, I don't want to do this. (Grawburg, 2014b)

This statement was given the research codes of "difficulty dealing with aphasia" and "learned to cope with sadness, loss, and grief." These research codes were mapped to the domain of General Tasks and demands and linked to the ICF code d240 Handling stress

and other psychological demands. Six codes were mapped as health conditions (i.e., depression, anxiety, vertigo, ulcer, hypertension, and mental health change) and not further classified by the ICF.

Despite these many negative changes, 80% of family members did report at least one positive effect of aphasia on their lives. These included positive changes to emotions (reported by 55% of family members), communication (15%), relationships (65%), recreational activities and social life (20%), and paid work, volunteer work, and/or education (25%; Grawburg et al., 2013b). For example, family members felt appreciative of their relationship with the person with aphasia and others, their own health, the ability to communicate, and the recovery of the person with aphasia. The 48-year-old father of a young man with aphasia said,

... we've [my son and I] got ... a very strong bond ... that's going to endure obviously down the track you know forever and a day which is lovely and ... we're very grateful for that ... so often through bad things, you know difficult things, good things come as well and we ... try and look ... at the good stuff. (Grawburg, 2014b)

The research code of “appreciation” was categorized as an emotional change, mapped to the ICF domain of Mental Functions, and linked to the ICF code b152 emotional functions.

This study demonstrated how the ICF can be used to systematically describe the effect of a significant other's health condition on family members, known as third-party functioning and disability. It provides an example of how a theoretical framework such as the ICF can provide consistency in analysis of the findings.

FAMILY-CENTERED CARE

Family-centered care has been acknowledged as the most effective way to include family members in the rehabilitation process. Family-centered care is based on partnership and collaboration between the persons with the health condition, their family, and the

health professionals through health care planning, service delivery, and evaluation of care (Creasy, Lutz, Young, & Stacciarini, 2015). Family-centered care facilitates an environment where the persons with the health condition and their family have the information and support they need to participate fully in decisions about their care and rehabilitation (Bamm, Rosenbaum, Wilkins, Stratford, & Mahlberg, 2015). A stroke-specific definition of family-centered care includes identifying and utilizing appropriate communication strategies, being aware of outcomes that are valued and prioritized, identifying goals based on desired quality of participation, timing outcome measurement appropriately for individual needs, being aware that needs change over time, and sharing assessment results to allow for informed decision making (Lawrence & Kinn, 2012).

Note that the terms patient-, client-, person-, and family-centered care are often used interchangeably (Bamm et al., 2015); however, use of the term family-centered care is preferred in this vein of research as it acts to reinforce the central role of family members in rehabilitation, as well as the position that in almost all cases family members are involved.

FAMILY-CENTERED CARE IN APHASIA

There has been a call for the rehabilitation of family members to be integrated into regular aphasia care (Oddy, 1999). Indeed, the consequences of aphasia on family members are so profound that it has been suggested that care of family members is equally important to the rehabilitation of the person with stroke (Holland & Fridriksson, 2001; Servaes, Draper, Conroy, & Bowring, 1999). Family members themselves have highlighted the importance of their inclusion, “I would put a case for families ... the person who's observing the most, I would put a case for that [person] every time to be heard” (62-year-old daughter; Grawburg, 2014b).

The provision of family-centered care in aphasia necessitates the inclusion of individuals who are affected by aphasia, often

spouses, children, and other close family and friends. They are the same family members who act as caregivers and form part of the rehabilitation team (Le Dorze & Brassard, 1995). It is vital that family members are also included as patients with their own rehabilitation needs. Family-centered care may be even more important in cases of aphasia than in stroke without aphasia, as aphasia is a specific factor identified as contributing to negative outcomes for family members (Choi-Kwon, Hwa-Sung, Kwon, & Kim, 2005), and family members of people with aphasia often experience more significant effects (Artes & Hoops, 1976; Bakas et al., 2006).

Although the impact of aphasia on family members is well-known, aphasia care that includes family members is not commonly practiced (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Johansson, Carlsson, & Sonnander, 2011; Law et al., 2010). The difficulty in including family members in the rehabilitation process is not specific to aphasia or stroke; however, given the two-way nature of communication, the need for family members to support rehabilitation for the person with aphasia (Bamm et al., 2015), and the demonstrated impact of aphasia on family members, use of a family-centered care model in this population may have maximal benefit for both the person with aphasia and the family member.

REHABILITATION FOR FAMILY MEMBERS OF PEOPLE WITH APHASIA

Although there are no known intervention studies of third-party disability specifically, previous rehabilitation programs have included family members of people with aphasia and may help inform future intervention. For example, Fox, Poulsen, Clark Bawden, and Packard (2004) conducted a 2-day residential program for people with aphasia and their family members. Rehabilitation for family members included group support sessions to explore their experiences and develop coping strategies. Qualitative analysis revealed four critical elements of the program, includ-

ing a physically and emotionally safe environment, respite from caregiving, learning from observing and listening to other family members, and the value of having participants with varying experience (post-onset time) with aphasia for both mentoring and learning.

van der Gaag et al. (2005) reported on the effects of a 7-week intervention program for people with aphasia, which included therapy groups for family members and optional counseling sessions. Many family members reported on positive aspects of the program, including an improvement in their significant other's communication, benefiting from advice from other family members, and a feeling of being appreciated for their support of the person with aphasia. Some family members said that the therapy groups were not helpful for them and a measure of family member coping showed no significant improvement, though the direction of change was positive.

