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REVUE CANADIENNE D'ORTHOPHONIE ET D'AUDIOLOGIE | RCOA

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Communicating care La communication à coeur

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Resilience in dementia: Perspectives of those living with dementia

La résilience en démence : Perspectives d'individus qui vivent avec la démence

KEY WORDS

DEMENTIA CAREGIVERS CARE PARTNERS RESILIENCE PROTECTIVE FACTORS VULNERABILITY FACTORS COMMUNICATION Tawnya Williamson Teresa Paslawski

Abstract

This study interviewed individuals living with dementia and their care partners to examine their perspective on the concept of resilience and factors associated with it. Resilience is a process through which individuals demonstrate positive adaptation despite exposure to adverse life events, such as a diagnosis of dementia. In the present study, persons with dementia and their care partners described what it meant to them to be resilient in the face of dementia and the factors they identified as contributing to or interfering with resilience through the use of semi-structured interviews. The study identified eight factors associated with resilience organized under three major themes: 'active and purposeful living', 'perspective', and 'resources'. Speech language pathologists can play a critical role in identifying team goals to bolster resilience in individuals with dementia and in their care partners. Further, because communication is an element of many of the factors associated with resilience is a focus is argued to be clinically useful to speech language pathologists and other members of the rehabilitation medicine team to identify areas of strength and weakness for individuals living with dementia, guide intervention efforts, and support more resilient outcomes.

Abrégé

Dans cette étude, nous avons interviewé des individus vivant avec la démence et leurs partenaires de soins afin d'examiner leurs perspectives sur le concept de résilience et les facteurs qui y sont associés. La résilience est un processus qui permet aux individus de démontrer une adaptation positive malgré l'exposition à des situations négatives dans leur vie, tel un diagnostic de démence. Dans la présente étude, les individus vivant avec la démence et leurs partenaires de soins ont décrit qu'est-ce que signifiait pour eux être résilient face à la démence et ont identifié les facteurs qui contribuent et interfèrent avec la résilience, par l'entremise d'une entrevue semi-structurée. L'étude a identifié huit facteurs associés à la résilience, organisés selon trois thèmes majeurs : « une vie active et qui a du sens », « la perspective » et « les ressources ». Les orthophonistes peuvent jouer un rôle crucial dans l'identification des buts d'équipe pour augmenter la résilience des individus vivant avec la démence et celle de leurs partenaires de soins. De plus, puisque la communication est un élément important identifié dans plusieurs facteurs associés à la résilience dans cette étude, elle peut potentiellement avoir un impact positif ou négatif sur la résilience. Nous discutons de l'utilisation de la résilience comme objectif qui peut être cliniquement utile aux orthophonistes et aux autres membres de l'équipe de réadaptation pour identifier les forces et les faiblesses des individus vivant avec la démence, pour guider les efforts d'intervention et pour appuyer des résultats plus résilients.

Tawnya Williamson, M.Sc. S-LP, Alberta Health Services, AB CANADA

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Introduction

Resilience is a process through which individuals demonstrate positive adaptation despite experiencing adverse life events. It is commonly described in the literature simply as individuals 'doing okay' when exposed to events or situations that have potentially negative outcomes. It is an area of substantial relevance in the rehabilitation sciences as it defines 'doing okay' as behaviours that result in adaptive functioning in the face of adversity, including disease or impairment. Importantly, the discussion of resilience has moved beyond it being viewed as a personality characteristic to an adaptive process involving interaction at multiple levels or systemsindividual, family, and community or societal-as a dynamic process that can vary between and within individuals (Garmezy, 1974; Masten & Powell, 2003; Schoon, 2006; Ungar, Ghazinour & Richter, 2013). Protective factors, those that promote resilience, and vulnerability factors, those that deter resilience, can function within or across these levels and are potential targets for intervention (Luthar & Cicchetti, 2000; Masten, 2001).

To date there has been limited research examining resilience in dementia, in order to understand what it means to be adapting positively following a diagnosis of dementia. The current study examines the concept of resilience for individuals who live with dementia- the persons with dementia and their care partners- what constitutes resilience for them, and what factors they identify as promoting or impeding their resilience. The term care partner is used to refer to any individual associated with and involved in caring for the person with dementia, including family, friends, and professionals. A care partner, as opposed to the term care-giver was suggested by Bryden (2005) to represent equalized care relationships and ensures that "the person with dementia is at the centre of the relationship, not alone as an object to be looked at, as merely a care-recipient" (p. 150).

Speech language pathologists (S-LPs) have a significant role to play in understanding and promoting resilience in those living with dementia. Disordered communication is a prominent part of the presentation of most forms of dementia (Mahendra & Hopper, 2011), which is a barrier to understanding what constitutes resilience and what facilitates or impedes resilience for individuals living with dementia. Holland (2007) argues that "appropriate to our goals [is coaching clients about] learning to live with a disorder or a disability- developing resilience" (p. 21). Communication may also be a component affecting the ability to be resilient in the face of dementia, therefore S-LP treatment of communication disorders have the potential to positively influence the response to dementia.

Resilience in Aging Populations

The demonstration of resilience depends on two fundamental judgments: (i) that there is a significant threat or adversity and (ii) that the outcome is "good or OK" (Masten, 2001, p. 228). Relatively few studies have examined the concept of resilience in aging populations (e.g. Harris, 2008; Hildon, Montgomery, Blane, Wiggins & Netuveli, 2010; Hildon, Smith, Netuveli, & Blane, 2008; Wiles, Wild, Kerse, & Allen, 2012). These studies examined resilience in older adults with a variety of adverse life events including illness, relationship loss, or change in socioeconomic status, which are not uncommon in aging populations, and determined that older adults can demonstrate resilience, 'be okay', in response to acute or chronic threat or adversity. While the manner in which resilience is demonstrated may differ from individual to individual, Wiles and colleagues also reported that older people understood that it was possible to face constraints in one area but exhibit resilience in another, emphasizing the complexity of the notion of resilience as a "multidimensional, contextual and ongoing process" (Wiles et al., 2012, p. 423), which is consistent with the developmental literature on resilience.

Although there are components of the resilience process that are internal to an individual, such as positive coping styles or attitude (Hildon et al., 2008; Wiles et al., 2012), focusing on the components of resilience that may be easier to modify and that are within the scope of practice of more rehabilitation professionals, lends itself to practical application from the perspective of rehabilitation. Understanding resilience, and identifying protective and vulnerability factors that affect resilience in specific populations, has the potential to contribute to individualized focused rehabilitation efforts as well as community initiatives to foster resilience in adults facing adverse situations or events.

Resilience and Dementia

Dementia is an umbrella term for a number of etiologies that result in memory loss, changes in mood, behaviour, and communication abilities that are severe enough to interfere with activities of daily life, occupation, and social interaction (Mahendra & Hopper, 2011). It is the most significant cause of disability for adults over the age of 65. There are currently approximately 500,000 Canadians living with dementia and that number is expected to increase 2.3 times by 2038 (Alzheimer Society of Canada, 2010). Because of the cognitive underpinnings of dementia, individuals may be less able to adapt to changes in their environments or everyday demands (Mahendra & Hopper, 2011), leading to a decrease in competence and a corresponding loss of independence. Communication deficits are common in dementia, increasing in severity as the disease progresses (Yorkston, Bourgeois, & Baylor, 2010). Cognitive and communication deficits are inter-related and can negatively affect daily functioning.

Because of the progressive nature of dementia, many intervention efforts are of a pharmacologic or palliative nature, however, a number of intervention studies indicate that therapy directed at maintaining function and improving quality of life have efficacy in this population (e.g. Hopper et al., 2013; Mahendra, Scullion, & Hamerschlag, 2011). The functioning of individuals with Alzheimer's disease can be improved by utilizing intervention techniques that focus on spared memory skills as well as principles of learning that have been shown to be effective for some individuals with dementia (Woodward, 2013). A focus on resilience could contribute to maintaining functioning and improving quality of life by reinforcing or bolstering protective factors and reducing the impact of vulnerability factors.

Studies of dementia and resilience. Cotrell and Schulz (1993) suggest that in much of the research on dementia "the afflicted person is viewed as a disease entity to be studied rather than someone who can directly contribute to our understanding of the illness and its course" (p. 205). However, Harris (2008) examined resilience in two individuals with dementia, and was among the first to demonstrate that individuals with early stage dementia can exhibit resilience. Resilience was examined from multiple perspectives: the individual with dementia, the care partner of the individual with dementia, the referral source, and the researcher. Including the perspective of the person with dementia in the discussion of resilience demonstrated that individuals with dementia can contribute to our understanding of resilience, which is important given the criticism that the literature on resilience in older adults often excludes the individual with dementia as a direct participant (Wild, Wiles & Allen, 2013).

Applying the concept of resilience to dementia is a strengths-based approach to understanding living with dementia (Bailey et al., 2013). Further, it acknowledges that older individuals may "thrive in spite of and even at times *because* of their experience with these difficulties" (Wild et al., 2013, p. 142). Hildon et al. (2010), "resilience overrides the idea that once health begins to deteriorate and disability sets in, aging successfully is no longer possible" (p. 37). Resilience provides an opportunity to demonstrate positive outcomes despite dementia and other disabilities. Particularly, insight into the specific protective and vulnerability factors that contribute to resilience for individuals with dementia will guide future intervention. If common internal and external protective factors are identified within a specific population, such as individuals living with dementia, it may be possible to bolster the external modifiable factors and reduce the impact of vulnerability factors by focused intervention efforts.

Purpose and Goals of the Study

The goals of this study were (i) to describe resilience in dementia, and (ii) to identify protective and vulnerability factors that may influence resilience in dementia, from the perspectives of individuals with dementia and their family members or care partners.

Methodology

Because there is limited research on the concept of resilience in dementia, it is important to develop a clear description of resilience and how it is understood within the population, prior to measuring or quantifying the processes that underlie resilience in this population. To that end, interpretive description was used as the methodological approach as it allows for an examination of the commonalities within a specific phenomenon and is very practical in nature, focused on generating a rich description of the concept in order to inform clinical understanding (Thorne, Reimer-Kirkham, & O'Flynn Magee, 2004). This study provides an understanding of resilience from the perspective of individuals with dementia and those close to them, and begins to explore the factors they view as positively or negatively affecting their resilience.

Participants

Consistent with qualitative research design (Sandelowski, 2010), purposeful sampling was used to recruit participants. Seven individuals with dementia and five care partners participated in this study. Following ethics approval by the Health Research Ethics Board-Health Panel of the University of Alberta, participants were recruited through the Alzheimer Society of Alberta and the Northwest Territories by means of an intermediary contact who identified potential participants and distributed a recruitment letter outlining the criteria and description of the study. Individuals interested in participating in the study contacted the authors and eligibility to participate was confirmed prior to scheduling a meeting for data collection. Individuals were invited to participate if they had dementia associated with probable Alzheimer's disease or were the family member and/or care partner of a person with dementia associated with probable Alzheimer's disease, and believed they were 'doing okay' in the context of that diagnosis. Participants had to agree to be audioand videotaped during data collection and to not have family members or other care partners present during the data collection. In addition, participants with a diagnosis of dementia were required to complete standardized measures of cognition, depression, and quality of life.

Standardized Measures. Participants with dementia also completed the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005), the World Health Organization Quality of Life– BREF (WHOQOL- BREF, 2004) scale, and the Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986). These well-established screening tools provided context for study participants' descriptions of their understanding of their own resilience and were administered and scored as outlined by each measure's instructions. The semi-structured interviews were intentionally conducted first; the participants with dementia have had experience with memory and cognition tests as part of their dementia diagnosis and it was anticipated that beginning the session with these measures might have negatively impacted rapport and their willingness to fully participate in the interviews.

Seven participants with dementia met the inclusion criteria and participated in the study: four women and three men. The average age of participants was 72, with a range from 65-82. In addition, five care partners participatedtwo were wives of individuals with dementia, two were husbands, and one was the daughter of a person with dementia. Demographic information and scores for each of the screening tools for participants with dementia are reported in Table 1.

Participant	Number of Years Post-	of Montreal ot- Cognitive Documenting		World Health Organization Quality of Life BREF (WHOQOL)				
Gender	Dementia Diagnosis	Assessment (MoCA)	Scale (GDS)	Domain 1	Domain 2	Domain 3	Domain 4	
female	9	14	6	38	44	69	56	
male	5	18	0	56	69	75	88	
female	<1	15	1	69	69	100	88	
female	<1	18	7	56	56	56	63	
female	1.5	12	2	24	20	12	35	
male	3	19	2	69	81	44	88	
male	4	17	3	56	76	75	88	

Table 1. Results of Standardized Measures Administered

Note: Maximum score for the MoCA is 30, a score of 26 or above is considered normal. Maximum score for the GDS is 15; a score above 5 suggests depression. WHOQOL domains: 1- physical health, 2- psychological, 3-Relationships, 4- Environment. Maximum score for each WHO-QOL scale domain is 100 with higher scores indicating higher quality of life.

Data Collection

Semi-structured interviews were conducted with all of the participants. The semi-structured interview questions (Appendix A) were developed from a previous project examining resilience in adults with neurologic disorders (in preparation) as well as thorough discussion with a panel of experienced researchers. Two factors, physical activity and spirituality, were specifically probed as possible influences on resilience, having not emerged in the previous project (in preparation) but represented in some of the literature related to resilience. Physical activity has been identified as playing a positive role in mental health and cognitive functioning in aging (Daffner, 2010; Voelcker-Rehage, Godde, & Staudinger, 2010), which may relate to resilience. The case study by Harris (2008) identified religious beliefs as a protective factor for individuals with dementia. Specific questions regarding religion were developed based on Koenig and Bussing (2010) and the use of the term 'religion' over 'spirituality' in the interviews was purposeful, as Koenig (2011) proposes that religion is a clearer and more distinct concept than spirituality. All questions in the interview were based on levels previously identified as impacting resilience in the literature: individual, family, and community (Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000).

Data Analysis

Transcript verification. Each interview was transcribed verbatim and spot-checked by a second listener with a sampling ratio of 2 or more minutes per 10 minutes of recording (Easton, McComish, & Greenberg, 2000; Maclean, Meyer, & Estable, 2004). Transcripts were verified with 95% agreement between the two listeners. Qualitative data analysis software (NVivo) was used to assist in organizing themes in the data related to the research questions.

Method. Thematic analysis, a process commonly used in qualitative research to identify patterns or themes in a data set, was employed as the framework to assess the data (Guest, MacQueen, & Namey, 2012). Two reviewers independently developed coding schemes based on themes and sub-themes or 'factors' within the interviews, then compared notes and arrived at a consensus. Creating operational definitions of themes and factors ensured reliability of the coding system. Reliability and validity in this study were established following Patton's (1999) recommendations. Data triangulation occurred across the participants with dementia and the care partners (Guion, Diehl, & McDonald, 2011). Analyst triangulation was accomplished by having two coders involved in analysis.

Results

Analysis of the data from the study participants revealed three major themes associated with resilience for individuals with dementia: 'active and purposeful living', 'perspective', and 'resources'. Each of these major themes are comprised of several factors that operate at one or more of the following levels: individual, family, and community. There is overlap and interaction between the factors; they are not mutually exclusive. While it is acknowledged that the data could be classified differently, there was agreement by the coders of the current data set that the divisions highlight the concepts most salient to the study participants and are an authentic representation, in the spirit in which they were discussed. The relationship between themes and factors is undoubtedly more complex than represented here, and worthy of further exploration.

Table 2 summarizes themes and factors that were identified by participants. Each factor exists on a

Theme	Factors
Active and Purposeful Living	Participation Physical Activity Social Interaction
Perspective	Attitude/acceptance Openness
Resources	Education Support Strategies

Table 2. Summary of Themes and Factors.

continuum, operating as a protective factor at one end of the continuum and as a vulnerability factor at the other end. Participants in this study identified the majority of factors to be operating primarily as protective. Participant quotes are utilized to illustrate each factor; for ease of reading, interjections, repetitions, and pauses were removed and participant quotes are italicized.

Active and Purposeful Living

'Active and purposeful living' is a major theme that refers to being engaged in a variety of everyday activities following a diagnosis of dementia. Participants identified filling their days with meaningful, fulfilling activities and having a purpose in their daily life as contributing to resilience. The theme of 'active and purposeful living' is comprised of the factors 'participation', 'physical activity', and 'social interaction'.

Participation. The factor of 'participation' refers to participants becoming or staying busy in their everyday lives. All 12 of the participants referenced it as a protective factor. Participation overlaps with the other two factors under 'active and purposeful living', however it was conceptualized as broader than 'physical activity' and 'social interaction' as it includes activities that are not social or physical in nature and was therefore justified as a separate factor. It included activities that the individual had engaged in prior to the diagnosis of dementia as well as new activities based on interest and opportunity, including attending community groups, and hobbies. For most participants, continuing to engage in activities that were central in their daily lives prior to the diagnosis of dementia was beneficial, in that there was a sense of continuity between life before and after the diagnosis. When asked what helped her do better with dementia, one participant stated: "Do your life, do the same thing that you've been doing before. Don't stop, activity is important." Another participant acknowledged that how she participated in her activities has shifted since the onset of her dementia, however the maintenance of these activities despite these changes was important. She stated:

I work out, I go to the gym, I still go out with people. I still go to friends. Things have changed, but I still go out.... I've had to make adjustments; like I can't do those things on my own. But I haven't stopped.

Participation or 'staying busy' was used as a distraction from his disease for one participant. When asked what advice he would give to someone recently diagnosed with dementia, he stated: *"They should try to keep busy. It takes you away from thinking about your Alzheimer's for a certain length of time."* For care partners, participation was seen as important for the person with dementia and for themselvesmaintaining their own interests and activities was considered important in their ability to cope with their family member's dementia. Care partners also believed that having the person with dementia engaged in activities offered some respite for them as well as slowing the decline associated with the disease. *"It's important for her [person with dementia] to be involved, to stay busy, for her own sake, but also- if she wouldn't go do things it would be harder on me." "Sometimes it is the only time I get a break, where I don't have to worry about him, what he's doing." "We both need intellectual outlets. She's in there somewhere and maybe she doesn't always get it, but I think it's important for her."*

The factor of 'participation' operates at all three levels as it includes activities that can be completed individually (e.g. hobbies), within the family (e.g. family outings), as well as in the wider community (e.g. church groups).

Physical Activity. 'Physical activity' was defined as engagement in physical exercise of any kind. Physical activity was identified as a protective factor for all seven participants with dementia and by four of the five care partners. The types and frequency of physical activity varied across participants and included activities such as walking, going to the gym, cleaning a local community centre, and swimming.

For all study participants, physical activity was something they had done prior to the diagnosis of dementia and continued to do following diagnosis, and was considered an important component of their adaptive functioning. One participant with dementia discussed the importance of square dancing and stated:

It's amazing how the brain works, because I couldn't go and teach somebody how to do it. I couldn't say you need this step, but once the music comes on and the steps come back in my brain, I can dance....I think it's what's kept me good.

For another participant with dementia, physical activity was an especially important means of social interaction, as a means of engaging with other individuals at the local gym. The significance of physical activity for mood regulation was identified by a study participant who stated *"I really don't have too many bad moods, but usually if I get myself turned around a little bit, all I do is put my clothes on and go for a walk."* Another participant with dementia solely attributed his resilience to physical activity, and that going for walks became even more integral to his daily life following his diagnosis of dementia. When asked whether physical activity helped him 'do okay', he claimed: "*It's the best thing I can think of.*" Physical activity was identified to serve a variety of purposes, however, regardless of the reason study participants engaged in exercise, the physical activity itself was central to their daily lives.

For care partners, physical activity served a number of functions. It served as stress control for themselves and for their family members. "We've walked every day for the last ten years, maybe longer. If we don't get out, we won't be happy. Sometimes I tell him '<u>You</u> need to take a walk', and I mean it!", and "It's not a lot [of exercise] but I need it, so I'm glad I still get to do it." "It wasn't to cope with this, but because we both had other activities going on they're part of probably what's helping us get through this right now." It was also an activity they could engage in with their family member or as discussed under 'participation', as a means of occupying the person with dementia, "She goes to [the gym] where they know her and I don't have to worry, and I get to do something for myself."

The factor of 'physical activity' operates at all three levels, as it can include physical activities done alone (e.g. going for walks independently), with family (e.g. weekly family swims), or in the community (e.g. going to a public gym).

Social Interaction. 'Social interaction' was defined as any meaningful interaction between individuals. These types of interactions could be formal, organized situations such as Alzheimer's support groups, or casual interactions such as brief conversations at the local gym. For five of the seven participants with dementia and for all of the care partners, this was a protective factor they believed contributed to their resilience.

The types of social interaction varied across participants. Participants with dementia identified engagement with and staying in contact with friends as something that contributed to their resilience. By remaining in contact through phone conversations and lunch dates, these participants felt that their close friends played an important role in their adaptive functioning. Further, a variety of different types of social groups were mentioned by study participants, including sorority, church groups, and Alzheimer's support groups, as a means of social interaction and engaging with others. One participant noted that having a role within an organized group gave her a sense of purpose : "I like that, because it makes me feel a part of [group] because we all have to do certain things." When describing the nature of her community group, one participant described it as "a really fun place to be with great, great

people."

One participant noted that social interaction, although an important factor for her resilience, was something that was especially difficult with dementia. When asked what plays a role in helping her 'do okay', she stated that:

Interaction with people too. With this illness, it's really easy for me to stay in and I find you get a spot that you like. And it's really hard, as I like that one spot. Sometimes when you go out, I can't wait to get back to that one spot. But I haven't stopped doing, which would be easy to do. Really easy because you just want to stay in that spot and not make a mistake. I have to fight that to make myself still go out and interact.

Four of the five care partners of persons with dementia identified 'social interaction' as a factor contributing to resilience for the individual with dementia. "Several of [her friends] phone her once or twice a week and they'll get engaged in an hour long conversation going nowhere but the person on the other end knows that they're just doing their part to support her." The fifth care partner noted that her family member with dementia "was never very social, so there's very little change. If anything, I think she does more now because of the [Alzheimer] Society." The only reference care partners made to themselves regarding this factor was in the context of their participation in activities through the Alzheimer Society. The Alzheimer Society was seen as extremely important to all of the care partners, but will be discussed in the context of the theme 'resources.'

'Social interaction' operates at two levels: the family level (e.g. interactions with family and friends) and the community level (e.g. interactions with community or support groups).

Perspective

'Perspective' is the second major theme that refers to the view individuals with dementia and their care partners took in regard to their diagnosis. The factors included under 'perspective' were 'attitude/acceptance', and 'openness'.