A study evaluating the effectiveness of a 12-week support group offering emotional support and information for spouses of people with aphasia showed that spouses who attended regularly experienced improved social function, fewer physical complaints, and reduced anxiety (Rice, Paull, & Muller, 1987). This study reported no change to depression with participation in rehabilitation. Draper, Bowring, and Thompson (2007) found that family members of people with aphasia demonstrated decreased stress when support was provided immediately post-stroke, though changes were not maintained over time.

Recently, people with aphasia and their family members participated in the Aphasia Action, Success, and Knowledge (ASK) pilot program. The aim of this psychoeducational early intervention study was to facilitate positive adaptation poststroke through sessions with a speech-language pathologist that included goal setting, education about aphasia and stroke, learning and practicing communication strategies, measuring communication improvement, telling one's own stroke story, and discussion of emotional changes and

support (Ryan et al., 2017). The participants provided feedback about the program through semi-structured interviews. One of the identified strengths of the program was inclusion of family members and the ability to include more than one family member. The specific benefits were having time together, hearing each family member tell his or her stroke story, and ensuring that everyone was provided with the same information (Ryan et al., 2017). A randomized controlled trial based on this pilot is currently underway (Worrall et al., 2016) and will determine whether participation in the ASK program has an impact on the caregiver burden experienced by family members and their mental health.

These studies provide evidence for positive outcomes of rehabilitation provided to family members of people with aphasia. However, despite the known and emerging evidence of benefits of the provision of family-centered care in aphasia, existing rehabilitation is inadequate to support the need, "... aphasia has a more devastating effect upon the lives of aphasic people and their families than any other disease or disability, there is still a significant gap between these findings and the amount of time provided by for treatment" (Code, 2012, p. 729).

BARRIERS TO FAMILY-CENTERED CARE IN APHASIA

Despite the extensive rationale for family-centered care in aphasia, it has not been well implemented. There are several potential barriers to the provision of family-centered care by speech-language pathologists, such as constraints on time, insufficient financial backing for family-centered care, limited experience addressing the needs of family members, unfamiliarity with cultural safety, unclear guidelines and policy regarding "who" the client is and "who" the speech-language pathologist can provide care for, and the use of inconsistent terminology and generic assessment tools.

Presumably, providing treatment to address the consequences of aphasia on everyone

that it impacts will take extra time, which is always in short supply (Law et al., 2010). Speech-language pathologists commonly identify limited time as a barrier to the provision of family-centered care; consequently, in a clinical setting, family member rehabilitation becomes a lower priority (Dalemans et al., 2010). Indeed, it may seem like a question of choosing to support one person or the other, a trade-off between providing care to the person with aphasia or his or her family member. With a full and busy caseload, speech-language pathologists may default to treating family members as caregivers or part of the rehabilitation team in a sincere attempt to provide the best possible care for the person with aphasia. Although there may be short-term benefits to this approach, including saving time and money, over the longer term, neglecting to treat family members of people with aphasia can be detrimental to both the family member and the person with aphasia. This is particularly the case when speech-language therapy focuses on Impairments, Activity Limitations, and Participation Restrictions, forgetting the influence of the family members as an Environmental Factor, either supporting or facilitating aspects of recovery and adaptation. Certainly, areas of Impairment, Activity Limitation, and Participation Restriction require therapeutic attention, but directing all resources toward the person with aphasia ignores the fact that the family members' ability to contribute will likely diminish should they experience third-party disability. Moreover, lack of support may result in greater disability and increased use of the formal health care programs (WHO, 2011). Thus, making time to deliver family-centered care that includes therapy for family members likely pays off in the long term. In some areas, it is not time per se but the cost of time that is problematic. In health care models where insurance companies will not reimburse for family member rehabilitation, finances will also be a barrier.

Speech-language pathologists may also lack experience and specific training for the rehabilitation of family members. Most

speech-language pathologists are familiar with some areas of supporting family members (e.g., communication training, collaborating with families for assessment and intervention targeted toward the person with aphasia, and providing education about stroke and aphasia), which are a starting point for family-centered rehabilitation. However, speech-language pathology training ought to include skills that go beyond communication training and education to include such things as early identification of health conditions and addressing the individual needs of family members themselves (Sorin-Peters, 2004). For example, aphasia has been associated with changes in family member's Functioning and the development of health conditions, such as depression and anxiety (Grawburg et al., 2014). Early intervention that includes family members may prevent the occurrence or reduce the severity of symptoms; however, speech-language pathologists also need to be aware of the signs of health conditions in family members to make timely referrals and provide appropriate care.

A focus on family-centered care in aphasia may lead to broadening the speech-language pathology scope of practice. Sorin-Peters (2004) has suggested that this may involve the formal inclusion of marital therapy, family systems theory, adult education, and psychotherapy in aphasia therapy and collaboration with psychologists, social workers, and marriage counselors in an interdisciplinary context. At a minimum, speech-language pathologists must ensure that family members have access to support, regardless of the source (Brown, Worrall, Davidson, & Howe, 2012).

Cultural awareness is one consideration in understanding the international problem of ethnic disparities in stroke outcomes (Cruz-Flores et al., 2011) and must be an integral part of rehabilitation to prevent a lack of cultural safety from becoming a barrier to the delivery of family-centered care. For example, in the studies leading to the development of the FAMILI, 6%–10% of the participants identified as Māori, the indigenous people of New Zealand (Grawburg, 2014a; Grawburg

et al., 2013b, 2014). For Māori, health is not considered to pertain solely to an individual but to the extended family (whānau) and inextricably linked to the environment (Durie, 1998). "Individual health is built into a wider system, the boundary between personal and family identity being frequently blurred" (Durie, 1998, p. 73). Because of these beliefs, culturally specific family-centered care with full inclusion and participation of whānau is vital to the engagement of Māori with aphasia. The indigenous people of South Africa and Aboriginal communities in Australia are also part of a collectivist society, rather than individualistic society, which places family and community at the center of health care (Penn & Armstrong, 2017). Brewer, McCann, and Harwood (2016) have developed a hierarchy of clinical skills for speech-language pathologists working with Māori; however, the concepts and steps to follow will likely be helpful for any clinician working with an unfamiliar culture. These steps include learning why to be culturally safe, learning how to be culturally safe, learning how to interact, resources to build relationship, resources for education, and finally resources for therapy (Brewer et al., 2016). Note that the final step in the sequence is therapy, which is unlikely to be successful without first passing through the preceding steps. Health professionals, organizations, and professional bodies must recognize the cultural, social, and political context that may influence the implementation of family-centered care (Brewer & Andrews, 2016).

Gaps in health policy and stroke guidelines may also be a barrier to the delivery of family-centered care in aphasia. van Heugten, Visser-Meily, Post, and Lindeman (2006) described the development of the Dutch stroke guidelines, which included recommendations for family member participation in assessment, intervention, and education, as well as consideration of the role of family members as rehabilitation partners supporting the person with stroke, as patients at risk for developing depression, and as caregivers with support and respite needs, with acknowledgement

that these needs change over time. They reported that few countries include a specific plan for the care of family members of people with stroke in their guidelines and those that do provide loose recommendations that may not generalize well to a clinical situation.

More recently, Shrubsole, Worrall, Power, and O'Connor (2017) evaluated and summarized existing post-stroke aphasia rehabilitation guidelines through a systematic review. Clinical practice guidelines for family members included regular meetings with the stroke team, person with aphasia, and family members for goal setting, management, and discharge planning; ongoing training and information for family members specific to the needs of their significant other with aphasia; and family counseling. A research gap was identified in the area of support for family members of people with aphasia. Further evidence is needed to inform guidelines for the assessment of family member's needs for support and long-term rehabilitation, as well as provision of information and training. Future research may better establish which professionals are most appropriate for providing services in each area of need.

The ICF can support the development of policy as the language used is understood at various levels of management and by different health professionals. Integral to the establishment of family-centered care is the understanding that considering the impact of aphasia on family members through the lens of third-party disability changes them from the default role of caregiver to patient. Therefore, health policy and funding must reflect that family members are patients who will need to be considered as part of a health professional's caseload (Michallet, Le Dorze, & Te'treault, 2001). The role of policy or changes at the organizational level may involve revising mission statements to include family-centered care, providing ongoing professional development to clinical staff, providing education to patients and families (Bamm et al., 2015), and advocating for changes in funding regulations.

Another barrier to providing family-centered care in aphasia is that the impact

of a significant other's health condition on family members has been defined with inconsistent terminology and measured with generic assessment tools. This is problematic for developing family-centered rehabilitation practice and policy, which rely on clear conceptualization of an issue and a consistent definition.

Diversity in the methods of analyzing and classifying the effects of aphasia on family members has led to inconsistent terminology and may include vocabulary such as caregiver burden (e.g., Rombough, Howse, Bagg, & Bartfay, 2006) and strain, stress, or burnout (Visser-Meily et al., 2004). The results of qualitative studies are most frequently presented as a description of the experiences of family members following analysis of interviews (Howe et al., 2012; Le Dorze & Signori, 2010). These methods provide extremely valuable insight into the effects of aphasia on family members but make measurement and comparison more difficult. In clinical practice, the status of family members is not routinely included in clinical outcome measures during aphasia rehabilitation (Simmons-Mackie, Threats, & Kagan, 2005).