Attitude/acceptance. This refers to being positive and coming to terms with the diagnosis of dementia. Six out of seven participants with dementia and all of the care partners identified having a generally positive attitude or disposition or specifically a positive attitude about their diagnosis of dementia, as contributing to their resilience. 'Attitude/acceptance' includes being positive, having a sense of humour, positive self-esteem, and accepting the diagnosis. It was discussed as a protective factor by the participants with dementia. "I feel I've had a very good life. I don't want you to feel that I've got this thing [dementia] hanging over me all the time." When asked what advice she would give to someone recently diagnosed with dementia, one participant stated: "You just have to keep smiling, because that's one of the biggest things. Don't give up." "Acceptance would be a big part of this. Having to accept my limitations and be okay with it." Self-image and self- esteem for the person with dementia played into this:

I think it's important to build self-esteem too. And it's a hard one because when you're doing stupid things - when you can't add your money anymore, when you can't make a sandwich, when you can't drive your car anymore - you feel stupid.

Other participants noted that positively reframing changes in ability following the onset of dementia was important. "I went through 'poor me' and feeling sorry and depressed. Then I changed my thoughts - 'I'm retired, 'What would I do if I was retired?'" By changing her attitude about new limitations imposed by dementia, this participant felt she was able to look at dementia in a different, more empowering way. "I've never said 'why me?' I've just said to myself 'This is me now, I've got to make the best of this I can.'"

Three participants with dementia explicitly referenced having a sense of humour, being able to joke, make light, and laugh about their diagnosis, as something that helped them 'do better' following their diagnosis of dementia. One participant noted that rather than being upset at her memory loss, she would tell others "Oh I forgot, I've got dementia, I've got Alzheimer's, that's why I forgot! And I'll make a joke about it." "I was angry at God. I really was. And sometimes I'd say, 'Why me God?' and then I'd say 'why not?' You have to look at it from that angle too; there are hundreds of people who have Alzheimer's."

And

I was so acceptant of this [dementia] because I knew when they say it, that's it. It can't be fixed. And what are you gonna do about it? I mean you can sit there and go back to bed. Or you can get off your dot and do something.

Care partners of persons with dementia discussed attitude in the context of separating the person from the disease and the importance of humour. "I focus on the successes more than the struggles. But I'm realistic. And I keep a sense of humour. You have to, you have to." Another care partner acknowledged:

There's frustrating moments, but you have to sit

back and realize that you can't see the white cane, so there are reasons this is happening. It's not my wife that's causing the problem it's this disease that is. And I think you have to keep reminding yourself of that when you get frustrated.

And

You have to keep it sort of jovial even though you are in fact nagging but her mind doesn't realize that I told her 5 minutes ago the same thing I just told her now. At least I think that's what goes on.

Two study participants with dementia and two of the care partners also noted that frustration or negative emotions related to the diagnosis of dementia made it more difficult to for them to 'be okay'. The participants with dementia worried about letting others down, had concern over negative stereotypes of people with dementia, and anxiety about making mistakes in public. This factor operates at the individual and family levels and relates to personal approaches towards living with dementia.

Openness. 'Openness' refers to sharing the diagnoses of dementia with other individuals in one's life and is strongly related to 'attitude/acceptance'. 'Openness' was identified as something that positively contributed to well-being and operated as a protective factor by five out of seven participants with dementia and by all of the care partners.

Study participants saw openness as a way of decreasing embarrassment and increasing understanding of dementia, particularly in public situations. Participants had varying degrees of openness, which appeared to be related to decisions about who to share the diagnosis with. One participant with dementia noted that she shared her diagnosis at the grocery store and stated: *"I tell people ahead of time so if I make a mistake, I don't feel silly."* While another participant noted that it was important to tell *"trusted"* friends, however this individual was not comfortable sharing with more casual acquaintances.

Several participants with dementia noted that by sharing the news of their diagnosis with others, there was a wider range of support that was available should they need it, and openness also increased general awareness about their condition. In one case, a participant explained the influence his care partner had on sharing his diagnosis. By sharing his diagnosis with others, he stated that his care partner was able to advocate for him more readily and increase support for both of them. Because of this openness, he felt more comfortable with his current level of functioning and found that people were more understanding once they were aware of his diagnosis of dementia. Let me tell you what we did first. We told as many people as possible – good friends and even marginal friends if there was a good chance that we would meet up in different circumstances. I say that nobody said 'Oh, that's [name], he's away with the fairies.

Further, people discussed dementia as a 'hidden illness' in that it is not discernable as a visible disability, which increased the need to be open and honest with others. One participant stated: "What's really hard about people with early dementia is I look well. People aren't there saying 'Can I help you?' so you have to advocate or your family has to advocate for you." "It's a hard disease, because one minute you're good and one minute you're bad. Or one day, you're perfect and nobody would have a clue there's something wrong with you."

For care partners of individuals with dementia, openness was unanimously agreed to be important in coping with the diagnosis for the person with dementia and for them as care partners. *"Everyone should find groups that they can be open with, and that's where the support comes from."*

"So the biggest thing for resilience is when [person with dementia] finally started getting relaxed, getting open with her friends.... and various people that she visits with. Everyone knows she has it. And that's helpful to me too because there's a support network out there now. If you keep it secret, it's hard."

And

"[Being open about the diagnosis] was valuable to both of us. She realizes it was beneficial. At first she was sorta letting a few people know [and making them] swear they won't divulge it to anyone else... but eventually she just allowed it. That's when it got a lot easier for everybody."

'Openness' operates at the individual and family levels, as the decision to share the news of a dementia diagnosis is personal (individual), however, family members or care partners also were identified to play a role in the decisionmaking process (family) and to benefit from sharing the diagnosis.

Resources

'Resources' is a major theme that pertains to external supports that contribute to an individual's resilience following a dementia diagnosis. Participants identified ways of adapting, problem-solving, or accessing supports as a means of coping with everyday life and how it has changed since the onset of dementia. The factors of 'resources' include 'education', 'support,' and 'strategies'.

Education. 'Education' refers to the process of becoming informed about dementia by actively searching out information regarding the disease itself, how everyday life may change, and what the future outlook of the disease is. Four out of seven participants with dementia and all of the care partners commented that learning about dementia was beneficial to them, as a means of helping them cope following the diagnosis; therefore, this factor was identified primarily as protective. Education took a variety of forms that included support groups at the Alzheimer Society, reading books about dementia, as well as using the Internet as a means of education. Several participants with dementia noted that receiving the diagnosis made it easier, however, they also acknowledged the importance of not letting their diagnosis overtake their life. One participant stated: "I read as much as I can about Alzheimer's, but I don't want to get clogged with it because looking through a book is not going to give me any cure." Another participant noted that education decreased the fear associated with the future, and when asked 'what helps her be okay' she stated: "I think knowledge - I sought out help with the Alzheimer Society. I'm not afraid of dementia."

Educating others and increasing awareness of the symptoms of dementia was identified as having a positive impact that would assist individuals living with dementia. Study participants commented on a lack of awareness about dementia with the general public, the medical community, and in their own lives as impeding their resilience and that increased awareness did, or would have, helped them 'do better' after their diagnosis. When asked what would have been beneficial following her diagnosis a participant stated:

Other people knowing about dementia: family and friends. People don't know. People know what Alzheimer's is, and of course, they think the worst. Some people don't understand the beginning stages of dementia or Alzheimer's. People are afraid of it. So I think knowledge.

Five of the participants with dementia and four of the care partners stated that the Alzheimer Society support groups played an integral role in their functioning following their diagnosis of dementia. The support groups were identified as having a variety of roles for individuals with dementia; attending meetings at the Alzheimer Society were a way of learning about the disease, its progression and everyday strategies, as well as being a place to socialize with others. As one care partner stated, *"Connecting with the Alzheimer Society was probably the biggest success part of this whole process for the two of us."* And another, *"I can't*

say enough about them-Best. Thing. Ever." 'Education' operates at all three levels and involves education for the individual with dementia (individual), for family members and care partners (family), as well as broader public and community awareness (community).

Support. The factor of 'support' refers to the different supports that loved ones or care partners provide to individuals with dementia and that are provided to care partners. All seven study participants with dementia commented on the integral role their family members, loved ones, or care partners, played in contributing to their resilience, identified as a protective factor when present but also observed as a vulnerability when referring to individuals who did not respond well to the diagnosis. Similarly, for care partners, 'support' was discussed as a protective and/or a vulnerability factor in terms of the value of healthy support systems and the toll that a lack of support took on the person with dementia and the care partner.

A variety of different support types were identified, depending on the participant and their relationships with their loved ones and their community. These included providing emotional regulation, compensating for memory loss (e.g. the name of an acquaintance in a public setting), transportation, assistance in public domains (e.g. at the grocery store), taking on additional household responsibilities, and keeping the individual with dementia company. Included in the description of 'support' was the notion of independence and freedom, balancing safety with independence, autonomy, respect, and graded support.

One participant commented on the role of his care partner, and the specific way she provides him with support, stating:

She helps me a lot, but there's some times she says nothing. And I appreciate that - she doesn't always step in. It's just the fact that she has recognized and responded to my need, but not in such excess that it's a bit embarrassing.

Having family and care partner support significantly contributed to resilience for study participants. Several participants commented on how much they appreciated having their loved ones take on the care partner role and how effective they felt their care partners were in that capacity. One participant noted that she could rely on her family, which helped her function in her every day life. She noted that: "Anything I need, they talk to me. They either come right away if they can, or they come as soon as they can. They always, always answer my calls." Another participant stated, in regard to her care partner: "I really rely on him." Conversely, having to rely on others was a challenge for some, "My biggest thing with my family is that I always, always wish I could do it myself because I hate being a burden."

Care partners also discussed concerns about family members and friends who were not supportive following the diagnosis.

[Family member] just doesn't get it, or doesn't want to get it. Doesn't understand that [person with dementia] needs help now, not tomorrow, not on the weekend. And when [family member] doesn't help it just makes it harder on all of us. And I think it makes [person with dementia] feel bad too.

Interestingly, a common thread was the challenge and burden of transportation. "Not being able to drive, not being able to just open the door and go. Freedom... freedom is gone to a certain extent and that's what really bothered me." Difficulties taking public transportation or lack of access to reliable and affordable transportation compounded the loss of independence felt by study participants. Several participants with dementia and care partners relayed traumatic stories about transportation that resulted in a lack of trust of public services, increasing pressure on family and financial resources (e.g. to hire private transportation), and concerns about increasing isolation and dependence for the person with dementia.

'Support' operates at the family level, as care partners and loved ones are the individuals who provide support and care to study participants (family) and at the level of community, resources that are available in the community publically or privately.

Strategies. 'Strategies' is the final factor of 'resources' and refers to ways of adjusting, compensating, or adapting to changing needs and abilities following a diagnosis of dementia, a protective factor for individuals with dementia and for their care partners. This factor is intimately associated with the factor of 'support' and may well be subsumed as part of the factor but in an effort to accurately represent the importance placed on strategies by the participants, it is listed as a separate factor.

Environmental modifications were identified as important strategies to support resilience for individuals with dementia. Five participants with dementia and three of the care partners specifically discussed sensitivity to noise, crowds, or visual distractions as barriers to 'doing okay', and that they mitigated these by changing their environment to improve functioning. These kinds of environmental changes included moving into a smaller home, changing how tasks were carried out, and reducing noise and clutter in the immediate environment. For example, devices or reminders to compensate for memory loss were identified as strategies to help with everyday functioning. These devices included iPads, other calendar, or reminder systems (e.g. alarms reminding participants to make lunch), as well as written notes or lists.

Several participants commented on a role-shift with care partners that occurred following the diagnosis of dementia. Changes in household responsibilities such as paying bills, buying groceries, or cooking meals often occurred, and acceptance of those changes by the person with dementia was important. One participant with dementia explained it as "You adapt, you buy groceries a little differently. Things have changed, my husband does the groceries, he has to do the cooking and being okay with that has helped me." Conversely, a care partner observed that he believed it was important to his spouse to continue to buy groceries "but now I make a list for her, and I watch from a distance so I can give her some help if I see that she needs it.... so we don't end up with 3 dozen bananas!" As a vulnerability factor, two participants noted that having support with meals and daily chores would be beneficial, but that costs of such services were an impediment to accessing them.

This factor operates at all three levels. 'Strategies' can be implemented individually (e.g. using devices for reminders), at the familial level through environmental modifications and role shifts (family), and at the broader community level by providing affordable, available access to needed supports, such as meals and transportation (community).

Discussion

Describing Resilience

For study participants, resilience appeared to be a process of maintenance, in that they felt that their resilience was related to a degree of continuity between life before and after the diagnosis of dementia. Even though their lives had changed following diagnosis, most participants noted that a sense of normalcy and similarity to their life prior to the diagnosis of dementia was central to a view of resilience and to their positive adaptation. The actions and activities of the participants served as evidence to them of their resilience but were also recognized as contributors to their resilience. What changed for most participants was *how* they did these activities, rather than *what* they did. Consistent with this finding, Bailey and colleagues (2005) suggest that resilience for individuals with dementia "can encompass the ability to continue with established roles and activities that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological, and material assets" (p. 394), an emphasis on the importance of continuity between life before and after dementia as identified in the current study.

Resilience Factors

Eight factors identified as contributing to resilience for persons with dementia and their care partners were grouped into three themes: 'active and purposeful living', 'perspective', and 'resources'. The factors represent a continuum from positive (protective factors) to negative (vulnerability factors).

Many factors identified in this study support previous findings in the literature. 'Participation' relates to the protective factor of *productivity* identified by Harris (2008) in a case study of two individuals living with dementia. Glymour, Weuve, Fay, Glass, and Berkman (2008) identified social integration as a protective factor for stroke patient's cognitive recovery, which parallels 'social interaction' in the current study. 'Attitude/acceptance' corresponds with several factors identified by Harris (2008) including: positive attitude, a fighting spirit, and positive self-concept. Harris (2008) also suggested that acceptance of changing self was a protective factor, which is similar to 'attitude/ acceptance' in the current study. All three factors of the major theme 'resources' in the current study were consistent with Harris (2008): 'education' (community resources), 'support' (social support networks, long-term supportive marriage), and 'strategies' (coping strategies, problem solving skills).

Factors not previously identified in the literature but highlighted by participants in this study as being important in bolstering resilience were 'physical activity', and two components of support, 'openness', and 'independence'. That 'physical activity' was identified as a protective factor reinforces the importance of establishing healthy habits prior to the identification of illness, given that participants referenced continuing the physical activities they had established prior to the dementia diagnosis. The identification of 'openness' as a factor may be influenced by participants' experience with the Alzheimer Society through which participants were recruited, since the Alzheimer Society encourages people to tell others about the diagnosis. Participants with dementia and their care partners validated this recommendation, with the majority believing it played a key role in their resilience.

'Independence' was identified as a sub-factor under 'support' in the current study. While not previously explicitly linked to resilience, Anderson, Wittrup-Jensen, Lolk, Andersen, and Kragh-Sorensen (2004) have suggested that dependency for activities of daily living was a significant factor in measures of quality of life for individuals living with dementia. Several of the participants with dementia in this study noted that their biggest impediment to resilience was their loss of independence as a result of their dementia diagnosis. Similarly, it was a focus for care partners, explicitly attempting to provide support and structure to allow for a level of independence on the part of the person with dementia; this also affected their own independence and freedom.

Limitations and Challenges of the Study

This study employed a qualitative methodological approach yielding rich information on resilience; however, there were limitations to this study related to procedure and to the population studied. Procedurally, diagnosis and medical history were not confirmed, because it was anticipated to discourage participant recruitment and significantly delay collection. It is therefore likely that study participants had varying types and severities of dementia and possible that the factors associated with resilience in dementia may not be consistent across dementia types and levels of severity. Second, while participants were invited to participate in the study if they felt they had demonstrated resilience in the face of the diagnosis, several participants noted that their primary reason for participating in the study was to help others, not necessarily because they felt they were demonstrating resilience. However, because recruitment for the study occurred through the Alzheimer Society, study participants were individuals actively taking part in support groups and accessing community resources, which arguably illustrates a degree of resilience. Further, responses during the semistructured interviews suggested that at least in some situations or at specific points in time all of the participants identified and described themselves as being resilient. Finally, varying degrees of cognitive impairments across participants with dementia and the changing nature of dementia may have influenced the accuracy of the data obtained and was the main factor in there not being a verification step in this study.

Implications for Clinical Practice and Future Research

The concept of resilience may prove to be a useful lens through which to view approaches to clinical management in dementia. By considering resilience and the factors that support or undermine it, goals may be set to bolster resilience. Bailey and colleagues (2013) suggest asking, "What resources does the person living with dementia have and how might they inform notions of risk?" (p. 395).

This work lends itself to a collaborative approach, given the many levels at which resilience can be considered, with speech-language pathologists playing an integral role. Given the significant communication deficits that are part of the presentation of dementia and which potentially make direct discussions more challenging, S-LPs can facilitate discussions of resilience with individuals with dementia. to inform health care teams and provide guidance regarding team goals for management and treatment. More specifically, because communication is a component of many of the factors associated with resilience identified in this study, including social interaction, participation, and openness, it has the potential to serve as both a vulnerability and a protective factor. To illustrate, for one participant with dementia, being able to express herself was difficult, but communication operated as an important strategy to get her wants and needs recognized and met. When asked what helps her be resilient she responded:

Being able to communicate, and that's hard with dementia, because when I'm tired, the communication isn't there. So it changes. I've been okay up to now, but that can be a real problem for me when I won't be able to communicate.

Using resilience as a framework, management and treatment goals and activities can be structured to focus on communication as a protective factor, to encourage resilience in our clients.

The defining characteristic of resilience for individuals living with dementia, as suggested in the current study, is that of maintenance or continuity between life before and after dementia. Assuming this bears out with further research, this finding provides insight and direction regarding the kinds of interventions and supports that would be beneficial for individuals diagnosed with dementia. These interventions and supports could include, for example, increasing accessibility and affordability of transportation for individuals with dementia, and increasing support and care to care partners as a means of benefitting both the individual with dementia and the people who care for them. Supports specific to communication enable individuals with dementia to maintain a degree of independence and autonomy, encourage social participation, and maintain safety, all of which potentially impact the resilience of care partners as well. The use of augmentative and alternative communication is an important component given the degenerative nature of dementia. S-LPs can also provide

education regarding strategies to maximize communication in various contexts as the dementia progresses.

Originally, this study sought to examine the concept of resilience in individuals with mild dementia and their care partners; however, participants with dementia had much lower scores on the MoCA than initially expected, suggestive of a more significant cognitive impairment. Despite this, themes were identified across participants with dementia and all of the interviews provided useful and meaningful data. This suggests that impairments in communication ability may not preclude participation in examinations of the experience of living with dementia if the researchers are trained to work with individuals with communication disorders. This finding challenges the assumption that data collected from individuals with cognitive impairment are inaccessible and unreliable (Cotrell & Schulz, 1993; Hess-Wiktor & Opocyňska, 2012). It is also interesting to note that even with cognitive impairment, study participants still felt they were resilient.

The potential presence of depression, identified on scores on the GDS greater than 5, suggests that even individuals who may be depressed can still consider themselves to be resilient. From the perspective of persons with dementia in our study, resilience may be exclusive of depression, as individuals may be depressed and still be resilient. Similarly, the WHOQOL-BREF measure revealed a vast range of scores across participants, from within normal range to significantly below average compared to individuals with no cognitive impairments or chronic illnesses (Hawthorne, Herrman, & Murphy, 2006). Even with what would be considered 'low' quality of life scores, study participants still considered themselves to be resilient. This is especially interesting because in previous studies on resilience in older adults, the measure of resilience was 'better-than-expected' quality of life scores. The finding that participants in the current study described themselves as resilient, even with low quality of life scores suggests that resilience is not directly associated with quality of life, and although these factors may be related, resilience and quality of life do not presuppose each other. These observations regarding the apparent lack of relationship between resilience, depression, and quality of life are important for clinical management and worthy of further research.

Despite being specifically queried, religion was not identified as contributing to resilience in this study, with the exception of 2 participants who were related to each other and therefore had a similar background. Because of the limited size of this study, and the identification of religion as a factor in resilience in some of the literature on resilience (Harris, 2008), this cannot be ruled out as a contributor to resilience and should be considered for further investigation.

The results from the semi-structured interviews provide evidence that resilience is both an inclusive and optimistic position from which to approach dementia. Even individuals who appear to be significantly cognitively impaired, depressed, and have low quality of life scores, can still be resilient.

Summary

Using data gathered from semi-structured qualitative interviews and qualitative thematic analysis, this study described resilience as well as identified protective and vulnerability factors associated with resilience from the perspective of individuals living with dementia and their care partners. The factors found in this study build on those previously identified in the literature, and suggest additional factors that may impact resilience in this population, namely physical activity, openness in sharing news of their diagnosis, and maintaining some level of independence.

The concept of resilience, as described in the current study, corresponds to maintenance or a degree of continuity between life before and after a diagnosis of dementia. Clinical implications of resilience for this population include supporting continuity between life before and after dementia as well as bolstering the multiple, modifiable factors identified as promoting positive adaptation for those living with dementia, both the persons diagnosed and their care partners. This study emphasized the importance of firsthand perspectives of individuals living with dementia as well as the inclusivity and optimism inherent in the notion of resilience and provides a basis for future investigations into the concept of resilience as applied to individuals living with dementia.

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Appendix A Interview Questions

1. What made you sign up for this study?

- a. Are you doing okay?
- b. If so, why are you doing okay
 - i. At home?
 - ii. At work?
 - iii. With family?
 - iv. With friends?
 - v. Out in the community?
- c. What does it mean to you to be resilient/be doing okay?

2. What helps you do okay?

- a. [Individual] How are things with you personally?
- b. [Family] How are things with your family?
- c. [Community] How are things in the wider community?

3. What makes it hard for you to do okay?

- a. [Individual] personally?
- b. [Family] in your family?
- c. [Community] in the wider community?
- 4. What would have helped you do better after your diagnosis of dementia?
 - a. What would help you now?
- 5. What advice would you give to someone that may be able to assist them with overcoming hurdles, such as a dementia diagnosis?

6. Are you religious or spiritual? Tell me about that.

- a. Do you think religion played a role in doing okay?
 - i. How often do you attend church or other religious meetings?
 - ii. How often do you spend time in private religious activities, such as prayer, meditation, or Bible study?
 - iii. Do you feel like you experience the presence of the divine in your life?
 - iv. Do your religious beliefs lie behind your approach to life?
 - v. Do you try to carry your religion over into all other dealings in life?

7. Are you physically active? Tell me about that.

- a. Do you think physical activity was important to you once you learned you had dementia?
- b. Do you think it plays a role in helping you be okay?
- 8. Is there anything else you would like to tell me about doing okay with dementia?

BLANK PAGE BY DESIGN Speech-Language Pathology Diet Texture Medical Directive: Impact on Accuracy and Timeliness of Diet Order Entry

Directives médicales de l'orthophoniste concernant la modification des textures alimentaires : impact de la précision et de la rapidité de l'entrée des directives

Carolyn Chalmers Nesanet Girma Jennifer Barker Louis W.C. Liu Carol S. Heck

Abstract

In Ontario, Speech-Language Pathologists (S-LPs) can use medical directives to order, modify, and discontinue diet textures. This study evaluated the use, safety, and timeliness of a S-LP medical directive in an acute care inpatient setting. Chart reviews (n=1574) were completed for patients seen over a one month period in three consecutive years: 1) one year prior to implementation (2008), 2) the month of implementation (2009), and 3) one year post-implementation (2010). The interprofessional teams' perceptions regarding the usefulness of the medical directive prior to (n=151) and one year post-implementation (n=154) were surveyed using a questionnaire. One year post-implementation, the use of the directive was high (98.2%) and the number of diet texture orders that were correctly entered on the first attempt was higher one year post medical directive (89.5%) when compared to baseline (80.6%). The timeliness of orders was significantly improved one year post-implementation, on average, 4.6 hours less than before implementation of the directive. S-LP ratings across all questions for timeliness, time consumption, and error rate were, on average, 61.7% more positive post-implementation. The ratings for the interprofessional team (excluding S-LPs) was not significantly different between the two time periods. An issue was identified with S-LPs entering diet orders when no therapeutic diet was specified on the chart (15.5%). Overall, there was a positive impact from the introduction of a S-LP medical directive.

Abrégé

En Ontario, les orthophonistes peuvent utiliser des directives médicales pour ordonner, modifier et cesser la modification des textures alimentaires. Cette étude a évalué l'utilisation, la sécurité et la rapidité des directives médicales des orthophonistes dans une unité de soins aigus. Une analyse des dossiers médicaux de patients suivis sur une période d'un mois (n=1574) a été effectuée pendant trois années consécutives : 1) un an avant l'implantation (2008), 2) le mois de l'implantation (2009) et 3) un an après l'implantation (2010). Les perceptions des équipes interprofessionnelles concernant l'utilité des directives médicales avant l'implantation (n=151) et un an après (n=154) ont été examinées en utilisant un questionnaire. Un an après l'implantation, l'utilisation des directives était élevée (98,2%). Le nombre de directives de modification de textures entrées correctement au premier essai était plus élevé un an après l'implantation des directives médicales (89,5%), lorsque comparé au point de comparaison obtenu avant l'implantation des directives médicales (80,6%). La rapidité des directives s'est sensiblement améliorée un an après l'implantation avec une moyenne de 4,6 heures en moins qu'avant l'implantation des directives. Les évaluations des orthophonistes sur les questions de rapidité, du temps nécessaire et du taux d'erreurs, étaient, en moyenne, 61,7 % plus positives après l'implantation. Les évaluations des équipes interprofessionnelles (orthophonistes exclus) ne montraient pas de différence significative entre les deux périodes. Un problème a été identifié lorsque les orthophonistes entraient une directive alors qu'aucune modification de texture n'était spécifiée au dossier médical (15,5%). Globalement, l'implantation de directives médicales par les orthophonistes a un impact positif.

KEY WORDS

MEDICAL DIRECTIVE SPEECH-LANGUAGE PATHOLOGY QUALITY IMPROVEMENT DEGLUTITION DISORDERS NUTRITION THERAPY ELECTRONIC HEALTH RECORDS

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Dysphagia (swallowing disorder) is commonly assessed and treated in acute care practice. Reported incident rates of dysphagia range from 51-78% for acute stroke patients, 55% in acute geriatric unit patients, and 82% in patients with Parkinson's Disease (Cabre et al., 2010; Kalf, De Swart, Bloem & Munneke, 2012; Martino, et al., 2005). It is within the scope of practice for Speech-Language Pathologists (S-LPs) in the province of Ontario to assess and manage swallowing disorders, including making recommendations to initiate, discontinue, or modify a diet texture (College of Audiologists and Speech-Language Pathologists of Ontario, 2007). Findings from the S-LP's assessment may indicate if the patient has normal swallowing function and for these patients typically a regular texture diet would be recommended. This is consistent with Hinds and Wiles (1998) finding that when a patient had a normal swallowing screening, 98% of these patients were not recommended for therapy (which included diet texture modification). If dysphagia is present, the S-LP may recommend a modified diet texture (puree, minced, or dental soft) or modified liquids (nectar or honey thick) (Garcia, Chambers, & Molander, 2005; O'Gara, 1990; Pardoe, 1993; Penman & Thomas, 1998). When swallowing is severely impaired, the S-LP may recommend nothing by mouth (nil per os [NPO]) and alternative means of nutrition and hydration are considered by the interprofessional team (Marik & Kaplan, 2003). Reasons for modified textures typically address the efficiency of swallowing or attempt to reduce the risk of aspiration (the passage of foreign material into the airway) (Baijens & Speyer, 2009; Foley, Teasell, Salter, Kruger, & Martino, 2008; Hamilton et al., 2012; Rosenbeck, Robbins, Roecker, Coyle, & Wood, 1996; Troche, Sapienza, & Rosenbeck, 2008). While modified diet consistencies have benefits, they also have been found to be associated with reduced energy and protein intake (Wright, Cotter, Hickson, & Frost, 2005), as well as reduced intake of fluids (Whelan, 2001). In addition, 48.3% of surveyed S-LPs indicated they felt patients had a strong dislike of honey thick liquids (Garcia, Chambers, & Molander, 2005). These issues with safety, suboptimal oral intake, and preference emphasize the importance of timeliness in diet texture change for patients assessed by S-LPs. In Ontario hospitals, orders for all treatments, such as diet texture, are legislated by the Public Hospitals Act (1990) as the responsibility of physicians, dentists, midwives, and registered nurses (RNs) in extended class. Prior to August 2009, the S-LPs at the study site (a tertiary academic acute care hospital) made recommendations written as a "suggestion" and were not implemented until authorized by a physician or physician delegate in writing. This practice potentially led to delays in implementing the appropriate diet texture and therefore

imposed a safety concern for patients that continued to consume foods and liquids that they were at risk of aspirating. Given the negative sequelae of inappropriate diet textures, this practice could also impact patients' satisfaction and confidence in their care provision. The impact of delays of S-LP orders has not previously been investigated; however, the impact of delays in registered dietitian (RD) orders for diets and enteral feeds have been shown to significantly prolong length of stay, lower albumin levels, and lessen weight gain at discharge (Braga, Hunt, Pope, & Molaison, 2006). For these reasons, the S-LPs decided to develop a medical directive to address this concerning gap in practice.

The Federation of Health Regulatory Colleges of Ontario (2007) indicates regulated health professionals, including S-LPs, can receive a medical directive to order diet texture changes (such as initiating a diet texture, modifying the texture, or discontinuing oral nutrition) when patients meet the criteria defined by the medical directive. They define a medical directive to include a process where a regulated health professional can receive advance authorization from a physician or physician delegate to perform the ordered procedure under specific conditions without a direct assessment by the physician or physician delegate at the time.

When modifying diet textures, the College of Audiologists and Speech-Language Pathologists of Ontario (2007) practice standard suggests that "the composition of the diet itself is most likely to be formulated by a dietitian". The S-LP works collaboratively with the RD who makes recommendations about supplements and therapeutic diets (e.g. regular, 1800 kcal, healthy heart). Wildish (2001) outlined the process for RDs to obtain a medical directive to order diet and enteral feeds. In the Wildish study (2001), RDs conducted a quality review and reported that, in a oneyear period, 469 orders were written by the RDs and 88% of these orders were implemented within 24 hours. Imfeld et al., (2012) found that providing RDs access to enter signed diet orders in their electronic record significantly reduced transcription error rates by 15% and increased timeliness to implement orders by 3.4 hours on average. These studies, focusing on RD practice, suggest that a medical directive is feasible and access to entering orders may improve speed and accuracy.

In 2009, the S-LPs at the study site (a tertiary academic acute care hospital) developed a medical directive that allowed trained and authorized S-LPs to initiate, discontinue, or modify a diet texture for acute care inpatients following receipt of a referral from a physician or physician delegate

to assess swallowing. The S-LP was required to write the diet texture order in the physician orders of the paper chart and was also required to enter the order in the electronic patient record (EPR) unless the therapeutic diet type had not been specified in previous diet in EPR or in the physician orders by a physician, physician delegate, or registered dietitian. The S-LP would not be permitted to use the medical directive if the patient was NPO for an acute gastrointestinal issue, prior to a test or procedure, or if the patient/substitute decision maker refused recommendations. To further enhance safety, additional standard phrases were included for specific recommendations. For example, if the S-LP recommended a diet texture for an NPO patient, the S-LP would add "MD, MD delegate, or RD to specify therapeutic diet type". If the S-LP ordered NPO, the written order was required to include "medications and fluid status/intake to be reviewed by MD or MD delegate". The medical directive received approval from the hospital clinical operations committee and the medical advisory committee as is standard required practice at our hospital. In preparation for implementation of the directive, all S-LPs in acute care were expected to complete an educational module developed by the research team. To ensure ongoing competency, S-LPs were also required to pass a quiz annually as well as complete at least five orders per year in order to be authorized to use the medical directive. Coincidentally, at the same time, the registered dietitians also implemented a similar medical directive, which also included the ability to order therapeutic diets. The only other additional health professions that wrote orders for diet texture were physicians and physician delegates.

While it is not uncommon for S-LPs to have a medical directive to order diet textures, the impact and use of a medical directive for diet texture change by S-LPs has not been studied.

Purpose

The purpose of the current study was two-fold: (i) to evaluate the impact (use, safety, timeliness) of a medical directive for S-LPs in acute care to initiate, modify, and discontinue a diet texture and, (ii) to evaluate interprofessional teams' perceptions of safety, efficiency, and quality of patient care related to diet texture changes recommended by the S-LP.

Methodology

Study Design and Timeline

A retrospective chart review was completed on all consecutive patients seen by S-LPs at a tertiary academic acute care hospital for the month of August in three consecutive years: 2008 (one year prior to implementation of a medical directive), 2009 (the month of implementation), and 2010 (one year postimplementation). Patient names and medical record numbers were collected from the workload measurement reporting tool for any patient seen by the S-LP for greater than 15 minutes of assessment. The review included audit of scanned paper documents and the electronic patient record.

The interprofessional teams' perspectives of the S-LP practice were assessed by employing a self-administered paper survey. The surveys were conducted at two time points: Time 1, the month prior to implementation the medical directive in July 2009 (n=151); and Time 2, one year after implementation of the medical directive in August 2010 (n=154).

Data and Outcomes Collection

Chart review

All eligible patient charts were reviewed by one study team member to extract the data of interest for each of the three time periods. Care was taken to ensure there were no errors in either data extraction or management. Data was entered into an electronic spreadsheet for subsequent data analysis. Information was collected on the following outcomes: date and time for both written and correctly entered electronic order, written diet texture order, diet texture ordered in EPR, how the order was written (by medical directive or by "suggestion"). If the time of the order in EPR was more than 15 minutes earlier than the written order, the data was not included in the study. Timeliness was measured as the time interval between the written order and the time to enter correctly in EPR. If the time interval was a negative value (to a maximum of 15 minutes between when order was written and entered) the number was converted to zero. If the S-LP entered the order, the following data were collected and analyzed for accuracy: therapeutic diet prior to and after change, supplement prior to and after change, diet change type (initiation, upgrade, downgrade, mixed, and discontinuing oral diet).

Survey Study Tool

A questionnaire was developed by the research team for evaluation of the interprofessional teams' perceptions of safety, efficiency, and quality of patient care related to diet texture changes recommended by the S-LP. Once a week for 3 weeks during the data collection phase, hospital volunteers provided paper copies of the questionnaire to 29 inpatients units in the hospital and collected all completed questionnaires. When distributing the questionnaires, where possible, the volunteer informed staff on each unit about the survey. An e-mail notification about the survey was also sent to all hospital speech-language pathologists and registered dietitians and they were encouraged to complete the survey.

The survey consisted of a demographics section (profession, years of experience) and closed-ended questions regarding perceptions of safety, efficiency, and quality of diet texture changes recommended by the S-LP. These factors were rated using a 5-point Likert scale (ranging from 1=strongly disagree to 5= strongly agree). The second questionnaire, administered one year later (2010), was identical with the exception of an additional question that asked individuals if they had completed the initial survey in the previous year. Responses were entered into a password-protected database file. All data was expressed as collated group data for each professional group.

Study Sample

For the chart review, the workload measurement tool identified 1,574 patient visits with 15 minutes or more of S-LP assessment time from the three time periods of interest that were eligible for inclusion in the study. The inpatient interprofessional team, consisting of nurses, physicians, RDs, and S-LPs on 29 inpatient units were included as the sample of interest for the study.

Data Management

Data was imported into SPSS version 16.0 for subsequent management and statistical analysis. Data obtained from the chart review were expressed as mean ± standard deviation for hours from writing the order to entering the order in EPR for all orders as well as by type of order (e.g. downgrading the texture). Data were expressed as percentage frequencies for orders correctly entered, never entered correctly, and errors when entering diets in EPR.

A one-way analysis of variance (ANOVA) was used to determine differences in hours to enter in EPR for the three time periods (August 2008, one year pre-implementation; August 2009, the month of implementation; and August 2010, one year postimplementation of the medical directive).

A two-way ANOVA was used to determine differences between the time to enter Medical Directive in EPR (hours) based on the type of order (initiate, upgrade, or downgrade) for 2009 and 2010 time periods. The small number of orders that were for a "mixed" texture or for an "oral diet to NPO" order, precluded inclusion of this data in subsequent analysis.

For survey data, descriptive analysis (percentage frequencies) was completed for all demographic characteristics of survey participants. Chi-square or Fisher's exact tests were used for categorical data to determine differences within groups (interprofessional team, excluding S-LP only) over time (Time 1 pre- versus Time 2 postimplementation of the medical directive) for each of the survey questions.

For all statistical measures differences between groups were reported as significant if $p \le .05$.

Results

Chart Review

Of the 1,574 eligible patient visits from the three study time periods, 351 (22.2%) had new diet texture orders written by the S-LP (2008, n=98; 2009, n=139; 2010, n=114). In the month of implementation, just over half (54.0%, 75/139) of S-LP orders were written with the medical directive but by one year after implementation almost all (98.2%, 112/114) were written with the medical directive. Of all S-LP orders written with the medical directive, the S-LP subsequently entered the order in the EPR at a frequency of 61.3% (46/75) in 2009 and 51.8% (58/112) in 2010.

The time from when the S-LP wrote the order to when any professional entered this into EPR was, on average, 8.1 ± 14.2 hours in 2008. This time was significantly less (p=.01) one year after (2010) implementation of the medical directive (3.5 ± 13.1 hours - combined data for suggest and medical directive); an over 50% decrease in the time taken to enter orders (Figure 1). When the S-LP entered the order, it was entered in 0.3 hours (range from 0.0 to 4.7 hours) in 2009 and 4.9 hours (range from 0.0 to 123.4 hours) in 2010. For orders such as initiating a diet when the patient was NPO and, therefore, receiving no food or liquids by mouth, another professional (specifically physician, nurse practitioner, or RD) was needed to provide the therapeutic diet type before a S-LP could enter the order directly into EPR. The average time to enter these orders in EPR took more time than when the therapeutic diet was already available from a current diet in EPR. In fact, initiating diet texture order, on average, resulted in an additional 7.2 hours delay compared to downgrading (7.3 hours for initiate versus 0.1 hours for downgrade orders) a diet texture in 2009 (Table 1). In 2010, this was an average difference of 5.4 hours (5.7 hour for initiate and .3 hours for downgrade orders). The time to enter medical directive orders correctly in EPR to initiate or upgrade an oral diet

texture were significantly longer than for downgrading oral diet texture in both 2009 (p=.000) and 2010 (p=.01). At baseline (2008), the majority (80.6%) of S-LP orders matched the EPR order. This rate was almost 10% higher the month of implementation (89.9%) in 2009 and remained at this level in the audited month one year later (2010). The number of occurrences where orders were entered incorrectly and required correction was less than 5% and was similar across the 3 time periods (Table 2). In 2008, 16.3% of S-LP's written orders were never entered correctly into EPR, this decreased to 8.8% in 2010. For orders written with the medical directive that had EPR entry errors (specifically never entered correctly or entered incorrectly then corrected), 40% (2009) and 81.8% (2010) required another professional to specify the therapeutic diet before the S-LP could enter the texture. There were no significant differences across the three time periods for any of these measures.

For orders entered into EPR by the S-LP, there were no therapeutic diet errors in 2009. In 2010, a S-LP removed a therapeutic diet (controlled fat, low cholesterol, low saturated fat) for 1 of 58 patients (1.7%) and a S-LP added a therapeutic diet when none was specified for 15.5% (9/58) of orders that the S-LP entered (see Figure 2). In 2010, among the orders where a texture was added without a written therapeutic diet, just over half (55.6%, 5/9) were either starting a limited amount of oral intake or upgrading the texture from clear fluids. In 2009, there were only two (4.4%) errors with supplements when the S-LP changed the diet texture. This included one occasion when the S-LP ordered supplements without a written order and on another occasion the S-LP did not change the thickness of the supplement to match the diet texture. In 2010, there were two patients (3.4%), that the S-LP deleted the supplement when changing the texture.



Figure 1. Average Time to Enter Orders in EPR (Hours)



Figure 2. Percentage of Errors Entering Diet Orders in EPR by S-LP

	Initiate Diet Texture	Upgrading Oral Diet Texture	Mixed*	From Oral Diet to NPO	Downgrading Oral Diet Texture	p value
2009	7.3 ± 9.7 (0.0-29.3) n=27	3.9 ± 14.1 (0.0-68.3) n= 28	0.2 ± 0.2 (0.1-0.3) n=3	0.1± 0.1 (0.0-0.3) n=3	0.1 ± 0.2 (0.0-0.9) n=14	.01
2010	5.7 ± 19.7 (0.0-124.3) n=47	2.3 ± 5.9 (0.0-4.3) n=45	0.6 n=1	0.6 ± 1.1 (0.0-2.1) n=4	0.3 ± 0.4 (0.0-1.6) n=15	.01
2009+2010 combined data	6.4 ± 16.1 (0.0-124.3) n=74	2.9 ± 9.8 (0.0-68.3) n=73	0.3 ± 0.3 (0.1-0.6) n=4	0.4 ± 0.8 (0.0-2.1) n=7	0.2 ± 0.3 (0.0-1.6) n=29	.01

Table 1. Average Hours to Enter Medical Directive Orders Correctly in EPR by Type of Diet of Order

Data is presented as mean ± standard deviation (range in brackets) for hours to enter directly to initiate, upgrade, downgrade, oral to nil per os and mixed (includes *upgrade solid or liquid with downgrade of solid or liquid) regardless of professional that entered the order. Orders that were never entered correctly were excluded from this calculation.

	2008 (n=98)	2009 (n=138)	2010 (n=114)
Entered Correctly	80.6% (79)	89.9% (124)	89.5% (102)
Error then Entered Correctly	3.1% (3)	2.9% (4)	1.8% (2)
Never Entered Correctly	16.3% (16)	7.2% (10)	8.8% (10)

Table 2. Accuracy of Diet Textures Entered Regardless if Order Written with Medical Directive or With a Recommendation

Data is presented as percentage (number in brackets) of orders entered correctly, initially entered incorrectly and then corrected, and those orders never entered correctly at all.

Survey Results

Questionnaires were completed by S-LPs and the interprofessional team one month prior (July 2009) and again one year (August 2010) following implementation (see Table 3 for respondent demographics and Table 4 for number of respondents and number of medical directive orders by program). S-LP responses to the questions were analyzed separately from the rest of the interprofessional team (Figures 3 and 4). On average, responses to all questions by S-LPs were more positive than non-SLPs. There was a higher degree of agreement or disagreement following the implementation of the medical directive for S-LPs. For S-LPs, there was a mean difference across all six questions of 61.7% (range 40.0% to 83.3%). RDs responses were similar to S-LPs in that their responses were more positive post-implementation. There was an average difference of 29.7% across all questions (range 7.3% to 50.0%) for RDs. For the grouping of nursing, the average difference between baseline and post-survey was 13.3% (range -6.8 to 63.9) with the most negative response relating to the need to change process while the most positive related to their perception of error rates. The physician grouping responses had a difference of -12.3% post survey (range -71.4% to 28.6%). The lowest negative difference was regarding how confusing the process was in which all chose the "neutral' response in the post-survey. The most positive was about the safety of the process. The survey responses of the interprofessional team, excluding the S-LPs, had an average difference of 2.5% (range -6.2% to 8.2%) across all questions. The responses were more favorable for all statements except for the statement about the process in which fewer (6.2%) disagreed or strongly

disagreed that a change was needed when surveyed postimplementation of the medical directive. For all ratings by the interprofessional team, there was no significant difference in ratings for all measures before and after the medical directive. Given the limited numbers of S-LP respondents that completed the survey at baseline (n=5) and post-implementation (n=6), statistical analysis could not be reliably preformed on their response.

Discussion

Obtaining approval for a medical directive in a hospital can be a time consuming process and there are a number of steps required prior to the directive being approved and implemented into practice. However, once approved, the additional effort to initiate the medical directive is minimal. The S-LPs participated in an hour education session to learn the appropriate use of the directive. They completed a written quiz to evaluate their knowledge and had opportunities to ask questions of the implementation team when they arose. All subsequent new staff were provided the same orientation process. According to one study, there are varying degrees of success with use of directives and a variety of factors influenced whether a medical directive was regularly used by RNs (Avarado, 2007). These included nursing confidence and willingness to assume responsibility, the amount of new learning required, additional paperwork, perceived usefulness of the directive, physician support, and frequency they encounter patients that required the directive. While these factors may have influenced the S-LPs in the study, these concerns were not specifically identified by the S-LPs nor highlighted in the education materials prior to implementing the directive. The S-LPs appeared eager to implement the directive.

Table 3. Number of Survey Respondents by Profession

	Number of Res	spondents (%)		
	July 2009 The month prior to implementation (n= 151)	August 2010 One year post- implementation (n=154)	Pvalue	
Profession				
Medical*	7 (4.6%)	2.9% (4)		
Nursing**	121 (80.1%)			
Occupational Therapy	0 (0.0%)		0.78	
Registered Dietitian	10 (6.6%)			
Speech-Language Pathologist	5 (3.3%)			
Ward Clerk	3 (2.0%)			
Did not indicate	5 (3.3%)			
Gender				
Female	132 (87.4%)	128 (83.1%)	0.00	
Male	15 (9.9%)	21 (13.6%)		
Did not indicate	4 (2.6%)	5 (32.5%)		
Years of Experience				
Less than 1 year	10 (66.2%)	6 (39.0%)	0.00	
Between 1 and 3 years	33 (21.9%)	30 (19.5%)		
Between 3 and 5 years	15 (9.9%)	14 (90.0%)		
More than 5 years	65 (43.0%)	71 (46.1%)		
Did not indicate	28 (18.5%)	33 (21.4%)		

*Medical includes staff physician, physician assistant and/or medical resident **Nursing includes APN, RN, RPN, RN student combined

Table 4. Survey Responses by Program and Number of Orders by Program

	Number of Orders				Number of Survey Responses		
	One year prior to implementation (August 2008)	The mo impleme (August	onth of entation t 2009)	One year post- implementation (August 2010)		Pre- Implementation (July 2009)	Post- Implementation (August 2010)
Programs	Suggestion	Suggestion	Medical Directive	Suggestion	Medical Directive		
Arthritis / Ortho (1 unit)	0	0	5	0	1	0	1
Cardio- vascular (4 units)	5	11	3	0	7	27	20
General Internal Medicine (6 units)	28	35	35	1	44	27	27
Intensive Care (4 units)	3	7	2	1	8	29	17
Neuro Science (3 units)	31	0	30	0	34	18	21
Oncology (6 units)	6	0	0	0	1	19	13
Surgical (5 units)	21	4	0	0	9	13	25
Transplant (2 units)	4	7	0	0	8	1	6
Multiple						14	21
No Response						3	3
Total	98	13	89	11	4	151	154

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Figure 3. Survey Reponses: Percentage Strongly Agree and Agree





One year after implementation, almost all orders written by the S-LP used the medical directive. This evidence strongly supports a successful implementation and uptake of this initiative. It was not expected that all orders would be written with the medical directive since not all patients can meet the specific criteria in order to use the directive (for example, no active gastrointestinal issue). Although it was uncertain what factors enabled the S-LPs to use the directive with such success, it is likely, given the results of the survey responses of the six S-LPs, that S-LPs perceived they could safely, effectively, and efficiently implement the medical directive as well as improve quality of patient care. S-LPs were able to capitalize on the benefits of implementation of the medical directive with minimal risk or disruption to their clinical care. In considering the enablers identified by Alvarado (2007), the S-LPs had frequent opportunities to use the directive and the positive ratings on the survey suggested a possible perceived usefulness. Specific factors impacting the high level of use of the medical directive would require further investigation.