Researchers have used generic assessment tools, such as health and quality-of-life measures or measures of caregiver burden, to determine the impact of a significant other's health condition on family members. These tools are generic in the sense that they can be used in relation to any disease or disability and may not include communication-specific questions (e.g., the Bakas Caregiver Outcome Scale; Bakas et al., 2006). Generic indicators also include those assessing general health (e.g., with the General Health Questionnaire; Goldberg & Hillier, 1979, as used by Hemsley & Code, 1996), depression (Centre for Epidemiological Studies Depression Scale; Radloff, 1977, as used by McGurk et al., 2011), and marital satisfaction (Marital Satisfaction Scale; Roach, Frazier, & Bowden, 1981, as used by Williams, 1993). In aphasia, failing to assess the impact of communication changes may overlook key outcomes for family members.

Other scales consider communication but focus on ascertaining the family member's assessment of his or her significant other's communication ability rather than comprehensive impact on the family member (e.g., SAQOL-39; Hilari, Owen, & Farrelly, 2007). Another example is the Carer-COAST, which includes 15 questions about the communication and cognitive skills of the person with aphasia/dysarthria and only five questions about the family members' functioning (Long, Hesketh, & Bowen, 2009). See also Visser-Meily et al. (2004) for a review of 16 tools used to assess caregivers in stroke research.

These issues of inconsistent terminology and generic assessment tools are problematic for the development of rehabilitation for family members because imprecise classification makes it difficult to understand the phenomenon, reach a conclusion, measure outcomes, and develop recommendations. For example, general health measures may adequately describe family member stress, but they do not allow for an integrated description of the overall impact of aphasia on family members. Furthermore, the elements that make up the concept of caregiver burden are not well understood, so many of the scales purported to measure caregiver burden may be missing important aspects of the experience. Condition-specific, family-centered assessment tools may be most effective for meeting the needs of families post-stroke (Lawrence & Kinn, 2012).

MEASURING THIRD-PARTY DISABILITY IN APHASIA

The FAMLI is a tool that has been developed specifically to assess the third-party disability of family members with aphasia secondary to stroke. It is the first such instrument to be based on the breadth of experience of family members of people with aphasia teased out through qualitative interviews with items based on the ICF and rigorously psychometrically tested through item response theory (Grawburg, 2014a). Item selection was informed by the results of the qualitative stud-

ies, described previously (Grawburg et al., 2013b; 2014). Items were developed on the basis of research categories and codes and using participants' own words (Grawburg, 2014a). The labels and numbering for the item responses were based on the ICF using a 7-point response scale, with choices ranging from "−3 a complete problem" to "0 no change" to "+3 a complete positive change" (WHO, 2001).

As part of the development phase, 104 family members of people with aphasia completed the FAMLI (Grawburg, 2014a). Family members included 44 (42.3%) spouses/partners, 38 (36.5%) children, 7 (6.7%) siblings, 7 (6.7%) parents, and 7 (6.7%) other relationships. Psychometric testing, including Rasch analysis, was completed to assess internal construct validity and reliability of the FAMLI. Feasibility was also assessed (Bowen et al., 2009). Many speech-language pathologists will be familiar with assessments and screening tools that have been developed using psychometric analysis (e.g., factor analysis) on the basis of classical test theory. A more modern option is to use item response theory (e.g., Rasch analysis). Baylor et al. (2011) have published an article explaining item response theory and Rasch analysis specifically for speech-language pathologists.

One advantage of using Rasch analysis for the development of the FAMLI is that the raw score can be converted to a logit score. A logit is a unit on an equal-interval scale, which can be thought of as a ruler that reflects the continuum of third-party functioning and disability. Interval scales, as opposed to ordinal scales, can accurately convey the difference between or within participants and can be manipulated mathematically. For example, changes in third-party disability of the patients can be calculated by finding the difference between the logit scores at different periods of time and then submitting to parametric analysis for significance testing.

Based on psychometric analysis, items in the FAMLI were grouped into five subscales labeled (1) Health and Daily Life; (2) Attitude and Personal Life; (3) Helping Others;

(4) Communication and Emotions; and (5) Outside Influences and Interactions. Each subscale of the FAMLI must be measured and scored separately; however, Rasch analysis facilitates flexible administration. For example, if just the Health and Daily Life subscale was relevant for a family member, only that section of the FAMLI would be administered and the score could still be interpreted accurately. When using the FAMLI clinically, the raw score must be converted to a logit score and can also be converted in a Rasch-transformed score, ranging from 0 to 100. Higher scores are more favorable as higher logit scores represent greater third-party functioning; lower scores indicate greater third-party disability. Administration time ranged from 5 to 16 min. The FAMLI administration kit is included in the Appendix. This includes scoring instructions, the FAMLI Assessment Form, the FAMLI Scoring Form, an example of the completed FAMLI Scoring Form, the FAMLI Rescoring and Conversion Tables, and details of the psychometric analysis.