Part of the motivation for implementing this directive was the amount of time it took for S-LP recommendations to be implemented (prior to directive). Time for orders to be entered in EPR significantly improved with the implementation of the directive regardless of the type of order written. This improvement could result in patients receiving appropriate meals in a more timely fashion, which in turn could reduce risk of aspiration or other negative sequelae resulting from inappropriate diet texture being ingested.

With a reduction in time from written order to implementation, patients could receive an upgraded consistency sooner. An upgrade in consistency, for example from puree to dental soft, may be more appealing to patients and improve caloric intake of food and liquid (Garcia et al., 2005; Whelan, 2001; Wright et al., 2005). In the current study, the timeliness was not consistent across all types of changes. Not surprisingly, diet orders that required input from other professionals to order the therapeutic type required more time, on average, than diets that did not require additional input.

Often S-LPs write orders to affirm that the same diet should be continued. In an attempt to capture new orders, only EPR orders entered no more than 15 minutes prior to the written order was used. This data management strategy worked for 2008 data, but for 2010 it was observed that S-LPs were entering a diet texture in EPR greater than 15 minutes prior to the written order. It was questioned if the S-LP entered the diet in EPR prior to starting to write the clinical note and order. Based on the criteria to exclude these orders, we may have overestimated the amount of time required between order entry and implementation for the 2010 data collection period.

One year after implementation of the medical directive, it was noted that some orders written by General Internal Medicine physicians for "SLP to assess swallowing" also included an order for the type of therapeutic diet that the S-LP could enter if appropriate after the assessment (e.g. "NPO. S-LP to see then 1800 kcal diet if appropriate"). This allowed the S-LP to enter the diet promptly after the assessment. While the physicians did not consistently write orders for S-LP to see with a prescribed therapeutic diet type, it would be interesting to determine if encouraging this practice would further shorten the time and allow S-LPs to enter appropriate diet orders efficiently.

The percentage of orders that were never entered correctly was less one year following implementing the medical directive compared to prior to the directive. Errors still occurred post medical directive implementation and the frequency was higher than expected. It was not possible to determine baselines rates for errors in supplements and therapeutic diets prior to the medical directive. In 2010, among all the orders entered by the S-LP, there were only two supplement errors but 15.5% of diet texture orders entered by S-LPs did not have a therapeutic diet specified on the chart or previous order. When these error rates were shared with the S-LPs, one reported that they were not aware of this requirement of having a written therapeutic diet order and suggested that their RD had told them the documentation was not necessary. A few others informally reported that they were not aware that the therapeutic diet type was still needed to be written when a patient was ordered clear fluids or limited amounts of food (e.g. one cup puree per meal). This is consistent with the finding that almost half of the orders that were entered without a therapeutic diet type were either starting limited amounts of oral intake or starting clear fluids. In an attempt to address errors, modifications were made to the in-service materials and guiz. To ensure continued competence, a mandatory annual refresher session was also added for all S-LPs who use the medical directive. Informally, RDs reported that supplements and therapeutic diets were frequently deleted by other professionals when changing texture prior to the medical directive. RDs who typically were the most involved in supplements and therapeutic diet orders, held more positive attitudes following the implementation of the medical directive suggesting these errors may actually be at a lower frequency than at baseline.

It is interesting that errors with therapeutic diet were not observed during the month the directive was implemented. It is questioned if individuals were more attentive with the use of the directive in the first month after initiating the directive, or if the recency of the medical directive education had an impact. This highlights the importance of ongoing monitoring of the accurate and appropriate use of the directive once it has been implemented.

The number of individuals indicating they had previously completed the perception questionnaire was very low. It is questioned if this number was accurate. The question was placed on the back of the page with the comment section which may have influenced respondents' likelihood to tick off the box indicating previous survey completion. The survey responses by S-LPs were all more positive on average than at baseline. For the rest of the interprofessional team that responded to the survey, the results for the two time periods were not significantly different. While this does not support a perceived need for the medical directive, it also did not suggest increased safety risk. The one item ("the process needs to be changed") was lower for the interprofessional team following the directive, although not statistically different. With the implementation of the S-LP medical directive, there were a number of new rules regarding which health profession could enter a diet under various circumstances. This may have contributed to the lower ratings. Alternatively the respondents may not have noticed a difference with implementation of the medical directive. This may be particularly true as some programs that had high volumes of responses to the survey did not have a high number of S-LP orders during the audited period. For example the oncology program had 19 responses at baseline and 13 post implementation but no orders (neither by suggestion or medical directive) during the sampling periods.

Limitations of the study include that a limited number of physicians responded to the survey (7 at baseline and 5 post-implementation). In addition, in the post-survey all respondents in the physician group were residents, therefore they may not have had experience with the process at baseline. Of the eligible S-LPs, the survey was completed by only 50% at baseline and 60% postimplementation.

In conclusion, this study demonstrated that an acute care hospital was able to implement the diet texture medical directive effectively with a high degree of uptake by S-LPs and that using a medical directive significantly improved the time for patients to receive the appropriate diet. The medical directive was valued and perceived to improve the quality of patient care provided by the S-LPs. The diet texture medical directive can offer positive and important implications for clinical practice and improved patient care. Future studies could focus on evaluating how to optimally incorporate a therapeutic diet order into referrals to S-LPs in order to minimize therapeutic diet errors and expedite diet change orders with the expectation that this practice may further improve the quality of care of patients with swallowing disorders.

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Authors' Note

Correspondence concerning this article should be addressed to Carolyn Chalmers, Toronto General Hospital, 1EN-812, 200 Elizabeth Street Toronto, ON Canada M5G 2C4. Email: <u>carolyn.chalmers@uhn.ca</u>. BLANK PAGE BY DESIGN The Impact of Group Format Therapy on Voice in Parkinson's Disease: A Pilot Project

L'impact de la thérapie de groupe sur la voix dans la maladie de Parkinson : un projet pilote

Camille M. Traverse

Abstract

At present, the most effective evidenced-based program of voice treatment in Parkinson's Disease (PD) is the Lee Silverman Voice Treatment (LSVT), an intensive 4-week program delivered on an individual basis. This individual format limits both access to and the ability to offer LSVT. Recently, research in the field of voice treatment in PD has begun to investigate alternative delivery formats such as group therapy. The pilot project described here provided an intensive group format voice treatment protocol to nine adults with idiopathic PD in Santiago, Chile. The project's goal was to offer quality voice therapy to as many participants as possible without compromising effectiveness of treatment, while creating an opportunity for cross-cultural sharing of knowledge between Chilean and Canadian speech-language pathology (S-LP) colleagues. The group treatment protocol is outlined in detail and brief statistical analyses of vocal loudness changes immediately posttreatment and at 3-4 months follow-up are provided. The results presented suggest that group format therapy may be an effective method of providing vocal therapy for some patients with PD. Although the project presented was not a research study and therefore results must be interpreted with caution, the improvements observed warrant further investigation in more controlled environments. Given the challenges of access to quality public health care in Chile and the large caseloads of Canadian S-LPs, the project results described may have relevance for treatment delivery in Canada.

Abrégé

Actuellement, le programme de rééducation vocale le plus efficace et le mieux supporté par la littérature pour la maladie de Parkinson est le Lee Silvermann Voice Treatment (LSVT), un programme intensif de quatre semaines offert de façon individuelle. Cette modalité individuelle limite à la fois l'accès au service et la capacité à l'offrir. Récemment, la recherche effectuée au niveau de la rééducation vocale chez des individus atteints de la maladie de Parkinson a commencé à explorer des modalités alternatives de prestation de services, tels que la thérapie de groupe. Dans le présent projet pilote, un protocole de rééducation vocale, offert sous la modalité de groupe, a été offert à neuf adultes atteints la maladie de Parkinson idiopathique à Santiago (Chili). Le but du projet était d'offrir une rééducation vocale de qualité au plus grand nombre possible de participants sans compromettre l'efficacité du programme de rééducation, tout en créant une occasion interculturelle d'échanges de connaissances entre collègues orthophonistes chiliens et canadiens. Le protocole de la thérapie de groupe est décrit en détail et de brèves analyses statistiques effectuées au niveau du changement du volume de la voix observé immédiatement après la rééducation vocale, ainsi qu'après un suivi de 3-4 mois, sont fournies. Les résultats présentés suggèrent que la modalité de groupe peut être une façon efficace d'offrir une rééducation vocale à certains patients atteints de la maladie de Parkinson. Même si le projet présenté n'était pas une étude de recherche et, donc, les résultats doivent être interprétés avec prudence, les améliorations observées justifient d'autres recherches dans des environnements plus contrôlés. Étant donné les difficultés d'accès à des soins de santé publics de qualité au Chili et les lourdes charges de travail des orthophonistes canadiens, les résultats du projet décrit pourraient s'avérer pertinents dans la prestation de services au Canada.

KEY WORDS

PARKINSON'S DISEASE
LEE SILVERMAN VOICE TREATMENT
GROUP THERAPY
CHILE
CANADA
SPEECH-LANGUAGE PATHOLOGY
VOICE THERAPY
PUBLIC HEALTH CARE
THERAPY PROTOCOL

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1.0 Background:

It is estimated that 70-90% of people with Parkinson's disease (PD) experience some change in their speech and voice or are dissatisfied with how they communicate (Halpern et al. 2012; Majdinasab, Karkherian, Moradi, Ali Shahidi, & Salehi, 2012; Miller, Deane, Jones, Noble & Gibb, 2011; Trail, Fox, Ramig, Sapir, Howard & Lai 2005). These changes most frequently result in a hypokinetic dysarthria, characterized by monoloudness, a monotone voice, and imprecise articulation (Fox, Ebersback, Ramig & Sapir 2012; Kwan & Whitehill, 2011; Skodda, Grönheitet, Mancinelli & Schlegel, 2013). Impaired speech, voice, and communication are reported to have a significant, negative impact on ratings of communicative participation and quality of life for the PD population (Baylor, Burns, Eadie, Britton & Yorkston, 2011; Chenausky, MacAsulan & Goldhor, 2011; Majdinasab et al., 2012; Sackley et al, 2014; Schrag, Jahanshahi & Quinn, 2000). Despite this, less than 30% of these people receive speech treatment (Miller, et al., 2011; Simberg, Rae, Kallvik, Salo, Martikainen 2012; Trail et al, 2005). Physical immobility, and geographical constraints as well as under-staffing, large caseloads, and under referral to speech-language pathology (S-LP) all contribute to this under serving of those living with PD (Constantinescu et. al, 2010; Fox et. al, 2012; Miller et. al 2011).

The most effective, evidence-based program in speech and voice treatment for PD is Lee Silverman Voice Treatment (LSVT), a therapy program in which one of the key components is high frequency, high intensity, individual treatment (Mollaei, Shiller & Gracco, 2013; Ramig, Countryman, Thompson & Horii, 1995; Sackely et al 2014; Sapir, Spielman, Ramig, Story & Fox, 2007; Varanese, Birnbaum, Rossi & Di Rocco, 2010; Whitehill, Kwan, Lee & Chow, 2011; Whitehill & Wong, 2007). In LSVT, clinicians see a client 4 times per week for 1 hour over a 4-week period, totalling a minimum of 16 hours of direct-client contact. To offer therapy using the name LSVT, a clinician must be LSVT certified and must provide the protocol exactly as outlined above (Fox, Morrison, Ramig, Sapir, 2002). In Canada's public health care system it is difficult, if not impossible, to dedicate so much time to a single client. According to the background document of the Steering Committee of the Inter-Professional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada (2009), speechlanguage pathologists (S-LPs) working with adults already report caseloads more than twice the recommended size. Furthermore, the Steering Committee notes unmanageable caseloads are a source of job dissatisfaction for S-LPs, as they feel they cannot deliver quality service to their clients.

These challenges are not unique to Canada – a study of S-LP service delivery in PD in the United Kingdom revealed that clinicians provided an average of 4.5 hours of service per client over an average of 6 weeks (Miller et al., 2011), compared with LSVT's 16+ hours in 4 weeks. Considering limited resources and heavy caseload demands as well as patient challenges with travel and access to treatment, it is becoming increasingly recognized that the LSVT schedule and method may limit the number of S-LPs providing, and how many persons with PD receive, LSVT (Searl, Wilson, Haring, Dietsch, Lyons & Pahwa 2011; Skodda, Grönheit, Mancinelli & Schlegel, 2013; Spielman, Ramig, Mahler, Halpern, & Gavin, 2007).

1.1 Alternative forms of intensive voice treatment

In an attempt to diversify methods of voice therapy in PD, recent investigations have examined the efficacy of alternative forms of LSVT. Extended versions of LSVT on various schedules have demonstrated improved vocal sound pressure level immediately post-treatment (Spielman et al, 2007). Extended versions of LSVT may be a viable alternative in some circumstances, however they continue to present problems for an overburdened health care system, as extended formats still require a dedication of time from clinicians and patients which can limit access to programming.

In an attempt to reduce time and travel demands for patients, use of telehealth forms of LSVT have also been investigated (Constantinescu et al., 2010; Constantinescu et al., 2011; Halpern et al., 2012; Howell, Tripoliti & Pring, 2009). Initial results of these protocols are promising, demonstrating significant gains pre- to post- treatment as well as pre-treatment to 6-month follow-up. The use of technology removes several barriers to treatment such as mobility and geographical constraints (Halpern et al., 2012), however caseload issues would likely not be improved by this method, as telehealth treatment protocols continue to require an individual, high intensity, and high frequency therapy format.

In their 2011 study, Searl et. al provide a summary of group format therapy investigations which have been completed to date. De Angelis and colleagues, Robertson and Thomson and Sullivan, Brune and Beukelman (as cited in Searl et al., 2011) have all investigated group format therapy alternatives, though to the best of this author's knowledge, only Searl et al. have tried to closely mimic the LSVT protocol. Searl et al's results demonstrated improved vocal loudness immediately post-treatment though the lack of long-term follow-up to evaluate retention of gains was
noted as a limitation of their study (2011). Detailed discussion of their treatment protocol is offered later in this report.

1.2 The health care system in Chile

The pilot program presented here was delivered in Santiago, Chile. Chile's health care system is a two tiered one, in which public health insurance covers 69% of the population, private insurance plans support 17% of citizens, and the remaining 14% either receive assistance through other public agencies (such as Military Health Services) or live without health coverage (Vargas & Poblete, 2008). In the early 2000s, the country introduced health reforms aimed at improving the inequalities in this system. The reforms identified 56 conditions, including PD, which would receive a guaranteed basic, uniform benefit plan, with fast-track access to care. The supports created by these reforms are criticized as being "obviously insufficient" for the needs of those living with PD (Sáez, 2008, p 254), as access to medications remains limited and only a single neurological review per year is covered. Therapeutic services such as S-LP or physiotherapy are not included at all (Saez, 2008; Homedes & Ugalde, 2005).

In an attempt to fill the gap in services offered by current health care programs, and to improve the quality of life for those living with PD, the Liga Chilena Contra El Mal De Parkinson (2008) (hereafter referred to as the Liga) offers access to medications, consultations with neurologists and psychologists, and therapeutic support from physiotherapists, occupational therapists, and one speech-language pathologist. Members pay a minimal yearly fee to access these services, while fundraising and individual donations cover the majority of program costs (www.parkinson.cl). At the time of publication, although the LSVT method is known by name in Chile, only four speechlanguage therapists (SLT) in the country are LSVT certified (http://www.lsvtglobal.com/clinicians). The full-time SLT at the Liga is not an LSVT certified clinician.

1.3 Pilot Project Background & Purpose of Brief Report

The project described was the result of a partnership between a Canadian, LSVT-trained S-LP living in Chile and the coordinators of the Liga, who were looking for new and novel ways to provide therapeutic services to their members. Funding for this pilot program was obtained through a national program of sponsorship from Chile's Servicio Nacional de la Discapacidad (SENADIS). The goals of this project were two-fold: 1) to provide intensive, high effort voice therapy to as many patients as possible without compromising the integrity of therapy and 2) to promote cross-cultural sharing of therapeutic knowledge between Chilean and Canadian S-LP colleagues. Given the challenges of access to quality public health care in Chile described previously and challenges with access and provision of services in Canada, results described here may be of relevance for S-LP service provision within Canada's health care system.

This report will describe the group therapy protocol that was used, as well as offer analyses of treatment results that may add to the body of information on group therapy in Parkinson's disease. A 3-4 month longitudinal review is included in this report as an early indicator of the potential for long-term maintenance of skills acquired in a group environment. The report presents an evaluation of the feasibility of group therapy for people with PD; as it was a clinical project and not an experimentally controlled study the results outlined here are intended to neither confirm nor refute the productivity of group therapy in PD disease, nor to suggest that this method is better or worse than an individual approach to treatment. Rather the intention is to examine whether group voice therapy may be promising as a treatment option for people with PD. Further investigation in the field of group therapy in PD are necessary to fully ascertain the efficacy of this method of treatment.

2.0 Methods

2.1 Participants

Ten adults with idiopathic PD were selected to participate in this project. Participants were selected according to four criteria: 1) membership in the Liga 2) possession of a 'carta de descapacidad' (disability card), a requirement of the funding grant given by SENADIS 3) no more than mild cognitive changes identified by the Liga SLT, based on her observation and evaluation of participants during prior therapies. No formal cognitive evaluations were completed to corroborate the SLT's subjective descriptions 4) A caregiver willing to bring them to and from therapy sessions. Individual participant information is summarized in Table 1.

In keeping with the ethical requirements and clinical treatment procedures of the Liga, all participants were given an explanation of the group protocol and each provided their informed consent to participate prior to enrolment in the project, as well as signing a written consent for release of information in order to have their results included in this article. Thanks to the funding obtained by SENADIS, participation in this pilot project was free for all participants.

Participants were divided into two groups (group A & B) of 5; gender was evenly distributed so that one group

consisted of 3 men and 2 women, the other of 2 men and 3 women. Attempts were made to evenly divide the groups based on degree of vocal and cognitive impairment, so that each group had one nearly aphonic patient, one minimally vocally impaired participant, and one participant with mild cognitive challenges. A brief neurological and medical verbal history, taken from each participant before the start of treatment, revealed a relatively healthy group, with the exception of one participant who became critically ill and could not complete the program. Medical issues reported included: osteoarthritis, osteoporosis, diabetes, hypertension, myoma, hysterectomy, hernia, reflux, and back pain. To the best of this author's knowledge, none of these medical issues contribute to a hypokinetic dysarthria. As one participant was unable to complete the program due to medical complications, all descriptions below and

all statistical analyses include 9 participants and not the original 10 selected for the project.

2.2 Aspects of the voice group

In an attempt to mimic LSVT as closely as possible session structure, amount and type of instruction, treatment focus, therapy activities, subjective therapist feedback, homework, and total hours of treatment in this group protocol were all designed in a manner comparable to those of LSVT. Differences between the group format and the standard LSVT method included increased duration and reduced frequency of sessions, absence of daily instrumental feedback, and limited individualization of activities during sessions. All aspects of the protocol are described in detail below. It should be noted that all participants were clearly

Group	Subject	Gender	Age	Time Since Diagnosis (years)	Cognitive Changes Noted? S = Self noted O = S-LP noted N= None noted by self or S-LP
A	1	F	67	6	Ν
	2	F	69	28	Ν
	3	Μ	71	15	S, O
	4	Μ	68	29	Ν
	5	М	69	12	Ν
В	6	F	75	12	Ν
	7	Μ	72	13	Ν
	8	F	67	4	S, O
	9	F	77	2	S
	10	Μ	76	28	S, O
Summary		M =5 F = 5	Mean = 70.5	Mean = 13.1	N = 6 S = 4 O = 3

Table 1. Participant demographics.

informed that they were not receiving LSVT but were part of a pilot group voice therapy protocol.

2.2.1 Language & Instruction

All of the sessions were in Chilean dialect Spanish. The LSVT-trained clinician (Canadian), who is conversationally fluent in Spanish, led all sessions for the first group of participants while the Chilean Liga speech-language therapist (SLT) observed sessions, offered translation and language support in instances where instructions may not have been clear, and provided assistance during individual activities (described below). As one of the goals of this project was to promote cross-cultural learning and information sharing, the second group received instruction from a combination of the Liga SLT and the Canadian S-LP. Chilean SLTs, including the Liga SLT, study for 5 years to receive a Bachelors in Fonoaudiología (Speech Therapy). The Liga SLT additionally holds a 1 year Diploma in Adult Neuropsychology and Neuropsychiatry.

Two Chilean SLT students, who were completing their practicum with the Liga as part of the requirements for graduation from the Bachelor of Speech Therapy program, were also in attendance throughout this project. These students had the opportunity to observe and occasionally support individual practice during group sessions, with the mentorship and guidance of the Canadian S-LP and her Chilean SLT colleague.

2.2.2 Timeline and treatment hours

Three 1.5-hour group sessions were given per week for four weeks. When compared with the LSVT method, which provides four 1-hour sessions per week for 4 weeks (240 minutes/week x 4 weeks = 960 therapy minutes), the group program presented here provided slightly more therapy minutes (270 minutes/week x 4 weeks = 1080 minutes). All sessions were mandatory and it was emphasized at pretreatment evaluation and in all sessions that participation and attendance were essential if participants hoped to achieve any change in vocal production. Despite this emphasis, a few participants were unable to make one or more sessions due to health or caregiver issues (i.e. unable to be driven to/from the Liga for sessions). See Table 2 for a summary of attendance.

2.2.3 Session Outline

All sessions began with a review of loud voice principles: the importance of thinking loud and the difference between a 'loud' and a 'shout' voice were explained, and participants were instructed to use the effort of a loud voice whenever Table 2. Summary of attendance. Subject #10 became critically ill at the midpoint of therapy and was unable to complete the program.

Subject	Sessions Attended	% Attendance
1	12/12	100%
2	12/12	100%
3	12/12	100%
4	12/12	100%
5	12/12	100%
6	10/12	83%
7	12/12	100%
8	11/12	92%
9	12/12	100%
10	Did not complete the	rapy
Total sessions attended	105/108	
Total % Attendance		97%

they spoke. This educational portion was followed by warmups and hierarchical tasks, as in LSVT. In each session, attempts were made to mimic LSVT in ratio of time per task as closely as possible (Table 3).

Warm-ups

A vocal 'warm-up' phase that attempted to closely approximate the LSVT program's 'daily tasks' was completed at the start of each session. Warm-ups consisted of three parts, designed to exercise the vocal folds and calibrate participants' loudness through cues, modelling, and feedback from clinicians and other group members. Supports and feedback for all tasks were gradually reduced within and across sessions so that in the final session minimal or no cues were being provided as participants learned to self-calibrate and regulate their own vocal loudness. Table 3. Comparison of LSVT and group treatment protocol sessions in minutes per task. Although overall time in each task is comparable, in the LSVT protocol all minutes are dedicated to a single individual, while in the group protocol these minutes are divided amongst 5 individuals, therefore minutes per individual are reduced compared with the LSVT protocol.

Task	LSVT protocol	Group protocol
Total Session Duration	50 – 60 minutes	80 – 90 minutes
Warm ups	30	30 - 45
Sustained phonation	12 – 15	10 – 15
Fundamental Frequency ("highs and lows")	10 – 12	10 – 15
Functional Phrases	5 – 10	10 – 15
Hierarchy of Practice Tasks	30	40 - 50
Reading	20+	15 – 20
Conversation Tasks	5 – 10	20 - 25
Homework Assignment	5	5 - 10

Firstly, a sustained phonation task was completed. Each participant initially heard and watched the S-LP model a sustained 'ah', after which they imitated this production individually. Cueing (i.e. "keep going, louder!"), modelling and shaping (i.e. "watch me, do what I do!), and feedback (i.e. "was that your LOUD voice?" "Do you think you can be louder?" as well as asking other participants to rate their loudness) were employed to elicit proper loud phonation and calibrate the patient so they became accustomed to using the effort of LOUD as their 'new voice'. Each participant produced between 5-7 individual 'ahs' during this 'warm up' time,

A fundamental frequency range task was then completed using the same system of modelling and shaping individual productions. Using the same effort as in their sustained 'ahs', participants were instructed to individually glide or step pitch as high and low as possible. Clinicians listened for inappropriate pitch breaks or glottal fry and shaped appropriate high and low phonation through modelling, cueing, and feedback.

The third warm-up activity consisted of repetition of functional phrases. All participants were instructed to create a list of 10 sentences which they use every day, as

is done in the LSVT method. During the first week these phrases were altered as necessary to ensure they were truly functional for each participant. Participants took turns reading their phrases in a high effort, loud voice. Modelling, cueing, and feedback were provided throughout practice.

The decision to maintain individual practice during warm ups was done purposefully and differently from the method of the Searl et al. (2011) program in which, after an initial individual practice period, all group members repeated these same warm-up activities in chorus. In the currently reported project, it became quickly apparent that choral repetition was difficult to moderate, and those with less impaired volume 'drowned out' more aphonic participants, thus making individual feedback and support more difficult. It was also felt subjectively that through listening to other group members' productions, participants became more motivated to push their own vocal loudness and produce a higher level of vocal effort. See Table 4 for a detailed summary of differences between the Searl et. al study and the current project.

Hierarchy of Practice

Following warm ups, a series of hierarchical tasks meant to mimic conversation were then completed. A summary

Table 4. Comparison of Searl et al. (2011) study and current project's treatment protocols. Only differences in protocols are provided; similarities are excluded from this comparison.

	Searl et. al	Current project
Participants	15 participants with PD 1 group	10 participants with PD 2 groups (5 participants each)
Session Frequency	1x/week	3x/week
Session Duration	90 minutes	80-90 minutes
Session Format	 Warm up phase included choral reading of 20 functional phrases chosen by S-LP In hierarchy of practice, 75% time dedicated to choral reading, 25% to individual or group responses 	 Warm up phase included individual reading of 10 functional phrases chosen by each participant In hierarchy of practice, 25% of time dedicated to choral reading, 75% to individual or group responses
Format of Practice and Feedback	During warm up tasks, S-LP calibration of participant loudness is based on single sustained phonation, high, or low production. Once participants were considered calibrated, choral practice employed for remainder of warm up time. Clinician modelling and verbal reinforcement and encouragement of participants' louder voice throughout tasks. Feedback provided primarily based on productions in choral tasks. Re-energizer' activity (5-10 long loud ahs) completed as a group if sufficient loudness not being used during tasks.	During warm up tasks, SLP calibration of participant loudness within and across each production of sustained phonation, high or low. Individuals practice greater focus, with minimal choral practice employed during warm up time. Clinician modelling and verbal reinforcement and encouragement of participants' louder voice throughout tasks. Feedback provided primarily based on individual tasks, with frequent elicitation of opinions of other group members re: acceptable loudness. Individuals prompted to increase loudness through re-calibration (production of long loud 'ah' until appropriate loudness achieved) during tasks.
Homework	 Consisted of warm ups and repetition of hierarchy of practice task completed that week in therapy. No carry over tasks. 	 Consisted of warm ups and oral reading. Individual carryover tasks assigned for each day not receiving therapy.
Evaluation	 Pre- and post-treatment participants completed Voice Handicap Index pre- and post-treatment evaluation of dB SPL, maximum and minimum FO, and maximum phonation time on 5 tasks 	 Post-treatment questionnaire based on LSVT follow-up questionnaire format pre- and post-treatment evaluation of dB SPL and maximum phonation time on 3 tasks
Long-term follow up	None	At 3-4 months post-treatment

of hierarchical tasks used each week is provided in Table 5. As in LSVT, the goal of these tasks was to steadily increase the demands of duration to maintain loudness in gradually more cognitively complex tasks. During the first three weeks, all tasks were completed individually and participants were cued to use the same effort and loudness as they had during warm ups. In the final week, attempts were made to stimulate natural conversation, with turn taking and interruptions as in regular interactions and diminished, nearly absent clinician prompting. These conversations were occasionally recorded and immediately played back to the group to encourage peer and self-ratings of vocal loudness, in keeping with the LSVT method's use of feedback to improve self-monitoring (Fox et. al, 2002; Simberg et al., 2012).

The final portion of therapy was dedicated to reading aloud. Length and complexity of reading progressed over the course of treatment, beginning with reading single word lists and culminating with individually selected texts. For the first two weeks participants took turns reading aloud individually so that each read for approximately 3-5 minutes. In the final two weeks participants were split into pairs – each participant was matched with an S-LP or SLT, SLT student or other participant and took turns reading aloud for a total of approximately 10 minutes of sustained reading per participant. Verbal feedback took the form of encouragement to 'keep pushing', to 'be loud' etc.

In the LSVT method, greater time is dedicated to reading than to 'off the cuff' conversation. The time allotment in this group format was reversed, so that more time was spent in hierarchical conversation tasks than structured reading tasks. One of the advantages of group format therapy is that it closely matches real-world communication; as such it was decided to deliberately spend more time capitalizing on this and practicing vocal loudness in naturalistic (conversational) tasks, rather than in reading.

2.2.5 Homework

All participants completed one 15-20 minute session of home practice on days when they received therapy, two sessions on days without treatment. Homework consisted

Table 5. Examples of hierarchical conversation tasks by week. Tasks were based on activities in aphasia workbooks,
current events, and interests identified by group participants

Week	Tasks used	Example	Conversation level	Response type elicited
1	- synonyms - opposites - naming to category	"What is the opposite of happy?" "Tell me three things that are red"	Single words	Individual response
2	- similarities & differences - proverb completion - errors in phrases	Tell me one thing that is the same and one thing that is different about a candle and a lamp - Complete this saying "A bird in the hand" - Correct this sentence "she drank a glass of paint"	Phrase level	Individual responses
3	- mixed up sentences - hypothetical situations	- Put the words in this sentence in order "Feeling I happy am" - Why do we use seatbelts?	Sentence	Individual
4	Conversation on topics of personal interest	Who do you think will win the world cup this year?	Conversation	Group

of 10 repetitions of each warm-up task and 5-10 minutes of oral reading. For the first 3 weeks reading material of increasing complexity was provided. In the last week participants chose their own reading material. Participants were required to complete a recording form for each day of therapy, which was reviewed on the following day of therapy to ensure homework was being completed. As there was a reduction in the intensity of treatment during group sessions, homework time was slightly increased compared with the LSVT method in an attempt to balance the intensity of practice per day. At each treatment session participants were reminded that home practice was essential for improving their vocal function. The importance of establishing a routine of practice that should continue even after treatment had finished was emphasized when participants were given their homework assignments, and the 'use it or lose it' principle was repeated in every session.

In addition to homework, each participant was given one carry-over task per day of treatment. The purpose of these tasks was to assist with generalization of vocal loudness principles into communication activities of daily living. Carry-over tasks were individually tailored and became more cognitively complex and lengthy as weeks progressed. Table 6 provides examples of carry-over tasks used over the course of treatment. As participants were only seen 3x/week, and given the time restrictions of group format therapy, a single carry-over task was assigned to be repeated for 2-3 days between group sessions. This was done differently from the LSVT method in which a unique carry-over task is assigned every day for 30 days.

2.2.6 Calibration & Feedback

In the LSVT program, the concept of 'calibration' is heavily emphasized. Calibration refers to when "[the] patient knows and accepts the amount of effort needed to consistently produce a louder voice. [Calibration is when a] relationship between increased vocal effort and vocal output [is] established" (LSVT Global LLC, 2008). The goal is for participants to produce a louder voice automatically in their daily life, and to be aware that this louder voice improves their communication. Calibration in LSVT is embedded throughout education, daily tasks, carry-over, and homework activities.

The group protocol described here attempted to mimic LSVT techniques by similarly embedding opportunities for calibration throughout the treatment program elements. During the education portion of each session a visual diagram and brief summary of 'why LOUD matters' was offered; participants were encouraged to comment on these concepts based on their own experiences as treatment progressed. Throughout warm up and hierarchical tasks participants were encouraged to self- and peer-evaluate loudness and to comment on that loudness' impact on quality of communication within the group (i.e. "could you hear Mr. X better when he used his loud voice?"). Audio recordings both during conversation tasks and evaluation were played back to participants so that they might also hear their own louder voice and be further calibrated to the impact of loudness on their speech. Finally, attempts were made to make daily carryover tasks

Week	Conversation Level	Example
1	Words	Answer the phone in a loud voice Say hello to your grandchildren in a loud voice
2	Phrase	Order your lunch in a loud voice. Ask your grandchildren about their day at school in a loud voice.
3	Sentence	Give all instructions to the television repairman in a loud voice. Read a short book to your grandchild in a loud voice.
4	Conversation	Stay loud for the duration of lunch with your niece. Read a passage at Bible Study in a loud voice.

Table 6. Examples of carryover tasks.

as functional as possible, based on each participant's activities of daily living and the communication goals they had expressed during the pre-treatment evaluation so that the impact of a louder voice on quality of communication life might be made most salient for each participant. Due to the group structure, there was limited time to discuss how these carryover activities had gone and how family or community members were responding to each participant's new, louder, voice. This resulted in a natural reduction in individual calibration time compared with the LSVT program.

2.2.7 Caregiver training

One of the criteria for acceptance into this program was the presence of a caregiver who was able to bring participants to and from therapy each day, and would be available to support home practice. In order to capitalize on the presence of these caregivers, an education session was held for the caregivers of each of groups A and B at the mid-point of each group's treatment schedule (end of week 2). During this education session, caregivers were taught the principles of 'thinking loud' and how these principles can impact overall vocal loudness and speech clarity. They were introduced to techniques used in therapy and a brief question and answer period was offered. Sessions were scheduled to precede group therapy, and all caregivers were then invited to attend the therapy session in order to observe practice more closely. During this therapy session caregivers were invited to engage in aspects of practice with their PD partner while the S-LP moved between partners and provided feedback. Despite emphasizing to all caregivers that their presence at the education session was mandatory only 50% of caregivers attended their respective education sessions.

2.3 Evaluation

We measured participants' vocal loudness (expressed as decibels of sound pressure, or dB SPL) in the three different tests: Sustained Phonation, Phrase Repetition, and reading of standardized passage (the Grandfather Passage). We administered each test at three different times: prior to therapy in a Pre-Treatment session, Immediately Post-Treatment, and in a Follow-Up session. An interview format questionnaire was also completed with participants during Follow-Up evaluation. Follow-Up sessions were completed on one day, which fell between 3 and 4 months post-treatment for all participants to accommodate their vacation schedules. Despite this logistical accommodation, attrition was still evident as only 7 of 9 participants attended Follow-Up evaluation. At each evaluation, participants were also recorded stating their name and address using a loud voice as practised in therapy. These recordings were then played back to participants; immediately post-treatment and follow-up sessions provided the opportunity to listen to and compare their voice with pre-treatment recordings. Participants were then questioned as to whether they noticed a change in their vocal loudness and whether they felt positive about this change.

Because the follow-up session presented an opportunity to 'refresh' vocal strategies taught during treatment, subjects were cued to focus on loudness during Follow-Up evaluation. While this was done to meet the overarching objectives of the therapy, we recognize that it may have introduced some sampling bias into the data collection.

A Student's t-test for paired data was used to assess the significance of improvements. We compared pre-treatment results to the tests administered immediately post-treatment and compared pre-treatment results to the tests administered in follow-up.

In addition to vocal loudness, we recorded duration (in seconds) of sustained phonation and compared results of pre-treatment to immediately post-treatment and results of pre-treatment to follow-up.

Sound pressure level was measured using a Check Mate SPL meter, placed at a distance of 30 cm from the side of the participant's mouth. Placement to the side of the mouth was necessary as participants were required to read phrases from a sheet of paper placed directly in front of them, and their viewing of this would have been impeded if the SPL meter had been placed directly in front of the mouth. All measurements were taken in an office that was not soundproofed or controlled for background noise, although caution was taken to have comparable conditions for all measurements (window closed, participant in same spot in the room, no conversation in hallway). Maximum phonation time was measured using a Sportline stopwatch over 3 trials of sustained phonation 'ahs'. Recordings of name and address were done using a TeleMax TSVR2 Digital Voice Recorder, placed at 30 cm from the participant's mouth.

3.0 Results

Figure 1 provides a summary of overall group vocal loudness changes from pre-treatment to immediately post-treatment to follow-up in our 3 measures.

3.1 Pre to Post-treatment Analysis

Comparison of vocal loudness between Pre-Treatment

and Immediately Post-Treatment reveal a mean increase of 13.9 dB SPL (8.5 SD) for Sustained Phonation, 9.5 dB SPL (6.2 SD) for Phrase Repetition, and 10.5 dB SPL (4.9 SD) for Grandfather Passage. In these results we identified apparent improvements in vocal function across all three tasks following one month of intensive group format voice treatment. Average duration in sustained phonation increased by 5.56 seconds, suggesting that treatment also provides an immediate improvement in the duration of sustained phonation time. Table 7 summarizes these results. Results of our student's t-test support these conclusions with 97.5% confidence.

3.2 Long-term follow up

Comparison of pre-treatment to follow-up results indicates that participants maintained gains of almost 8 dB SPL (8.5 SD) in sustained phonation; they also maintained an average improvement in duration of sustained phonation of 0.8 seconds. Results of our student's t-test support these conclusions with 97.5% confidence. See Table 8 for a summary of these results.

In contrast, the improvements made in phrase repetition and grandfather passage tasks did not appear to be as

durable after the 3-4 month follow-up period had elapsed. Mean phrase repetition level vocal loudness at follow-up was greater than pre-treatment by 3.3 dB SPL (6.2 SD), and mean grandfather passage loudness at follow-up was greater than pre-treatment by 3.9 dB SPL (4.9 SD); however these differences were not significant at 97.5% confidence.

In sum, the results outlined above suggests that although participants do make strong gains in vocal loudness immediately following group therapy, there is a trend of return towards baseline at longer-term follow-up (Figure 1).

3.3 Qualitative Data

An interview format questionnaire was completed with each participant at follow-up evaluation to obtain information on participants' subjective impressions of the effectiveness of therapy. Participants were asked open- and closed-ended questions (i.e. "Did you experience a change in voice after treatment? Please describe") by the Canadian S-LP and their responses were recorded. Caregivers were not present for this interview, therefore are not suspected to have influenced participants' responses to questions, though participants may have been inclined to judge the program more favourably given that the clinician who had





Table 7. Vocal intensity and duration sustained phonation comparison pre- to post- treatment

Comparison	Mean (SD)	t-value	Significance (one-tailed)
Decibels of Sound Pressure (d Pre- vs. Post-Treatment	IB SPL)		
Sustained Phonation	66.2 (8.5) vs. 80.1 (8.5)	8.07	0.000020
Phrase Repetition	64.3 (6.2) vs. 73.8 (6.2)	7.42	0.000037
Paragraph Reading	59.8 (4.9) vs. 70.3 (4.9)	7.13	0.000050
Duration (sec) Pre- vs. Post-Treatment			
Sustained Phonation	9.8 (4.9) vs. 15.6 (4.9)	5.56	0.000268

Table 8. Vocal intensity and duration sustained phonation comparison pre-treatment to follow up

Comparison	Mean (SD)	t-value	Significance (one-tailed)
Decibels of Sound Pressure (d Pre-treatment vs. Follow-Up	B SPL)		
Sustained Phonation	66.2 (8.5) vs. 73.9 (8.5)	2.50	0.023417
Phrase Repetition	64.3 (6.2) vs. 67.6 (6.2)	1.28	0.124708
Paragraph Reading	59.8 (4.9) vs. 63.7 (4.9)	1.11	0.155081
Duration (sec) Pre-treatment vs. Follow-Up			
Sustained Phonation	9.8 (4.9) vs. 10.6 (4.9)	2.33	0.029207

provided them with treatment was interviewing them. Results of this questionnaire are summarized in Table 9. The information gathered suggests that all participants found the group protocol to be a positive experience, and the majority noticed improvements in their vocal functioning after treatment. Many felt that at follow-up they had lost these gains and were returning to baseline vocal function. When questioned regarding continued practice 14% reported they were no longer practicing at all, and of those who continued to practice only half were doing so on a daily basis. In addition, only one participant was completing all elements of home practice at long-term follow-up. It is suspected that this lack of continued, complete home practice contributed to the decline in loudness noted from post-treatment to long-term follow-up. Lack of practice and consequent reduced reinforcement of vocal loudness techniques is also suspected to have impacted on participants' subjective observations of a return to baseline loudness post-treatment, despite the fact that statistical analyses show vocal loudness remained above pre-treatment levels in the majority of cases.

Table 9. Participant responses to follow-up questionnaire at 3-4 months post-treatment; 7 of 9 participants completed this questionnaire.

Item	Response	Comments	# respondents	% of respondents
Did you experience	Yes		6	86%
following treatment?		Loudness declined	1	14%
		Loudness improved	2	29%
		Loudness improved initially, then declined	3	43%
	No		1	14%
Was treatment helpful?	Yes		7	100%
	No		0	0%
Following treatment do you speak		More	6	86%
		Less	1	14%
What do you do in order to be understood?		Try to speak clearly/ articulate well	3	43%
		Repeat myself	1	14%
		Speak/think 'loud' (without S-LP prompting response)	3	43%
		Speak/think 'loud' (S-LP prompting response)	3	43%
		Concentrate on what I am saying	1	14%
Are you still practicing?	Yes		6	86%
		Daily	3	43%
		3 – 4x per week	1	14%
		1 – 2x per week	2	29%
	No		1	14%

What parts of the practice do you do?		Sustained ah	5	71%
		High/lows	3	43%
		Functional phrases	1	14%
		Readingaloud	6	86%
		Other	2	29%

3.4 Individual Results & Exploratory Description

Given the small n of this project, the lack of experimental control and the variability in participants, group results may offer limited validity. As such, individual results were also evaluated for any trends that might help guide future treatment designs. Figure 2 provides descriptive analyses of individual participant characteristics and overall loudness changes from Pre-Treatment to immediately Post-Treatment and to Follow-Up in our 3 measures.

Comparison of these data suggests that several factors may influence short and long term gains made in group

therapy; namely severity of vocal impairment, degree of caregiver support and cognitive status.

Severity of vocal impairment did not appear to significantly impact short-term results as indicated by the improvements of both minimally impaired participants (1 & 3) and those with severe impairments (participants 2 & 6). The significant drop from posttreatment to follow-up for those with severe vocal impairment (i.e. participant 6), however, suggests that this may be a factor that negatively impacts on longterm maintenance of gains.



Figure 2. Individual participant characteristics and changes in vocal loudness (dB SPL) at Pre-Treatment, Immediately Post-Treatment and at 3-4 month Follow-Up. Note that participants 5 & 9 are placed at the end of the graphs, as they were not present for Follow-Up evaluation and so have incomplete data sets compared to the other participants.

The presence of strong caregiver support may help to mitigate the negative impact of vocal severity and allow for maintenance of long-term functional gains, as in the case of participant 2 (severely impaired but retained gains compared to pre-treatment levels, though lower than at immediately post-treatment) versus participant 6 (severely impaired and declined from pre-treatment levels at follow-up, with relatively poor caregiver support). Poor caregiver support may in fact have a greater impact than vocal severity when measuring long-term maintenance of gains as suggested by the results of participant 4, who, in comparison with participant 2, started treatment with only a moderate degree of vocal impairment and appeared to benefit at post-treatment from therapy, but had weak caregiver support and declined to lower that pretreatment levels at follow-up.

Cognitive status may also impact long-term outcomes, as both participants with mild cognitive impairments (3 and 8) showed a large drop in gains from post-treatment to follow-up. It may be, however, that cognitive status is not in itself what causes the drop, but rather, that changes in cognition may impact on understanding of the protocol and importance of home practice, resulting in a reduction in gains in the long-term. Table 10 summarizes how participants were maintaining home practice at follow-up, and to what degree they had retained the single focus of LOUD to help improve their intelligibility in conversation. In the cases of participants 3 and 8 neither maintained consistent or correct home practice at Follow-Up.

In summary, individual analyses suggest that severity of vocal impairment at pre-treatment, in combination with

Table 10. Individual responses to follow-up questionnaire items which probed how well participants had internalized the single treatment focus of LOUD and the degree to which they were maintaining appropriate home practice at 3-4 months post-treatment.