USE OF THE FAMLI IN FAMILY-CENTERED CARE

The FAMLI is a quick and simple tool for assessing third-party functioning and disability of family members of people with aphasia at different stages of rehabilitation. Results of the FAMLI can be used for treatment planning, particularly during transition times (such as when moving from acute care to rehabilitation or rehabilitation to community), to ensure that the speech-language pathologists are aware of changes to family member's needs over time. Use of the FAMLI can provide a direction for family-centered care by identifying areas of need and areas of strength for the development of targeted therapy.

The completion of a questionnaire can serve as a starting point for including family members in rehabilitation (Hétu, Riverin, Lalonde, Getty, & St-Cyr, 1988), thus setting the expectation that aphasia rehabilitation is for family members too. When completing the FAMLI as a self-report, the family mem-

bers may benefit from reflecting on their own health and be prompted to discuss their own health concerns with health professionals. The process of goal setting is an important part of family-centered care as goals provide a focus and structure for intervention and feedback (Ryan et al., 2017).

Although the FAMLI has not yet been used to measure the effectiveness of rehabilitation for family members, use of such a scale may facilitate the development and measurement of family-centered rehabilitation programs. Essential features of family-centered stroke intervention include delivery in the community (the patient's own home), appropriately intensive intervention, meaningfulness and relevance of content and delivery, close involvement of family members, and implementation by experts (Lawrence & Kinn, 2012). Targeted assessment will ensure meaningfulness and relevance of content by providing an understanding of how the family member is impacted by aphasia. Evidence-based family-centered rehabilitation can be specifically designed and existing programs can be evaluated against the measured needs of family members. Use of the FAMLI to measure effectiveness of intervention for family members and corresponding cost calculations may provide data to justify policy for family-centered care.

As the ICF is an internationally recognized framework for describing health and health-related states, its use in the development of the FAMLI may facilitate a health-based rationale for family-centered rehabilitation and form the basis for accumulation of evidence for the provision of services to family members. Thus, the FAMLI is comprehensive in the scope of measurement, family-centered, flexible in use, and based on vocabulary broadly understood throughout the world by most health disciplines.

DIRECTIONS FOR FUTURE RESEARCH

Future research may use the FAMLI to determine the impact of family-centered care. Prospective, longitudinal studies can

measure the course of third-party disability and determine efficacy and cost-effectiveness of intervention. It is not known which aspects of family-centered care may be most beneficial for ameliorating third-party disability; communication training, education, counseling, referral, and respite are some aspects to be considered, as well as the various roles of family members in rehabilitation (e.g., as patients, rehabilitation assistants, and caregivers). Extending the scope of practice of speech-language pathologists to include interdisciplinary work to address relationship problems secondary to aphasia is an important area for future development. In addition, investigation of the effect of Environmental Factors on third-party disability in family members of people with aphasia would further inform the development of family-centered care.

CONCLUSION

In summary, this article has shown how the ICF can be used to describe third-party disability in aphasia, examined using the concept of third-party disability to provide a foundation for the development of family-centered care, and discussed barriers to delivery of family-centered care in aphasia. Finally, the FAMLI was introduced as a

potential tool for measuring third-party functioning and disability instead of more generic assessment tools to allow for consistent and comprehensive measurement of family members' needs and strengths. Speech-language pathologists should be aware of the pervasive effects of aphasia on family members, beyond communication and relationship changes. In some cases, changes will include the development of depression and anxiety, which require referral.

Despite the considerable barriers to family-centered care, it is imperative that it becomes common practice in aphasia rehabilitation in order to achieve optimal outcomes for the family member and the person with aphasia. Use of the vocabulary and framework of the internationally recognized ICF facilitates a clear conceptualization, definition, and description of third-party disability in family members of people with aphasia. The FAMLI is a family-centered assessment that speech-language pathologists and other health professionals can use to identify the needs of family members at all stages of rehabilitation. Use of the term third-party disability and the FAMLI provide a starting point for implementing family-centered care in aphasia and may facilitate increased consistency and generalizability to inform future research, practice, and policy.

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APPENDIX

The family aphasia measure of life impact: An assessment of third-party functioning and disability (FAMLI)

Assessment Form

We are interested in finding out what it is like to have a family member with aphasia. We are particularly interested in the effects of aphasia (the communication problem) rather than the stroke as a whole.

Directions: Please think about the statements below and circle the response that best describes **how your family member’s aphasia has affected you in the past month**. We have included some examples to help you think about the question. Even if your situation is different than the example, the item may still apply to you.

1. Overall, the effect of my family member’s **aphasia** on my life is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

A. HEALTH & DAILY LIFE

2. Because of my family member’s **aphasia**, my own health has changed. For example, my health has improved, or I have developed a health condition, or an existing health condition has worsened (e.g., depression, ulcer, hypertension, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

3. Because of my family member’s **aphasia**, my body’s physical functioning has changed (e.g., changes in sleep, energy, weight loss/gain, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

4. Because of my family member’s **aphasia**, I feel more/less stressed. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

5. Because of my family member's **aphasia**, I tend to be more/less emotional. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

6. Because of my family member's **aphasia**, my recreational activities have changed (e.g., time for myself, sports, hobbies, friends, relaxation, vacation, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

7. Because of my family member's **aphasia**, my social activities have changed (e.g., I socialize more/less often, more/less desire to socialize, socialize with/without family member with aphasia, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

8. Because of my family member's **aphasia**, I have experienced a change in my finances (e.g., income increase/decrease, increased spending, saved money, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

9. Because of my family member's **aphasia**, I have experienced changes to my paid or volunteer work (e.g., work fewer/more hours, took time off work, quit or changed job, stopped or started volunteering, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

B. ATTITUDE & PERSONAL LIFE

10. Because of my family member's **aphasia**, I feel more/less appreciative (e.g., appreciate that my family member lived through a stroke, appreciate my own health, appreciate life, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

11. Because of my family member's **aphasia**, my attitude has changed (e.g., I focus on the positive and keep things in perspective, I am less judgmental of others, I am more critical of the health care system, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

12. Because of my family member's **aphasia**, I have experienced personal changes (e.g., learned about myself, became stronger, learned to cope with a difficult situation, grew up quickly, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

C. HELPING OTHERS

13. Because of my family member's **aphasia**, I am the central source of social contact for him/her (e.g., I visit often, include him/her in my own social activities, take my family member on outings). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

14. Because of my family member's **aphasia**, I help my family member with speech therapy (e.g., I sit in on sessions with my family member, help my family member with speech therapy homework). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

15. Because of my family member's **aphasia**, I explain what aphasia is to others. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

16. Because of my family member's **aphasia**, I now help people with aphasia in my paid or volunteer work. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

D. COMMUNICATION & EMOTIONS

17. Because of my family member's **aphasia**, I feel more/less sad. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

18. Because of my family member's **aphasia**, I feel more/less worried. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

19. Because of my family member's **aphasia**, ease of communication with him/her has changed. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

20. Because of my family member's **aphasia**, I have to communicate with my family member in a new or different way (e.g., I speak slowly, use shorter sentences, wait to give him/her time to find his/her words). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

21. Because of my family member's **aphasia**, I help him/her to communicate with others (e.g., interpreting, using visual cues, helping him/her to understand and make decisions, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

E. OUTSIDE INFLUENCES & INTERACTIONS

22. Because of my family member's **aphasia**, I feel more/less frustrated, angry, and annoyed. For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

23. Because of my family member's **aphasia**, my friendships have changed (e.g., I have made new friends/lost touch with old friends, friends do not understand aphasia, need my friends more/less, see friends more/less, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

24. Because of my family member's **aphasia**, I have experienced changes to my education and/or learning. (e.g., changed type of training; learned more about aphasia, stroke, and caregiving, etc.). For me this is:

-3	-2	-1	0	+1	+2	+3
A complete problem	A moderate-substantial problem	A mild problem	No change because of aphasia	A mild positive change	A moderate-substantial positive change	A complete positive change

Administration Kit**Directions for scoring the FAMLI:**

1. The family member completes the FAMLI Assessment Form.
2. Copy the family member responses (e.g., -3, 0, 1) for each item into the corresponding box in the "Raw Score" column on the FAMLI Scoring Form. Alternatively, raw scores can be entered at famli.health.nz where rescoring and conversion are done automatically and results can be printed or exported to csv. Family members cannot enter responses directly on the Web site as it does not include instructions or the response labels.
3. Use the Individual Item Raw Score Rescoring Table to identify the appropriate rescore value for each item and write it in the corresponding box in the "Rescore" column on the FAMLI Scoring Form.
4. Sum the rescore values for each subscale and write the sum in the subscale totals box on the FAMLI Scoring Form. Subscales with incomplete data should not be summed and ordinal to interval conversion cannot be completed.
5. Use the Ordinal to Interval Measure Subscale Conversion Table to identify the corresponding logit score for each subtest and write it in the "Logit Score" box for each subtest (e.g., "Health and Daily Life Subtest Totals") on the FAMLI Form. A logit is a unit on an equal-interval scale that acts as a ruler to measure a third-party disability.
6. Use the Ordinal to Interval Measure Subscale Conversion Table to identify the corresponding Rasch-transformed score for each subtest and write it in the "Rasch-transformed Score" box for each subtest (e.g., "Health and Daily Life Subtest Totals") on the FAMLI Form. A low Rasch-transformed score (0) corresponds to a higher amount of third-party disability and a high Rasch-transformed score (100) corresponds to more third-party functioning. Because of the multidimensionality of third-party functioning and third-party disability, it is not accurate to calculate a summary score by adding the subscale totals (rescore, logit, or Rasch-transformed).