	Questions				
Subject	"What do you do in order to be understood?"	"How often are you practicing?"	"What parts of the practice do you do?"		
1	Try to be LOUD (unprompted)	1-2x/day	Sustained ahs		
			highs & lows		
			Reading aloud		
2	Repeat myself	2x/day	Sustained ahs		
			Functional Phrases		
	Try to be LOUD (unprompted)		Reading aloud		
3	Speak clearly	Not at all	n/a		
	Do my exercises				
	Try to be LOUD (prompted)				
4	Try to concentrate and relax	4x/week	Reading aloud		
			Repeat words that are hard to pronounce		
5	Did not attend follow-up evaluation				

6	Increase my effort	2v/dov	Sustained ahs
	Try to be LOUD (unprompted)	Zx/Udy	Readingaloud
7	Speak clearly	2x/week	2 Sustained ahs
	Try to be LOUD (prompted)		1 high, 2 low
			Readingaloud
8	Speak clearly and slowly	2x/week	Sustained ahs
	Try to be LOUD (prompted)		Readingaloud
9	Did not attend follow-up evaluation		

quality of caregiver support and, perhaps to a lesser degree, cognitive status, may all impact on participant success in a group treatment context. Age and time since diagnosis do not appear to have an impact.

4.0 Discussion

This pilot project provided a group format intensive voice treatment program, modelled on the LSVT principles, for PD participants in Santiago, Chile. Results suggest that there are improvements in vocal SPL and duration of sustained phonation immediately following this group therapy protocol. Unfortunately these gains appear to diminish over the ensuing 3-4 months. These results are comparable to those of other group format studies of a similar nature and further add to the body of literature that suggests that group therapy may be a viable option for providing voice treatment to some patients with PD. It may be that further adaptations to the group format program can improve long-term maintenance of vocal loudness.

4.1 Benefits of group format treatment

Public health care speech-language pathologists and the PD population they serve may benefit from treatment options where more patients can be offered services at once, such as in group therapy programs. LSVT requires a minimum of 4 hours of direct client time per week, yet Miller et al's 2011 survey reports that S-LPs are only providing an average of 45 minutes per week, suggesting that clinicians may not be able to provide the frequency and intensity of therapy required for LSVT. In contrast, the currently described project demands an average of 50 minutes per patient per week (270 treatment minutes per week/5 patients = 54 minutes per patient per week), making group treatment an efficient per patient service delivery mode that more closely matches the current realities of S-LP caseloads.

In addition, there may be benefits to a group format that are not achievable in 1:1 programming. Psychosocial benefits of group programs in general have been documented in the literature and positive effects of group format treatment in PD have also been described (Elman & Bernstein-Ellis, 1999; Searl et. al, 2011). Similar benefits were noted in the current project, as participants reported feeling supported and encouraged by others in the group. All participants interviewed at follow-up reported feeling that the group protocol had helped them, despite the fact that nearly 60% felt their vocal loudness had declined since immediately post-treatment. Participants described feeling more comfortable in social situations and having a general sense that communication with others was easier. It is possible that this newfound ease in communication was not only due to changes in vocal loudness, but also in part to the naturalistic practice environment of the group treatment program, which offered participants the opportunity to practice communicating with others using treatment techniques in a safe, supportive environment. Subjective observation by program S-LPs also suggests that when participants observed others performing high effort tasks this increased their motivation and resulted in a higher level of effort than participants might have produced otherwise. Since high effort is an important component of LSVT (Ramig et al., 1995; Sapir et al., 2007; Trail et. al, 2005), this may be an unintended benefit of group format protocols. In their summary of speech treatment in PD, Trail et al. (2005) note that patients often feel that they are shouting when cued to speak more loudly, a phenomenon echoed by others in the literature (Kwan & Whitehill, 2011; Mollaei et al, 2013). In the current project peer feedback and recordings throughout group sessions were thought to have helped to mitigate this phenomenon, as participants had the opportunity not only to listen to their own voice, but also to hear from others with PD that their new. louder voice did not sound like a shout.

4.2 Challenges faced

Organization of session plans and resources was a lengthy process resulting in many hours of nonbillable preparatory work. While necessary for the initial administration of any program, the dedication of such large amounts of preparation time in the long term may not be feasible or desirable. It is felt, however, that many elements of the pilot program could be easily reused for future groups thereby reducing this non-billable planning time, though a certain amount of adaptations to the interests and needs of each group would likely always be necessary.

When compared with delivery of 1:1 LSVT, this program was unable to provide the same level of intensity and specificity of feedback during therapy tasks. The LSVT protocol requires the use of frequent, specific, individualized feedback and "functionally relevant exercises to capitalize on neuroplasticity of impaired neural systems" in order to achieve improvements in functioning (Halpern et al., 2012, p 355). In a group format, intensity and specificity of feedback are naturally reduced. Though models, cueing, and feedback were provided in a manner consistent with LSVT (initially with every trial of every task, then gradually reduced over time and across sessions), owing to the group format participants received fewer instances of individual feedback per session than occur in LSVT individual sessions. This reduced intensity of individualized feedback may contribute to lower mean gains in vocal loudness compared with the improvements typically noted in LSVT. Attempts were made to mitigate this reduced feedback by including a second SLT and two SLT students to support clients during this pilot program. Increased caregiver involvement and education may have also benefited clients as these caregivers could have ensured consistent feedback was being provided outside of therapy sessions.

The challenge of transportation to and from therapy is an often-noted barrier to treatment in the PD population and was evident in this project as well. While attempts were made to ensure all participants had reliable transportation, some participants missed one or more sessions. In a short, intensive therapy program like this, one missed sessions may have impeded or reduced positive outcomes.

In order to promote generalization and maintenance of gains, homework and daily practice is emphasized in LSVT (Howell et. al, 2009; Trail et. al, 2005). This group model attempted to emphasize the importance of continued practice as well however in LSVT, homework is reviewed each day and there is an opportunity to discuss challenges and successes the participant faced during the previous day(s) home practice. In the group protocol, individual check-ins of this nature were reduced in frequency and intensity due to time constraints, though all participants were required to keep a log of their home practice to ensure that it was happening on a daily basis. Given that questionnaire results indicate the majority of participants either did not continue with all elements of home practice, or did not continue with home practice at all after treatment had ended, it may be that the group format's reduction in individual 'check-ins' about home practice success impacted on this lack of practice. Lack of continued practice is suspected to have had an impact on the decline in vocal loudness from post-treatment to follow-up, and should be considered as a limitation of the currently presented project. Increasing time for homework review, or changing the format of the homework log may help mitigate this issue in future groups.

Finally, it is also suspected that not all participants benefit equally from a group therapy protocol. In this study, it appeared that a combination of severity of vocal impairment at pre-treatment, degree of caregiver support, and cognitive status all might have impacted on overall treatment outcomes. Consideration could be given to trialling variations of group composition based on these participant characteristics. For example, having only mild or moderately vocally impaired individual in a group, screening for any cognitive changes and excluding such participants, or altering the caregiver training and participation in group sessions might all result in improved short and long term gains. Other considerations for group profiles might include education, past treatment experiences or other social, medical, or cultural factors that might impact on participation. Further investigation would be helpful in determining which patient profiles benefit most from a group treatment format.

4.4 Conclusions & Limitations

Speech-language pathologists require options for delivering effective and efficient voice therapy services to patients with PD. The pilot protocol results described here indicate that service delivery in a group format may be a valid and effective means of improving vocal function for some patients with PD. With further revision of the homework and session structures, and consideration of revision of exclusionary criteria for group participation, it is believed that improvements could be maintained more long-term as well.

As this was a pilot program and not a true research study there were no control groups, and no randomization

or blinding of participants or S-LPs. There was limited ability to control the testing environment, and cueing for loudness was occasionally employed during post treatment evaluations. The results shared here must be interpreted with caution as this lack of controls may have impacted on measurements taken and could reduce the reliability of results. The small sample size must also be considered, as does the fact that statistical analyses completed assumed normality, which may not be the case in actuality. Sustained phonation was only measured on 3 trials in a single data collection session, and all data were captured on a single data collection session per participant per phase. Knowing that there can be substantial variation in performance within and across trials, data may not have properly captured participants' abilities. The population described here was also Chilean and there may therefore be cultural, demographic, and linguistic variables not accounted for in this report, which could impede generalization to other therapy environments. Finally, while the LSVT certified S-LP who administered this protocol is conversationally fluent in Spanish, there were occasions in which language differences could have impeded the effectiveness of treatment administration, potentially confounding results.

Despite these limitations, it is felt that the positive results described here offer a preliminary indication that group treatment may be a viable voice therapy alternative for some patients with PD. In the overburdened Canadian health care system, creative and innovative ways of providing voice therapy need to be developed. Other more rigorous studies will need to be conducted in order to draw any clear conclusions about the validity of group format therapy in treating voice disorders in PD.

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Trouble léger de la cognition : profils variés en compréhension de texte

Mild cognitive impairment: varied texts comprehension profiles

MOTS CLÉS

TROUBLE LÉGER DE LA COGNITION COMPRÉHENSION DE TEXTES PROFILS COGNITIFS

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Abrégé

La compréhension de textes est une composante complexe qui requiert à la fois des compétences linguistiques et cognitives. Aussi, l'apparition d'un trouble léger de la cognition (TLC) est susceptible de générer des difficultés en compréhension de textes. Toutefois, l'hétérogénéité du profil cognitif de ces personnes suggère un profil de compréhension en lecture tout aussi hétérogène. L'objectif de cette étude est, d'une part, d'identifier, chez des participants avec TLC, les atteintes de la compréhension de textes en fonction de la demande cognitive des textes et, d'autre part, d'étudier les liens présents entre la compréhension de textes et leur profil cognitif.

Méthodologie : Vingt participants avec TLC ont été inclus dans l'étude. Leur profil cognitif a été établi à l'aide de différents tests neuropsychologiques. Leur compréhension de textes a été évaluée à l'aide d'un test de compréhension de textes, le « T.C.T. », constitué de trois textes dont la charge sémantique varie et de trois questionnaires. Une analyse descriptive et qualitative des résultats a été faite ainsi qu'une analyse de corrélation entre les résultats aux tests neuropsychologiques et les résultats au T.C.T.

Résultats : Une atteinte de la compréhension (détails et idées principales) dépendante de la charge sémantique a été retrouvée chez 12 participants. Des corrélations significatives ont été observées entre le rappel des idées principales et des détails de deux textes sur trois et la mémoire épisodique.

Conclusion : Les résultats de cette étude permettent d'appréhender la variabilité des profils en compréhension de textes engendrée par un TLC et donc de mieux cibler les interventions possibles en orthophonie.

Abstract

Text comprehension is a complex component that requires both linguistic and cognitive abilities. Mild cognitive impairment (MCI) may cause difficulties in text comprehension. However, the heterogeneity of these individuals' cognitive profiles also suggests heterogeneous reading comprehension profiles. The purpose of this study was, first, to identify the text comprehension impairments associated to the cognitive load of texts in participants with MCI, and second, to study the links between reading comprehension and cognitive profiles.

Methods: Twenty participants with MCI were included in the study. The cognitive profile was assessed using various neuropsychological tests. Text comprehension was evaluated with the reading comprehension test, "T.C.T.", that included three texts with varied semantic load, and three questionnaires. A descriptive and qualitative analysis of the results was done, as well as a correlation analysis between the results of the neurosphychological tests and the T.C.T. test.

Results: Text comprehension impairments (details and main ideas) were found to be dependant upon the semantic load in 12 participants. Significant correlations were observed between episodic memory and the recall of the main ideas and details in two of the three texts.

Conclusion: The results of this study make it possible to understand the variability of text comprehension profiles in individuals with MCI. This may allow better-targeted speech-language interventions.

Introduction

Comprendre un texte est une fonction du langage importante pour la qualité de vie et le maintien de l'autonomie. Que ce soit pour lire un article de journal ou pour suivre une prescription médicale, une mauvaise compréhension de la lecture peut nuire au bien-être d'une personne et à son adaptation face aux exigences complexes de la vie de tous les jours. Si cette fonction se détériore, il est crucial d'y remédier. Mais encore faut-il en connaître la cause. La compréhension de textes requiert différentes habiletés tant linguistiques que cognitives. Une atteinte de la sphère linguistique à un niveau lexical, syntaxique ou discursif pourra occasionner un déficit en compréhension de textes de la même façon qu'une atteinte mnésique ou attentionnelle. En effet, différents systèmes cognitifs sont nécessaires à la mise en place des différents niveaux de représentation de la compréhension de textes (Ericsson & Kintsch, 1995; Kintsch, 1998). Le vieillissement entraîne certains changements cognitifs qui se répercutent sur le langage (Hupet & Nef, 1994) et particulièrement sur la compréhension de textes (Chesneau, Jbabdi, Champagne, Giroux, & Ska, 2007). La frontière entre un vieillissement considéré «normal» et celui associé à une pathologie neurodégénérative est parfois difficile à identifier. Le trouble léger de la cognition (TLC) est défini comme un état intermédiaire entre le vieillissement normal et la démence (Knopman, Boeve, & Petersen, 2003; Petersen et al., 1999). Cet état peut demeurer stable dans le temps, revenir à la normale ou progresser vers une démence. Néanmoins, il reflète le fait que les maladies neurodégénératives s'installent progressivement et débutent par une phase pendant laquelle les symptômes sont très légers. Au sein du continuum des pathologies neurodégénératives, les fonctions langagières sont affectées à différents degrés par l'état cognitif. Pendant la phase TLC, l'altération de certaines fonctions cognitives peut se répercuter sur la compréhension de textes. Aussi, lorsque des troubles de compréhension de discours ou de textes apparaissent, il est important d'en documenter l'origine afin d'intervenir au plus vite en proposant une thérapie ou encore des stratégies d'adaptation qui permettront à la personne de conserver une qualité de vie satisfaisante le plus longtemps possible.

Le modèle de compréhension de discours de Kintsch (Kintsch, 1988; 1994; 1998) permet de décrire et d'expliquer les différents niveaux de représentation ainsi que les traitements cognitifs qui interviennent dans la compréhension de textes. Les auteurs de ce modèle ont fait deux suppositions :

- Le texte est représenté à trois niveaux (linguistique, sémantique et situationnel);
- La construction de la compréhension est restreinte par les capacités limitées de différentes mémoires. La compréhension se fait par cycles, un cycle correspondant à une phrase ou une proposition.

Les études traitant de la compréhension de textes se sont particulièrement intéressées aux niveaux sémantique et situationnel de la compréhension. Le niveau sémantique est constitué de la compréhension des détails (microstructure) et la compréhension des idées principales (macrostructure). Le niveau situationnel est défini par la compréhension globale du texte ou encore le modèle de situation. Ce niveau de compréhension tient compte de ce que l'on apprend à partir des différentes parties du texte et de notre connaissance du monde. Il y a une mise à jour du modèle de situation à chaque cycle.

Les quelques études (Chapman et al., 2002; Hudon et al., 2006; Welland, Lubinski, & Higginbotham, 2002) qui ont portées sur la compréhension de textes chez des personnes présentant un TLC ou une maladie d'Alzheimer de degré léger se sont appuyées sur ce modèle. Elles ont mis en évidence des difficultés de compréhension de détails chez tous les individus testés. Toutefois, en ce qui concerne la compréhension des idées principales d'un texte, les avis sont divergents. Certains auteurs ont mis en évidence une atteinte concomitante de la compréhension de la macrostructure et de la microstructure (Chapman et al., 2002; Hudon et al., 2006) alors que pour d'autres l'atteinte de la compréhension de la macrostructure apparait plus tard dans l'évolution de la maladie, et pendant un certain temps, la compréhension de la macrostructure permet à la personne d'accéder à une compréhension globale du texte (Welland et al., 2002).

Plus récemment, une étude, portant sur la compréhension de textes chez des personnes atteintes d'un TLC (Schmitter-Edgecombe & Creamer, 2010) a associé les difficultés de compréhension globale de textes à un déficit dans la production des inférences qui permettent de mettre en lien les différentes parties d'un texte. À nouveau, on notera un manque de consensus concernant l'atteinte de la compréhension globale. La compréhension des détails et la compréhension des idées principales n'étaient pas questionnées par ces auteurs.

Les résultats mis en évidence dans les études de la compréhension de textes sont très liés aux différentes méthodologies utilisées (Hudon et al., 2006). Ainsi, une étude, portant sur l'évolution de la compréhension de

textes au cours du vieillissement normal, réalisée en 2007 par Chesneau et coll., a révélé que la compréhension d'un texte variait en fonction de sa charge sémantique (nombre de détails dans le texte), ceci particulièrement chez les personnes âgées. Des liens ont été mis en évidence entre la charge sémantique des textes et les fonctions cognitives requises pour accéder à leur compréhension. Ainsi, alors que la compréhension d'un texte avec une microstructure chargée en détails sollicitait essentiellement la mémoire épisodique, la compréhension d'un texte avec une microstructure allégée en détails sollicitait plus particulièrement la mémoire de travail et beaucoup moins la mémoire épisodique. Ces résultats allaient donc dans le même sens que les propositions de Kintsch quant à l'intervention de différentes mémoires dans la compréhension de textes (Kintsch, 1994). La compréhension d'un texte nécessitant la mise à jour du modèle de situation sollicitait l'intervention des fonctions inhibitrices, ce qui n'était pas le cas de textes dans lesquels la mise à jour du modèle de situation n'était pas nécessaire. Ainsi, non seulement la compréhension d'un texte demande l'intervention de plusieurs fonctions cognitives mais l'intervention de ces fonctions cognitives varie selon les textes (Chesneau & Ska, 2015).

Les personnes atteintes d'un TLC ne présentent pas toutes le même profil cognitif suggérant que leur profil de compréhension en lecture est tout aussi hétérogène (Gauthier et al., 2006). Cette hétérogénéité est présente au sein des populations ayant eu un diagnostic de TLC mais aussi chez un même individu. En effet, une personne peut être capable de comprendre certains textes mais pas tous les textes. Ces différences de compréhension dépendent de la demande cognitive des textes. Ainsi, si l'on veut rendre compte des difficultés rencontrées dans le quotidien de ces personnes, il est nécessaire de solliciter différentes fonctions cognitives au travers de leur lecture et pour cela il est nécessaire d'utiliser plusieurs types de textes pour tester leur compréhension.

Aucune des études précédemment citées n'a tenu compte de la charge sémantique des textes utilisés, ce qui pourrait expliquer le manque de consensus observé dans ces études concernant l'atteinte des niveaux de représentation de la compréhension de textes. Dans chacune de ces études, un seul type de texte était utilisé alors que pour documenter le déficit il aurait fallu faire varier la charge sémantique, et donc la demande cognitive des textes.

Les travaux de Chesneau et coll., portant sur la compréhension de textes dans le vieillissement (Chesneau,

Jbabdi, et al., 2007), ont donné lieu à l'élaboration d'un test standardisé de compréhension de textes. le T.C.T. (Chesneau, 2012). Ce test élaboré dans le cadre du modèle de Kintsch (Kintsch, 1988; 1998) permet d'évaluer la compréhension des détails, des idées principales et la mise à jour du modèle de situation effectuée par la production d'une inférence concernant la compréhension globale du texte (quand il y deux évènements dans le texte à concilier en un seul, le lecteur doit faire des liens entre les différentes parties du texte et sa connaissance du monde. Ex. : comprendre qu'une partie du texte fait référence à un rêve). Ce test, constitué de plusieurs textes, a la particularité de tenir compte de la charge sémantique du texte (nombre de micropropositions) et de la nécessité de produire ou non l'inférence concernant la compréhension globale du texte. Ce test a été normalisé auprès de personnes âgées de 16 à 80 ans pour deux niveaux d'études (plus de 12 ans de scolarité et moins de 12 ans de scolarité). Des corrélations significatives, liant d'une part la mémoire épisodique et le rappel de deux des textes du test et d'autre part la mémoire de travail, les fonctions exécutives, les fonctions inhibitrices et le rappel d'un des textes du test ont été mises en évidence telles qu'attendues dans l'étude sus-citée (Chesneau, Jbabdi, et al., 2007). Ces différentes corrélations appuient la validité de construit de ce test. Ce test n'a encore jamais été utilisé avec des individus présentant un TLC.

Objectifs

L'objectif principal de cette étude est de documenter, à l'aide du T.C.T., la compréhension de textes de personnes présentant un TLC en fonction de la charge sémantique des textes. L'objectif secondaire est d'étudier les liens entre la compréhension de textes et le profil cognitif des participants.

Hypothèses

- Plus la microstructure sera chargée (plus il y aura de détails dans le texte), plus son rappel sera altéré, s'éloignant ainsi de plus en plus des résultats des individus sains, ceci en lien avec un déficit de la mémoire épisodique.
- 2. Le rappel de la macrostructure sera inférieur au rappel des individus sains pour les textes dont la microstructure est chargée ou allégée, mais le rappel de la macrostructure sera dans les normes attendues pour le texte dont la microstructure est modérément chargée.
- 3. La compréhension globale du texte sera

altérée pour le texte dont la microstructure est modérément chargée et pour lequel il est nécessaire de produire une inférence, ceci en lien avec un déficit des fonctions inhibitrices. Elle sera réussie pour le texte dont la microstructure est allégée et pour lequel il est nécessaire de produire une inférence.

Méthodologie

Participants

Dans la perspective de réaliser une étude pilote, 20 participants présentant un TLC amnésique (présence d'un déficit de mémoire) ou un TLC amnésique multidomaines (présence d'un déficit des fonctions exécutives, attentionnelles ou de langage et d'un déficit de mémoire) ont été recrutés par une clinique de mémoire, sur la base des critères de Petersen (Petersen, 2004), avant de nous être référés. Ces participants devaient être de langue maternelle française et avoir suivi une scolarisation primaire complète. Ils ne devaient pas avoir présenté de troubles dyslexiques durant leur apprentissage, ce qui a été vérifié par un interrogatoire approprié. Ils ne devaient pas présenter d'atteinte rétinienne ni de glaucome ni de début de cataracte. Ils ne devaient pas souffrir d'affection neurologique sévère, de troubles psychiatriques ou d'alcoolisme. Ils ne devaient pas prendre ou avoir pris dans l'année précédente de médicament ayant une action néfaste sur la mémoire.

Tout déficit sensoriel majeur devait être compensé par les prothèses habituelles.

Un questionnaire a permis de recueillir de l'information sur l'histoire personnelle et médicale du participant. Le profil cognitif des participants a été établi par l'intermédiaire des tests neuropsychologiques suivants:

- Le « Mini Mental States Examination (MMSE) » (Folstein, Folstein, & McHugh, 1975) et le « Montreal cognitive assesment (MoCA) » (Nasreddine et al., 2005) ont permis de dresser un portrait global de diverses habiletés cognitives;
- Le « *Rappel libre/ rappel indicé (RL/RI)* » a permis l'évaluation de la mémoire épisodique (Van der Linden et al., 2004);
- Le « *Stroop Victoria* » a permis l'évaluation des fonctions attentionnelles et inhibitrices (Regard, 1981);
- L'épreuve de dénomination du « Boston naming test » a permis l'évaluation de la disponibilité lexicale. (Kaplan, Goodglass, & Weintraub, 1983).

La passation de ces tests s'est faite selon la procédure prévue par leurs auteurs.

Le tableau 1 présente les données démographiques et les données concernant les habiletés cognitives des participants.