FAMLI Scoring Form

ITEM #	RAW SCORE	RESCORE*	LOGIT SCORE†	RASCH- TRANSFORMED SCORE†
2				
3				
4				
5				
6				
7				
8				
9				
HEALTH AND DAILY LIFE SUBSCALE TOTALS:				
10				
11				
12				
ATTITUDE & PERSONAL LIFE SUBSCALE TOTALS:				
13				
14				
15				
16				
HELPING OTHERS SUBSCALE TOTALS:				
17				
18				
19				
20				
21				
COMMUNICATION & EMOTIONS SUBSCALE TOTALS:				
22				
23				
24				
OUTSIDE INFLUENCES & INTERACTIONS SUBSCALE TOTALS:				

*See Individual Item Raw Score Rescoring Guide.

†See Ordinal to Interval Measure Subscale Conversion Table.

FAMLI Scoring Form—Example

ITEM #	RAW SCORE	RESCORE*	LOGIT SCORE†	RASCH-TRANSFORMED SCORE†
2	-1	2		
3	-2	1		
4	-3	0		
5	0	3		
6	+1	4		
7	+2	4		
8	+3	4		
9	0	3		
HEALTH AND DAILY LIFE SUBSCALE TOTALS:		21	1.59	60.75
10	-1	0		
11	0	1		
12	1	2		
ATTITUDE & PERSONAL LIFE SUBSCALE TOTALS:		3	-1.53	46.05
13	+3	4		
14	0	3		
15	-3	0		
16	-2	1		
HELPING OTHERS SUBSCALE TOTALS:		8	0.05	50.51
17	+1	4		
18	0	3		
19	-1	2		
20	-2	1		
21	-3	0		
22	+3	4		
COMMUNICATION & EMOTIONS SUBSCALE TOTALS:		14	1.02	55.63
23	0	3		
24	-3	0		
OUTSIDE INFLUENCES & INTERACTIONS SUBSCALE TOTALS:		7	0.67	51.43

*See Individual Item Raw Score Rescoring Guide.

†See Ordinal to Interval Measure Subscale Conversion Table.

FAMLI Rescoring and Conversion Tables
 Individual Item Raw Score Rescoring Table

	FAMLI Raw Score Rescoring						
	-3 A complete problem	-2 A moderate- substantial problem	-1 A mild problem	0 No change because of aphasia	+1 A mild positive change	+2 A moderate- substantial positive change	+3 A complete positive change
Health & Daily Life Items 2, 3, 4, 5, 6, 7, 8, 9	0	1	2	3	4	4	4
Attitude & Personal Life Items 10, 11, 12	0	0	0	1	2	3	4
Helping Others Items 13, 14, 15, 16	0	1	2	3	4	4	4
Communication & Emotions Items 1, 17, 18, 19, 20, 21	0	1	2	3	4	4	4
Outside Influences & Interactions Items 22, 23, 24	0	1	2	3	4	4	4

Ordinal to Interval Measure Subscale Conversion Table

Total Raw	Health & daily life			Attitude & personal life			Helping others			Communication & emotions			Outside influences & interactions		
	Logit	SE	RTS	Logit	SE	RTS	Logit	SE	RTS	Logit	SE	RTS	Logit	SE	RTS
	Total Raw	SE	RTS	Total Raw	SE	RTS	Total Raw	SE	RTS	Total Raw	SE	RTS	Total Raw	SE	RTS
0	-7.50	1.89	0	-6.36	1.94	0	-8.59	1.92	0	-8.32	1.89	0	-8.50	1.96	0
1	-6.13	1.11	9.16	-4.81	1.25	14.79	-7.11	1.19	8.62	-6.94	1.13	8.24	-6.89	1.29	9.03
2	-5.22	.84	15.25	-3.37	1.22	28.52	-5.92	1.04	15.57	-5.97	.89	14.03	-5.34	1.24	17.71
3	-4.61	.73	19.31	-1.53	1.42	46.05	-4.83	1.07	21.95	-5.25	.81	18.28	-3.83	1.20	26.18
4	-4.13	.67	22.54	-.21	.89	58.57	-3.63	1.11	28.97	-4.62	.78	22.02	-2.52	1.09	33.53
5	-3.71	.63	25.34	.38	.68	64.20	-2.50	1.01	35.58	-4.02	.77	25.59	-1.40	1.04	39.87
6	-3.33	.61	27.89	.79	.61	68.12	-1.57	.93	41.02	-3.43	.77	29.12	-.36	1.00	45.67
7	-2.97	.59	30.29	1.15	.59	71.53	-.74	.90	45.89	-2.85	.76	32.61	.67	1.05	51.43
8	-2.62	.58	32.60	1.51	.60	74.91	-.05	.88	50.51	-2.28	.75	36.00	1.94	1.24	58.57
9	-2.29	.58	34.86	1.89	.64	78.55	.83	.89	55.06	-1.72	.74	39.30	3.92	1.54	69.68
10	-1.95	.57	37.07	2.34	.72	82.88	1.65	.93	59.84	-.118	.74	42.53	5.87	1.27	80.63
11	-1.63	.57	39.25	3.02	.97	89.29	2.58	1.00	65.25	-.64	.74	45.76	7.53	1.38	89.97
12	-1.31	.57	41.39	4.14	1.78	100	3.66	1.06	71.59	-.09	.74	49.02	9.32	2.02	100
13	-.99	.56	43.52				4.76	1.02	78.00	.46	.75	52.31			
14	-.67	.56	45.64				5.80	1.03	84.06	1.02	.75	55.63			
15	-.36	.56	47.76				7.00	1.21	91.12	1.58	.75	58.98			
16	-.04	.57	49.89				8.52	1.94	100	2.16	.77	62.42			
17	.28	.57	52.03							2.77	.79	66.05			
18	.61	.57	54.19							3.42	.81	69.91			
19	.93	.57	56.35							4.09	.82	73.87			
20	1.26	.57	58.54							4.75	.81	77.80			
21	1.59	.58	60.75							5.41	.83	81.75			
22	1.92	.58	63.00							6.14	.89	86.08			
23	2.27	.59	65.31							7.10	1.12	91.83			
24	2.63	.60	67.69							8.48	1.89	100			
25	2.99	.61	70.16												
26	3.38	.63	72.73												
27	3.78	.64	75.43												
28	4.22	.67	78.32												
29	4.70	.72	81.55												
30	5.28	.82	85.47												
31	6.15	1.08	91.22												
32	7.46	1.87	100												