Le tableau 2 présente les résultats individuels des participants obtenus aux tests évaluant la mémoire épisodique et les fonctions attentionnelles et inhibitrices, calculés en score Z par rapport à leur groupe d'âge.

Matériel

L'outil standardisé et étalonné intitulé Test de compréhension de textes (T.C.T.) a permis d'évaluer de manière approfondie les habiletés de compréhension de textes (Chesneau, 2012).

Il consiste en trois séries de trois textes et neuf questionnaires. Les trois séries (TCT1, TCT2, TCT3) varient en nombre de micropropositions (charge sémantique) et deux des trois séries (TCT1 et TCT3) nécessitent la compréhension d'une inférence portant sur la mise à jour du modèle de situation. À l'intérieur de chaque série, les textes diffèrent par le thème abordé. L'équivalence des textes à l'intérieur de chacune des séries de même que les possibilités d'apprentissage entre les textes ou encore l'impact de la fatigue ont été vérifiés dans une étude spécifique et aucune différence n'a été mise en évidence suggérant ces effets (Chesneau, Roy, & Ska, 2007).

La compréhension de textes est évaluée par trois textes choisis dans chacune des séries (TCT1, TCT2 et TCT3), les trois textes choisis devant être de thèmes différents.

- TCT1 : dans cette série de textes, la microstructure est composée de 90 micropropositions qui correspondent en moyenne à 244 mots et une mise à jour du modèle de situation est nécessaire. Le lecteur doit comprendre que les trois premiers paragraphes du texte font référence à un cauchemar. Ces textes permettent de tester les capacités générales du lecteur à traiter les différents niveaux de représentation du texte.
 - Exemple de quelques phrases extraites d'un texte TCT1 :

« Laura sentit l'avion s'élever rapidement. C'était une magnifique journée ensoleillée, un vent léger finissait de disperser la brume qui couvrait la ville plus tôt en matinée. Le pilote annonça que l'avion se dirigeait vers le nord-ouest pour contourner ensuite l'Angleterre en direction du Groenland... »

Tableau 1. Profils démographiques et cognitifs des participants présentant un TLC

Participants	Age (Année)	Sexe	Scolarité (Année)	MoCA(/30)	MMSE (/30)	Dénomination (/15)
P1	66	F	17	26	30	13
P2	80	F	12	21	25	9
P3	81	F	14	19	25	10
P4	73	F	16	24	27	15
P5	70	Μ	18	29	28	11
P6	76	Μ	13	27	30	14
P7	76	F	11	20	26	11
P8	75	F	16	27	28	14
P9	66	F	10	27	26	11
P10	69	Μ	15	29	27	11
P11	72	F	13	24	26	10
P12	67	F	19	29	29	14
P13	65	Μ	20	28	28	15
P14	74	F	9	23	27	15
P15	84	F	15	28	29	13
P16	78	F	15	26	30	13
P17	62	F	12	24	28	13
P18	74	Μ	22	22	24	13
P19	68	F	12	22	26	11
P20	76	Μ	22	28	29	15

Note : MMSE = Mini Mental State Examination, MoCA= Montreal cognitive assessment

Tableau 2. Résultats individuels des participants aux tests RL/RI et Stroop : Score Z des participants par rapport à leur groupe d'âge

Participants	RL/RI - RL3	RL/RI-RT3	RL/RI - RLD	RL/RI- RTD	Stroop Coul TR	Stroop Coul Erreurs
P1	0	0,5	0	0,6	0	-5,3
P2	-1,3	0,5	-0,4	-0,2	0	0
P3	-2,1	-0,5	-2,2	-0,2	0	1
P4	-1,9	-0,7	-1	-0,1	1,1	0,5
P5	-2,2	-5,7	-5	-5,9	0,8	0,7
P6	0	0,5	-0,8	0,8	1,4	0,7
P7	-3	-9,5	-3,6	-14,8	-0,7	-0,2
P8	0	0,5	-0,5	0,8	0,9	-2,1
P9	- 0,4	0,5	0	0,6	-0,7	0,9
P10	- 1,1	-0,7	-1,5	-0,9	1	0,5
P11	0	-0,7	1	0,6	1	0,6
P12	-1,1	-2	-1,5	-0,9	-0,9	-9,7
P13	0	0,5	0	0,6	-0,2	-2,4
P14	0,4	-0,7	2	0,6	1	-0,3
P15	1,3	0,5	0,9	0,8	0,9	1
P16	- 0,4	-1,5	-0,4	-2,5	0	-0,3
P17	-0,7	0,5	0,2	0,6	-2,34	-6,8
P18	-0,4	0,5	1	0,6	-0,31	0,66
P19	-2,6	-5,7	-2,5	-3,5	1,44	-5,35
P20	0,5	-1,5	0,2	0,8	-0,2	-1,2

Note : RL3 = 3^{ème} rappel libre; RLD = rappel différé libre; Stroop Coul TR = couleur temps; Stroop Coul Erreurs = couleur erreur

- TCT2 : dans cette série, la microstructure est composée de 135 micropropositions qui correspondent en moyenne à 342 mots, mais le modèle de situation ne nécessite pas de mise à jour. Ce texte vise plus particulièrement l'évaluation du traitement de la microstructure. De nombreux détails sont ajoutés par rapport au premier texte.
 - Exemple de quelques phrases extraites d'un texte TCT2 correspondant au même thème que dans l'exemple précédent afin de mettre en évidence les différentes charges sémantiques :

« Laura, belle et charmante jeune femme, profitait de quelques jours de vacances pour quitter Paris. Elle sentit l'avion s'élever très rapidement. C'était le 23 mai et il était 13h55. Elle était confortablement installée en première classe, un bon roman à portée de main. C'était une magnifique journée ensoleillée, pas un seul nuage n'assombrissait le ciel, un vent léger finissait de disperser la brume qui couvrait la ville plutôt en matinée. Le pilote, commandant chevronné travaillant depuis 17 ans dans une compagnie aérienne de renom, annonça que l'avion se dirigeait vers le nord-ouest pour contourner ensuite l'Angleterre en direction du Groenland... »

- TCT3 : dans cette série, la microstructure est allégée relativement aux textes 1 et 2 (43 micropropositions qui correspondent en moyenne à 128 mots). Les détails qui ne sont pas nécessaires à la compréhension de l'histoire ont été supprimés, mais une mise à jour du modèle de situation est nécessaire. Ce texte vise plus directement le traitement de la macrostructure et du modèle de situation.
 - Exemple de quelques phrases extraites d'un texte TCT3 correspondant au même thème que dans l'exemple précédent afin de mettre en évidence les différentes charges sémantiques :
 « Laura sentit l'avion s'élever. Le pilote indiqua le trajet qu'allait suivre l'avion... »
- Les neuf questionnaires permettent d'évaluer les différents niveaux de représentation de la compréhension de texte, soit la compréhension des idées principales, la compréhension des détails, et la compréhension globale par production d'une inférence concernant la mise à jour du modèle de situation. Ces questionnaires sont donc constitués de deux ou trois parties selon si la compréhension du texte nécessite la production d'une inférence ou non :
- 1. Le participant doit rappeler à l'oral les principaux

points du texte. (Ce qui teste la macrostucture.)

- Le participant doit répondre à un questionnaire oral portant sur les détails et évènements du texte (Ce qui teste la microstructure.)
 Exemple : Quelle était la météo au moment du départ de l'avion?
- Lorsque le texte présente deux évènements à concilier en un seul, le participant doit répondre à deux questions formelles montrant qu'il a bien produit l'inférence nécessaire à la compréhension globale du texte.

La fidélité inter-juge a été testée à partir des réponses de 25% des participants pris au hasard parmi les participants présentant un TLC. Le taux d'accord interjuge est de 98% dans la cotation de la microstructure et de 97% dans la cotation de la macrostructure.

Procédures

Trois textes de thèmes différents ont été sélectionnés dans les séries TCT1, TCT2 et TCT3. Les participants ont lu en silence chacun des textes avant d'être soumis au questionnaire correspondant. Leur lecture a été chronométrée. Le temps total de passation a été environ une heure 30 minutes, incluant la lecture et la signature du formulaire d'information et de consentement et la passation des tests neuropsychologiques.

Cette étude a été approuvée par le comité d'éthique de l'Université du Québec à Trois-Rivières et par le comité d'éthique de l'Institut universitaire de gériatrie de Montréal où les participants ont été rencontrés.

Analyses Statistiques

Les résultats au test de compréhension de textes T.C.T. ont donné lieu à une analyse descriptive et quantitative. Des scores Z ont été calculés pour chacun des participants à partir des données normatives du test. Chaque participant était apparié à son groupe de référence en âge et en niveau d'étude. Les résultats étaient considérés anormaux si la variation par rapport au groupe de référence (en âge et en niveau d'étude) était inférieure à -1,5 écarttype. Puis, des corrélations non paramétriques (test de Spearman) ont été calculées entre les différents résultats aux tests neuropsychologiques et le rappel de la macrostructure et microstructure des trois textes TCT1, TCT2 et TCT3.

Résultats

Résultats au test de compréhension de textes

Rappel de la macrostructure

Douze participants sur 20 n'ont pas été en mesure de rappeler correctement la macrostructure d'un ou plusieurs textes. La figure 1 représente les résultats individuels des participants au rappel de la macrostructure des textes TCT1, TCT2 et TCT3 par rapport à leur groupe de référence (âge et niveau d'éducation). Un score z a été calculé pour chacun d'entre eux. participants ayant présenté des difficultés avec TCT1 n'ont pas eu de difficultés avec les autres textes, alors que la plupart participants ayant présenté des difficultés à rappeler la macrostructure de TCT2 en ont eues aussi avec TCT3 sauf P4 et P18.

Rappel de la microstructure

Huit participants sur 20 n'ont pas été en mesure de rappeler correctement la microstructure d'un ou de plusieurs textes. La figure 2 représente les résultats individuels des participants au rappel de la microstructure des textes TCT1, TCT2 et TCT3 par rapport à leur groupe



Figure 1. Rappel de la macrostructure : score z des participants par rapport à leur groupe d'âge et à leur niveau de scolarité

P1, P2, P11, P14 et P17 ont présenté des difficultés avec le rappel de la macrostructure de TCT1.

P2, P3, P4, P5, P7, P12 et P18 ont présenté des difficultés avec le rappel de la macrostructure de TCT2.

P2, P3, P5, P7, P12 et P19 ont présenté des difficultés avec le rappel de la macrostructure de TCT3.

Les textes TCT2 (microstructure très chargée) et TCT3 (microstructure allégée) sont les textes à propos desquels les participants ont rencontré le plus de difficultés. Seul P2 a présenté des difficultés avec tous les textes. Les de référence (âge et niveau d'éducation). Un score z a été calculé pour chacun d'entre eux.

P4, P5, P12, P14 ont présenté un déficit dans le rappel de la microstructure de TCT1.

P2, P3, P5, P7, P12 et P19 ont présenté un déficit dans le rappel de la microstructure de TCT2.

P2, P3, P4, P5, P7 et P12 ont présenté un déficit dans le rappel de la microstructure de TCT3.

Les textes TCT2 (microstructure très chargée) et TCT3 (microstructure allégée) sont les textes pour lesquels les



Figure 2. Rappel de la microstructure : score z des participants par rapport à leur groupe d'âge et à leur niveau de scolarité

rappels de la microstructure sont les plus déficitaires. Les participants ayant présenté des difficultés de rappel de la microstructure à TCT1 ont présenté aussi des difficultés de rappel de la microstructure à TCT2 ou à TCT3 sauf P14 pour qui seul TCT1 était difficile. Cinq participants ont présenté des difficultés dans le rappel de la microstructure des deux textes TCT2 et TCT3.

Mise à jour du modèle de situation

Seulement deux participants n'ont pas fait l'inférence nécessaire pour faire la mise à jour du modèle de situation (réaliser qu'il s'agissait d'un cauchemar) (P2 dans le texte TCT1 et P12 dans le texte TCT3).

Ajout d'informations dans le rappel de la macrostructure

Douze participants sur 20 ont ajouté des éléments qui ne figuraient pas dans le texte dans le rappel de la macrostructure. Parmi ces ajouts, certains étaient sans lien avec un autre texte alors que d'autres étaient en lien avec une information lue dans le texte précédent. Ces contaminations ont été observées uniquement dans le rappel de la macrostructure de TCT2. Le tableau 3 rapporte le nombre d'ajouts d'informations par texte et par participant (ajouts simples et contaminations de TCT1 sur TCT2).

Corrélations entre les résultats aux épreuves neuropsychologiques et les résultats aux mesures des niveaux de représentation de la compréhension en fonction des différentes séries de textes.

Des analyses de corrélation non paramétriques ont été utilisées en raison du petit nombre de participants. Ces analyses révèlent d'une part des corrélations significatives entre les résultats au test MMSE et les résultats au rappel de la microstructure de TCT2 et d'autre part des corrélations significatives entre les résultats au test de RL/RI évaluant la mémoire épisodique et les résultats au rappel de la macrostructure de TCT2 (texte très chargé en détails) et TCT3 (texte allégé en détails) et entre les résultats au RL/ RI et les résultats au rappel de la microstructure de TCT2 et TCT3 (Tableau 4). Aucune corrélation n'a été mise en évidence avec les autres tests neuropsychologiques utilisés dans cette étude pour établir le profil cognitif des participants.

Participants Ajouts TCT1 Ajouts TCT2 TCT1/TCT2 Ajouts TCT3 P1 З P2 P3 P4 P5 P6 P7 P8 P9 P10 P11 P12 P13 P14 P15 P16 P17 P18 P19 P20

Tableau 3. Ajout d'informations et contaminations dans le rappel de la macrostructure de TCT1, TCT2 et TCT3.

Note : TCT1/TCT2 : ajouts d'information par contamination de TCT1 sur TCT2

Tableau 4. Corrélations entre les résultats aux tests neuropsychologiques et les résultats aux rappels de la macrostructure et de la microstructure des textes TCT1, TCT2 et TCT3.

	Rappel de la Macrostructure TCT1	Rappel de la Microstructure TCT1	Rappel de la Macrostructure TCT2	Rappel de la Microstructure TCT2	Rappel de la Macrostructure TCT3	Rappel de la Microstructure TCT3
Cognition						
MMSE	0,13	0,13	0,34	0,59*	0,31	0,26
MOCA	0,37	O,1	0,25	0,27	0,21	0,12
Fonctions inhibitrices						
Stroop (temps)	-0,23	-0,16	-0,3	-0,40	-0,35	-0,24
Stroop (erreurs)	-0,26	-0,26	-0,32	-0,13	-0,16	-0,03
<u>Mémoire</u> épisodique						
RL/RI:						
Rappel libre 3	-0,32	0,39	0,5*	0,76**	0,73**	0,62**
Rappel Total 3	-0,28	0,45*	0,23	0,44	0,53*	0,41
Rappel différé libre	-0,42	0,18	0,35	0,54*	0,7**	0,51*
Rappel différé total	-0,31	0,46*	0,45*	0,61**	0,74**	0,54*

Note : * La corrélation est significative au niveau 0,05 (bilatéral), ** La corrélation est significative au niveau 0,01 (bilatéral), MMSE = Mini Mental State Examination, MoCA= Montreal cognitive assessment

Discussion

L'objet de cette étude pilote était d'une part d'identifier l'impact d'un trouble léger de la cognition sur les différents niveaux de représentation de la compréhension de textes en fonction de la charge sémantique des textes et d'autre part d'étudier les liens possibles entre les profils cognitifs et les profils de compréhension de textes.

Les principaux résultats de cette étude montrent que 60% de nos participants TLC présentaient un trouble de compréhension de textes. Comme nous l'avions pensé, leurs difficultés variaient en fonction des textes. Le rappel de la macrostructure est apparu plus difficile pour les participants que le rappel de la microstructure puisque seulement 67% des participants ayant présenté un rappel déficitaire de la macrostructure ont aussi présenté une atteinte de la microstructure. Aucun participant ne présentait de difficulté avec le rappel de la microstructure sans présenter aussi des difficultés avec le rappel de la macrostructure dans l'un ou l'autre des textes. Ces résultats corroborent les résultats de Hudon et coll. (2006) et Chapman et coll. (2002) selon lesquels les personnes présentant un TLC peuvent présenter des

difficultés de rappel de la microstructure mais aussi de la macrostructure. Toutefois, ils s'opposent aux résultats de Chapman et coll. (2002) pour ce qui est de la proportion de participants présentant une atteinte du rappel de la microstructure. En effet, dans cette étude, 100% des participants TLC présentaient un déficit du rappel de la microstructure, ce qui est loin d'être le cas de nos participants qui ont présenté un déficit de rappel de la microstructure dans une proportion de 40% par rapport au nombre total de personnes évaluées. Il semblerait que cette différence majeure dans les résultats puisse être attribuée à des différences méthodologiques. En effet, dans l'étude de Chapman et coll. (2002), un rappel détaillé de l'histoire était demandé au participant sans qu'il ne soit guidé dans son récit alors que dans notre étude un questionnaire permettait au participant de ne pas omettre de détails s'il les avait compris et mémorisés. Le rappel proposé dans l'étude de Chapman pouvait inciter le participant à vouloir rappeler le récit «verbatim», ce qui sollicite bien plus la mémoire qu'un rappel de micropropositions exprimées dans les propres mots de la personne (Radvansky, 1999).

Par ailleurs, seulement deux participants de notre étude n'ont pas réussi à faire la mise à jour du modèle de situation, c'est-à-dire à faire l'inférence nécessaire à la compréhension globale du texte et donc à comprendre que certains textes faisaient référence à un cauchemar. En lien avec les conclusions de Schmitter-Egdebond et Creamer (2010) à propos de l'intervention mnésique dans la génération d'inférences explicatives permettant de relier les différentes parties du texte, nous avions posé l'hypothèse que les personnes avec un TLC auraient des difficultés à comprendre le texte TCT1 (modérément chargé en détails) et comprendraient sans difficulté le texte TCT3 (allégé en détails). Cependant, non seulement peu de participants ont montré des difficultés de compréhension globale des textes, mais les deux participants qui ont présenté ce déficit l'ont exprimé différemment, l'un dans TCT1 et l'autre dans TCT3. Ainsi, les résultats de notre étude s'opposent aux résultats de Schmitter-Egdebond et Creamer (2010).

Un autre sujet d'intérêt est apparu dans l'analyse des résultats de cette étude : l'ajout de fausses informations dans le rappel de la macrostructure (voir Tableau 3). Deux types d'ajout ont été constatés : d'une part des ajouts purs qui n'avaient aucun rapport avec les textes et d'autre part des ajouts qui faisaient référence au texte qui avait été lu juste avant, comme s'il y avait eu une contamination d'un texte sur l'autre. La cotation du T.C.T. ne prévoyait pas de points négatifs pour ce type d'erreur. Aussi, quelques participants ont obtenu le maximum des points alors qu'ils avaient modifié le contenu de la macrostructure en ajoutant des informations. Ces ajouts, peu courants lors d'un vieillissement cognitif normal mais fréquents lors d'un vieillissement pathologique et particulièrement dans la maladie d'Alzheimer, pourraient être considérés comme les prémices à l'installation de difficultés plus importantes. En effet, la présence d'intrusions dans un rappel d'informations de même que la présence de fausses reconnaissances font généralement partie du tableau clinique associé au TLC amnésique prodromal de la maladie d'Alzheimer (Belleville, Sylvain-Roy, de Boysson, & Menard, 2008; Dubois, 2002). Ainsi, il convient de porter attention non seulement aux résultats quantitatifs des tests de compréhension de textes, mais aussi d'examiner qualitativement les réponses des participants.

L'importance d'évaluer la compréhension avec plusieurs textes

Les résultats de notre étude ont permis non seulement de mettre en évidence, chez des personnes présentant un TLC, la présence d'un déficit de compréhension de textes aux différents niveaux de représentation de la compréhension, mais aussi de constater que ces déficits pouvaient s'exprimer différemment suivant les textes, en fonction de leur charge sémantique et de la nécessité de faire ou non une inférence pour accéder à la compréhension globale du texte. Au vu des résultats obtenus par les participants à chacun des textes, deux profils semblent se dégager. Ainsi, les participants qui ont présenté des difficultés à rappeler la macrostructure de TCT1 (texte modérément chargé en détails) n'ont par ailleurs eu aucune difficulté avec le rappel de la macrostructure de TCT2 (texte très chargé en détails) et de TCT3 (texte allégé en détails). En contrepartie, les participants qui ont présenté des difficultés à rappeler la macrostructure de TCT2 ont aussi présenté des difficultés dans le rappel de la macrostructure de TCT3. Si l'on regarde le profil cognitif de chacun de nos participants (voir Tableaux 1 et 2), on constate que les participants appartenant au sous-groupe qui a présenté des difficultés au rappel de la macrostructure de TCT1 ne présentent pas de déficit en mémoire épisodique mesuré par le 3^{ème} rappel ou le rappel différé du test RL/RI, ce qui permet de penser qu'ils sont encore capables d'un certain apprentissage alors que tous ceux qui ont échoué au rappel de la macrostructure de TCT2 et TCT3 présentent un déficit en mémoire épisodique mesuré par le 3^{ème} rappel et le rappel différé du test RL/RI. Ainsi, il est permis de supposer que le déficit en compréhension de textes varie en fonction des textes proposés au lecteur et du degré d'atteinte de la mémoire épisodique. Cette hypothèse semble confirmée par les corrélations significatives mises en évidence dans

notre étude entre la mémoire épisodique et le rappel de la macrostructure et de la microstructure des textes TCT2 et TCT3 (voir Tableau 4). Toutefois, cela ne permet pas de comprendre quels déficits cognitifs favorisent un déficit du rappel de la macrostructure du texte TCT1. Ce texte est modérément chargé en détails. Une intervention de la mémoire épisodique est nécessaire au rappel de sa microstructure comme le montrent des corrélations significatives entre mémoire épisodique et rappel de la microstructure de TCT1. Aucune corrélation n'a été mise en évidence entre la macrostructure de TCT1 et les fonctions cognitives qui étaient mesurées dans cette étude. Toutefois, plusieurs des participants pour lesquels le rappel de la macrostructure de TCT1 était difficile présentaient aussi une faiblesse des fonctions inhibitrices mesurée par le Stroop ou une baisse cognitive globale mesurée par le MMSE. Le petit nombre de participants inclus dans notre étude et ayant présenté un déficit dans le rappel de la macrostructure de TCT1 ne nous permet pas d'aller plus avant dans une interprétation. Cependant, sans pouvoir préciser ici quelles fonctions cognitives sont responsables du déficit de rappel de la macrostructure de TCT1, nous pouvons cependant rappeler des liens mis en évidence dans d'autres études entre communication et fonctions exécutives (Fridriksson, Nettles, Davis, Morrow, & Montgomery, 2006; Purdy, 2002) et, plus spécifiquement, entre compréhension de textes, mémoire épisodique et fonction inhibitrice (Chesneau, Jbabdi, et al., 2007; Ferstl, Walther, Guthke, & von Cramon, 2005). Par ailleurs, la mémoire sémantique, déficitaire chez certaines personnes présentant un TLC (Duong, Whitehead, Hanratty, & Chertkow, 2006; Joubert et al., 2008), pourrait aussi rendre compte chez ces personnes de certaines difficultés en compréhension de textes.