Note. RTS = Rasch-Transformed Score; SE = Standard Error. Guide for converting subscale total score from a raw score (ordinal measure) to logit and Rasch-transformed score (interval measures). This table cannot be used if all items in a subscale have not been completed. The Rasch-transformed score was derived through linear transformation onto a 0-100 scale.

The development of the FAMLI—Psychometric properties Examination of Internal Structure and Content Validity

Factor analysis and Rasch analysis confirmed that third-party disability as measured by the FAMLI is multidimensional, encompassing five underlying constructs. The implication of this is that it is inappropriate to calculate a summary score of all test items as a whole. Instead, through principal component analysis and consideration of clinical relevance, items that measured common constructs were grouped into five subscales labeled (1) Health and Daily Life; (2) Attitude and Personal Life; (3) Helping Others; (4) Communication and Emotions; and (5) Outside Influences and Interactions.

Each of the five subscales of the FAMLI demonstrated adequate construct validity (Grawburg, 2014a). Acceptable unidimensionality was confirmed in each subscale after removing misfit items and rescaling response scales in an appropriate manner. For example, subscales 1, 3, 4, and 5 were rescaled from a 7-point scale (0123456) to 5-point scale (0123444) and, similarly, subscale 2 was rescaled to the 5-point scale (0001234). Rescaling was completed when adjacent response categories represented indistinct levels of the trait or response categories were not used by participants.

If the Rasch-derived principal component accounts for greater than 50% of the variance and residual variance is randomly distributed, shown by eigenvalues in the second component of less than 2.0, the unidimensionality of a given scale will be upheld. In the case of the subscales of the FAMLI, 72.6%, 71.4%, 69.9%, 67.7%, and 67.2% of the variance was accounted for with no eigenvalues in the second component greater than 2.0, indicating the evidence for acceptable unidimensionality.

Reliability

Internal consistency of the FAMLI subscales was demonstrated with person reliability coefficients (.88, .80, .78, .89, and .59, for respective subscales). Person reliability coefficients are interpreted similarly to Cronbach's α where coefficients greater than .7 indicated adequate internal consistency (Bond & Fox, 2012). Subscales 1–4 demonstrate good internal consistency. Because of low person reliability on subscale 5, this scale should be interpreted with caution. Low person reliability could be due to a small amount of variance in the sample (e.g., participants demonstrated similar levels of third-party disability) or too few items in the subscale (Linacre, 2013).

Test–Retest Reliability

Test–retest reliability of the FAMLI was assessed using intraclass correlation coefficient (ICC) and weighted kappa, both interpreted as slight: 0–0.20, fair: 0.21–0.40, moderate: 0.41–0.60, good: 0.61–0.80, and very good: 0.81–1.00 (Deyo, Diehr, & Patrick, 1991; Landis & Koch, 1977). For individual items, the weighted kappa statistic demonstrated the strength of agreement. Twenty-one items demonstrated moderate or greater reliability and three items showed fair reliability. The items showing fair reliability may be interpreted more cautiously: #10 (I feel more/less appreciative), #16 (I now help people with aphasia in my paid or volunteer work), #24 (I have experienced changes to my education and/or learning).

Subscale test–retest reliability results showed moderate to very good response consistency over time (ICC for subscales 1–5 = .91, .59, .70, .87, and .70, respectively). Subscale 2, Attitude and Personal Life should be interpreted more cautiously. This subscale may be less reliable than the others as it contains only three items and one of the items (#10 appreciative) demonstrated only fair agreement.

Feasibility

Feasibility was demonstrated with a mean of 8 min:43 s completion time ($SD = 3:30$, range = 5:30-16:02), a high individual item completion rate (99.4%), and the ability to self-administer (94%).