En résumé, l'évaluation de la compréhension de textes de personnes présentant un TLC avec des textes de charge cognitive différente a permis de mettre en évidence, chez ces personnes, des profils en compréhension de textes variés généré par des profils cognitifs différents.

Perspectives futures

Une étude de plus grande ampleur permettra de préciser avec plus de certitude quels troubles cognitifs conduisent les personnes avec un TLC à présenter un profil particulier en compréhension de textes. Par ailleurs, une étude longitudinale permettra d'identifier les profils de compréhension de textes qui pourraient être considérés comme signe précurseur de la maladie d'Alzheimer.

Perspectives cliniques

Alors que de récentes études (Belleville et al., 2011; Carretti, Borella, Fostinelli, & Zavagnin, 2013; Rojas et al., 2013) ont mis en évidence, chez des personnes présentant un TLC, les bénéfices cliniques et les répercussions cérébrales observées en imagerie par résonance magnétique fonctionnelle de programmes de stimulation cognitive (Belleville et al., 2011), peu d'entre elles bénéficient actuellement d'une référence en orthophonie.

Toutefois, cette étude montre qu'une orthophoniste peut aisément identifier différentes atteintes de la compréhension de textes chez des personnes avec un TLC. Une orthophoniste pourra donc mettre en place une thérapie adaptée aux difficultés de compréhension de textes d'une personne avec un TLC afin de lui permettre de garder le plus longtemps possible une lecture fonctionnelle qui reste un enjeu majeur dans la conservation de son autonomie.

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Characteristics and outcomes of children with Auditory Neuropathy Spectrum Disorder

Caractéristiques et évolution des enfants ayant un trouble du spectre de neuropathie auditive

KEY WORDS

AUDITORY NEUROPATHY SPECTRUM DISORDER DIAGNOSIS MANAGEMENT

HEARING AIDS

COCHLEAR IMPLANTS

REHABILITATION

Abstract

Background. Auditory neuropathy spectrum disorder (ANSD) has been reported in up to 10% of all children with hearing loss. It is widely accepted that it can be difficult to identify and manage children with ANSD through typical clinical procedures, in comparison to children with sensorineural hearing loss (SNHL). An important limitation in managing children with ANSD is that behavioral pure-tone audiograms are less predictive of a child's intervention needs with respect to amplification and early rehabilitation. The objective of this study was to characterize the clinical profiles and audiological management of children with ANSD followed through a provincial universal newborn hearing screening (UNHS) program in one region of Canada from 2003-2013.

Methods. Population-based data were collected at the Children's Hospital of Eastern Ontario (CHEO), Ottawa, Canada between 2003 and 2013 for all children who were diagnosed with ANSD. Detailed characteristics were extracted including screening status, etiology, risk factors, and severity of hearing loss. Diagnostic, amplification, and intervention outcomes were also documented.

Results. Analyses of 418 children indicated that 22 (5.3%) children were identified with ANSD and more than 30% had other disabilities. Children were identified at a median age of 7.5 months (IQR: 4.7, 22.5), fitted with amplification at a median age of 17.3 months (IQR: 12.1, 26.6) and 12 underwent cochlear implantation at a median age 26.4 months (IQR: 18.0, 47.3).

Conclusion. More than 85.0% of children with ANSD are currently fitted with hearing aids or cochlear implants and have achieved some degree of open-set word recognition and communication development.

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Contexte : Les troubles du spectre de neuropathie auditive (TSNA) ont été rapportés chez des enfants ayant une perte auditive, avec une prévalence pouvant s'élever jusqu'à 10 %. Il est largement reconnu que l'identification et la prise en charge effectuées auprès des enfants ayant un TSNA peuvent être difficiles avec les procédures cliniques courantes, lorsque comparées aux enfants ayant une perte auditive neurosensorielle. Une limitation importante de la prise en charge des enfants ayant un TSNA est le caractère prédictif diminué des audiogrammes tonals pour les besoins d'intervention de ces enfants en ce qui concerne l'amplification et l'intervention précoce. L'objectif de cette étude était de décrire les profils cliniques des enfants avec un TSNA, ainsi que leur prise en charge en audiologie, suite à l'application du programme provincial de dépistage universel de l'audition chez les nouveau-nés dans une région du Canada, entre 2003 et 2013.

Méthodologie : Les données démographiques ont été recueillies au Centre hospitalier pour enfants de l'est de l'Ontario, Ottawa (Canada), et ce, pour tous les enfants diagnostiqués avec un TSNA entre 2003 et 2013. Des caractéristiques détaillées ont été extraites, ce qui inclut le statut de dépistage, l'étiologie, les facteurs de risque et la sévérité de la perte auditive. Le diagnostic, l'amplification et les résultats à l'intervention ont également été documentés.

Résultats : Les analyses effectuées auprès de 418 enfants ont montré que 22 des enfants (5,3 %) ont été identifiés avec un TSNA et plus de 30 % avaient d'autres difficultés. Les enfants ont été identifiés à un âge médian de 7,5 mois (EI : 4,7 – 22,5), ont été équipés avec une amplification à un âge médian de 17,3 mois (EI : 12,1-26,6) et 12 ont reçu un implant cochléaire à un âge médian de 26,4 mois (EI : 18,0 - 47,3).

Conclusion : Plus de 85,0 % des enfants ayant un TSNA sont actuellement équipés d'appareils auditifs ou d'implants cochléaires, ont atteint un certain degré d'identification de mots en choix ouvert et ont développé un certain niveau de communication.
Introduction

Auditory Neuropathy Spectrum Disorder (ANSD) is used to describe a complex hearing disorder that involves normal cochlear function but abnormal auditory nerve function. There is a change in neural synchrony, characterized by auditory behaviors in which the function of outer hair cells is preserved, while the afferent neural transmission is altered. Sound processing in patients with ANSD is highly variable, and the relationship between hearing sensitivity and the ability to process speech cannot be predicted based on the level of residual hearing (Hood, 2011).

ANSD is a hearing disorder, which presents distinct difficulties in speech understanding, particularly in competing noise. This audiological finding suggests disruption in processing time due to the lack of synchrony of the auditory pathways from the cochlea to the auditory cortex (Hayes, 2008; Sininger & Oba, 2001). Difficulties with the resolution of temporal processing (Rance, 2005) can have an impact on speech understanding and consequently on the development of oral language and communication. The term ANSD was adopted because there are a wide range of clinical manifestations, prognoses, and underlying etiologies associated with the disorder (Feirn, Sutton, Parker, Sirimanna, & Lightfoot, 2013).

Various studies have shown prevalence estimates ranging from 1.0% to 10.0% of children identified with permanent childhood hearing loss (Kirkim, Serbetcioglu, Erdag & Ceryan, 2008; Rance, 2005; Sininger and Oba, 2001) and 10.0% to 15.0% in schools for the deaf (Berlin et al, 2010). In population hearing screening studies, a prevalence of 24.1% to 40.0% has been reported in infants with hearing loss from the neonatal intensive care unit (NICU) (Berg, Spitzer, Towers, Bartosiewicz, & Diamond, 2005; Rea & Gibson, 2003).

Children with ANSD represent a subgroup of patients with hearing impairment with different pathologies most commonly associated with risk indicators for hearing loss related to admission to the NICU (Dowley et al., 2009). Children with histories of neonatal problems such as prematurity, low birth weight, anoxia, and hyperbilirubinemia, are at a greater risk for ANSD (Madden, Rutter, Hilbert, Greinwald, & Choo, 2002; Teagle at al., 2010). However, ANSD has also been reported in children in the absence of any clear risk factors (Sininger, 2002; Uhler, Heringer, Thompson, & Yoshinaga-Itano, 2012).

Children with sensorineural hearing loss (SNHL) or ANSD experience early deprivation of sensory input to the cortex and demonstrate changes in neuroplasticity and development upon introduction of auditory stimulation. Research regarding central auditory maturation suggests that plasticity can often be maximized via amplification and/or electrical stimulation to produce positive clinical outcomes in these patient populations (Kral, Hartmann, Tillein, Heid, & Klinke, 2001; Sharma, Dorman, & Spahr, 2002). For children with ANSD, auditory brainstem response (ABR) thresholds may differ significantly from behavioral hearing thresholds, therefore, hearing aid recommendations and adjustments should be based on behavioral audiological assessment results as soon as possible (Hayes, 2008), combined with careful observation of the child's hearing responses in everyday situations (Feirn et al., 2013). Cochlear implant (CI) surgery is also recommended for ANSD in children who are not making satisfactory auditory progress with conventional amplification; however, there is uncertainty about outcomes in cases of cochlear nerve deficiency (Breneman, Gifford, & DeJong, 2012; Buchman et al., 2006). Furthermore, it has been suggested that the site of lesion and the characteristics of pre and postsynaptic forms of ANSD may influence speech perception outcomes (Dimitrijevic et al., 2011). There is some evidence to suggest that electrophysiological tests such as auditory cortical measures might help differentiate between pre- and postsynaptic disorders and provide a better understanding of the differences in speech understanding in individuals with ANSD (Dimitrijevic et al., 2011; Santarelli, 2010).

There is considerable heterogeneity with respect to the severity of clinical manifestations and the benefit from hearing technology and different aural rehabilitation options in patients with ANSD (Pelosi et al., 2013; Roush, Frymark, Venediktov, & Wang, 2011). Given the prevalence and early diagnosis of ANSD in children, it is important to achieve a better understanding of management issues and potential outcomes for these children. The objective of this study was to characterize the clinical profiles and the audiological management and communication development outcomes of children with ANSD followed through a provincial universal newborn hearing screening (UNHS) program in one region of Canada from 2003-2013.

Methods

Population-based data were collected at the Children's Hospital of Eastern Ontario (CHEO), Ottawa, Canada between 2003 and 2013 for children diagnosed with ANSD. The hospital is the diagnostic centre for the region's provincially mandated UNHS program established in 2002. Children underwent newborn hearing screening and audiologic assessment following well-established provincial protocols. Screening protocols established by the province involved a two-stage screen for well-babies where the initial screen typically carried out in hospital involved Automated Otoacoustic Emissions screening (AOAE) followed by Automated Auditory Brainstem Response screening (AABR) when there is a refer result from the AOAE. However, babies deemed to be at risk for hearing loss, such as those in the NICU were screened with AABR and then referred for audiological assessment when a refer result was obtained (Hyde, 2005). Consistent with provincial protocols, infants with known risk indicators for hearing loss were placed on a surveillance list and followed to age 30 months. The audiological assessment consisted of a comprehensive test battery with well-defined protocols for neonates and young children and included frequency-specific ABR, a click ABR sub-protocol when ANSD was suspected, OAEs, and immittance testing (Hyde, 2005). Children identified with permanent hearing loss were referred to otolaryngology for further medical evaluation.

All children identified with permanent hearing loss received audiological management services including amplification, if indicated, and auditory rehabilitation through the hospital. Children with ANSD were managed similarly to children with SNHL and were initially fitted with hearing aids once a hearing disorder was confirmed. Children with ANSD who derived little benefit from amplification, that is, they showed limited progress in auditory and communicative functioning, were considered for cochlear implants and underwent a comprehensive candidacy assessment. In the clinical program, children with ANSD are considered for cochlear implants even if their audiometric thresholds are outside the typical range of cochlear implant candidacy of severe to profound hearing loss.

Clinical audiological data related to age of diagnosis, etiology, risk indicators, and other clinical characteristics and hearing technology information were collected prospectively as part of a database on all children identified since the implementation of UNHS in 2002. A total of 22 patients included in this database met the diagnostic criteria based on well-defined clinical profiles of ANSD (Feirn et al., 2013; Northern, 2008). Detailed audiological information (e.g. audiograms) and communication outcomes were extracted retrospectively through chart reviews, specifically for this study. This study was approved by the institutional review boards of the CHEO and University of Ottawa.

Clinical Assessment Procedures. Typical clinical protocols for these children were followed and included regular audiological assessments of speech perception

and communication development testing. Because speech perception abilities are age dependent and influenced by vocabulary and language levels, tests were selected clinically, based on the child's developmental level. Formal assessment tools are listed below and included speech perception measures, parent questionnaires, and language tests:

Speech perception measures

- Phonetically Balanced Kindergarten-PBK (Haskins, 1949) open-set monosyllabic word test.
- Hearing in Noise Test for Children-HINT-C (Nilsson, Soli, & Gelnett, 1996) open-set sentence test.
- Early Speech Perception Test-ESP (Moog & Geers, 1990) closed-set test; child points to picture from a set of 12 pictures.

Parent auditory questionnaires

- Infant Toddler Meaningful Auditory Integration Scale-IT-MAIS (Zimmerman-Phillips, Robbins, & Osberger, 2001) – a 10-item questionnaire administered in interview format to parents to probe the child's auditory function in his/her everyday environment in three areas: 1) vocalization behavior, 2) alerting to sound, and 3) deriving meaning from sound.
- Parents' Evaluation of Aural/Oral Performance of Children-PEACH (Ching & Hill, 2007) – a parent questionnaire that measures functional communication in real-world environments.

Language Measures

- Peabody Picture Vocabulary Test-PPVT (Dunn & Dunn, 2007) a measure of receptive vocabulary.
- Preschool Language Scale-PLS-4, (Zimmerman, Steiner, & Pond, 2002) – a measure of both auditory comprehension (receptive language) and expressive communication.

Results

Figure 1 shows the study selection process for the children with ANSD. A total of 418 children were identified with permanent hearing loss from 2003 to 2013, 22 (5.3%) of whom presented with ANSD.

Clinical profile of children with ANSD. Table 1 shows details of the clinical characteristics for the children with ANSD. The majority (90.9%) underwent neonatal hearing screening and 15 (75.0%) of these patients received a 'refer' result while the remaining 5 (25.0%) had a 'pass' status. The sample was predominantly male (77.3%). As shown, more than two-thirds (68.2%) of the children were diagnosed with



Figure 1. election of study participants HL: hearing loss; ANSD: auditory neuropathy spectrum disorder

congenital or early onset (< 6 months) ANSD. More than 60% showed at least one risk factor, as defined by the Joint Committee on Infant Hearing (JCIH, 2007). Notably, 86.7% of these children were NICU graduates and the gestational age was less than 36 weeks for 54.5% of children. Table 1 shows the severity of hearing loss at diagnosis, which was calculated based on the three-frequency (500, 1000, 2000 Hz) pure tone average (PTA). Nineteen (86.4%) children showed moderate or greater hearing loss (>40dB HL) with 59.1% of them having severe or profound hearing levels. All but one child had bilateral ANSD. The majority of the children (86.4%) had symmetrical hearing loss (defined as <20dB HL difference between thresholds in each ear). Some children experienced fluctuating hearing loss (5/22) or deterioration in hearing thresholds over time (6/22).

Hearing technology management. The median age of diagnosis of ANSD for the 22 children was 7.5 months (Interquartile range [IQR]: 4.7, 22.5). Nineteen children (86.4%) were initially fitted with hearing aids and one patient was fit with a Frequency Modulation (FM) system for a trial period. Two children were not fitted with hearing aids due to complex medical issues and developmental delays. Initial fitting of amplification occurred at a median age of 17.3 months (IQR: 12.1, 26.6). The status of current hearing technology for the 22 children is shown in Figure 2. Seven children with bilateral ANSD who were fitted with hearing aids are currently using them. Although two of these children had audiometric thresholds consistent with profound hearing loss, they achieved open-set monosyllabic word scores of 56% and 84% (Table 2), placing them outside the typical criteria for cochlear implants. One child with unilateral profound hearing loss discontinued using amplification (FM system).

More than half of the group underwent CI surgery (n=12) at a median age of 26.4 months (IQR: 18.0, 47.3). Six of these children received cochlear implants within 12 months of hearing loss identification, while three showed deterioration in audiometric levels over time and the remaining three likely experienced delays in cochlear implantation associated with other medical/developmental issues.

Auditory and communication development. Table 2 shows the best score achieved on clinical speech perception evaluations for the seven children with hearing aids. Age-appropriate speech perception testing was performed preoperatively and repeated at multiple intervals postoperatively. The evaluations reported, based on best score in the medical chart, were completed between 11 months and 60 months of amplification use. As noted previously, outcome measures included direct assessments of children and questionnaires administered to parents when children were unable to complete formal speech perception tests. As shown, five of seven were able to complete open set tests (PBK or HINT) and one of seven completed the IT-MAIS. One child using hearing aids could not complete formal speech perception tests, therefore only aided thresholds were available. As detailed in Table 2, the variability in children's auditory abilities is reflected in the scores, which ranged from 80% on the IT-MAIS to scores between 50% and 96% on the open-set PBK word test.

Table 1. Clinical characteristics of 22 children

Characteristic		n (%)
Sex		
	Male	17 (77.3)
	Female	5 (22.7)
Screening outcome		
Notscreened		2 (9.1)
Screened		20 (90.9)
	Refer	15 (75.0)
	Pass	5 (25.0)
Gestational status		
	Premature	12 (54.5)
	Full-term	10 (45.5)
Onset of hearing loss		
	Congenital	7 (31.8)
	Early	8 (36.4)
	Late	7 (31.8)
Risk indicators		
Norisks		7(31.8)
Risk		15 (68.2)
	NICU	13 (59.2)
	Familyrisk	1 (4.5)
	Syndromes	1 (4.5)
Degree HL - PTA (better ear)		
	Within normal limits	1 (4.5)
	Mild	2 (9.1)
	Moderate	2 (9.1)
	Moderate-severe	4 (18.2)
	Severe	2 (9.1)
	Profound	11 (50.0)
Hearing loss profile		
	Bilateral	21 (95.5)
	Unilateral	1 (4.5)
	Stable	11 (50.0)
	Fluctuation/inconsistent	5 (22.7)
	Deterioration ≥20dB	6 (27.3)
	Symmetric	19 (86.4)
	Asymmetric	3 (13.6)

NICU: neonatal intensive care unit; PTA: pure-tone average; HL: hearing loss



Figure 2. Hearing technology management for children with ANSD ANSD: auditory neuropathy spectrum disorder; CI: cochlear implant HA: hearing aid

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Child number	PTA unaided (R/L, dB)	Duration HA use (months)	Last PTA aided (R/L, dB)	Test	Best score (%)
1	40/60	55	25/25	PBK w	96
4	35/45	11	15/15	PBK w	92
16	95/NR	NA	CNT	PBK w	50
22	95/95	84	CNT	PBK w	84
19	40/45	60	20/20	HINT	88
9	NR/NR	96	30/30	IT-MAIS	80
10	75/NR	NA	50/30	CNT	CNT

PTA: threshold at 0.5, 1 and 2kHz; HA: hearing aid; dB: decibel; PKA: Phonetically-Balanced Kindergaten (PBK words); HINT: Hearing in Noise Test; IT-MAIS: Infant-Toddler Meaningful Auditory Integration Scale; CNT: could not test; R: right; L: left; NR: No response; NA: not available

Child number	PTA unaided ¹ (R/L, dB)	Age at Cl	Duration of CI use (months)	Bilateral CI / Unilateral CI	Test	Best score ² (%)
6	113/113	25m	36m	UCI	HINT	100
5	100/102	11m	48m	UCI	HINT	98
20	110/102	31m	3m	UCI	HINT	98
8	92/87	55m	34m	UCI	PBK w	92
14	85/80	51m	3m	BCI	PBK w	96
15	75/78	15m	36m	UCI	PBK w	88
18	95/88	18m	48m	BCI	PBK w	88
11	95/95	54m	41m	BCI	ESP	100
12	87/90	19m	17m	UCI	ESP	88
2	120/120	11m	1m	UCI	PEACH	100
7	80/110	29m	7m	UCI	PEACH	100
17	115/110	18m	NA	UCI	CNT	CNT

Table 3. Speech perception outcomes for cochlear implant group

PTA: threshold at 0.5, 1 and 2kHz; CI: cochlear implant; dB: decibel; PKA: Phonetically-Balanced Kindergaten (PBK words); HINT: Hearing in Noise Test; IT-MAIS: Infant-Toddler Meaningful Auditory Integration Scale; CNT: could not test; R: right; L: left; NR: No response; NA: not available

Table 3 summarizes auditory performance for children with CI and shows the best score achieved on speech understanding (direct measurement or parent questionnaire). Cochlear implant use ranged from 1 to 48 months. These children obtained detection levels after implantation between 15 and 30 dB HL. Speech perception outcomes varied greatly from one child to another. As shown, 7 of 12 children were able to complete open-set speech perception tests (HINT or PBK word), achieving scores ranging from 88% to 100%. Two children (#11 and #12) could only complete closed-set testing and two others (#2 and #7) had only parent questionnaire scores. Child #2 was too young to complete speech perception testing (< 1 year of age) and child #7 was unable to complete testing due to severity of disabilities.

Communication development outcomes are presented in Table 4 for all children. As indicated previously, children had received various speech-language assessments depending on their level of functioning, therefore scores were summarized to reflect the child's overall functioning. Test results were not available for seven children because they received rehabilitation in other centers. For the 15 children followed locally, 6 (35.3%) obtained scores on standardized assessments comparable to those expected for typically developing children and another seven had severe language delays. The remaining two children were within the moderate range of delay in language. Of the seven with severe delay, six presented complex medical issues and developmental delay.

Outcomes	НА	CI	No amplification
Within normal limits	3	3	-
Moderate delay	-	2	-
Severe delay	2	3	2
No local follow up	2	4	1

Table 4. Communication development outcomes for children with ANSD

HA: hearing aid: CI: cochlear implant

Discussion

We described the characteristics of a cohort of children who were identified with ANSD since the implementation of a UNHS program. Prevalence rates of ANSD in this study were 5.3% of children with permanent hearing loss, which is consistent with international reports (Bielecki, Horbulewicz, & Wolan, 2012; Madden et al., 2002; Rance, 2005). It is important to note that prevalence rate can be underestimated in clinical practice because children can be missed when otoacoustic emissions screening is carried out.

In our cohort, we found that there were substantially more males with ANSD, however, Sininger and Starr (2001) state that ANSD shows no difference in the number of boys and girls affected. In our study, more than 50.0% of children were <36 weeks gestation age, a finding consistent with Teagle et al. (2010) who reported prematurity in over 40% of cases with ANSD.

Our findings showed primarily early onset ANSD, corroborating the findings of several other investigators (Berlin, Morlet, & Hood, 2003; Sininger & Oba, 2001). Both genetic factors and conditions in the neonatal period including asphyxia, ototoxic drug exposure, hyperbilirubinemia, neuroinfections, and intraventricular hemorrhage have been reported to be associated with ANSD (Bielecki, Horbulewicz, & Wolan, 2011; Martinez-Cruz, Poblano, & Fernandez-Carrocera, 2008). A close examination of these specific neonatal indicators was beyond the scope of this study. However, based on the JCIH (2007) risk indicators for hearing loss recorded in our database for these children, we documented that 68.2% of patients showed risk indicators, with NICU being the most frequent risk condition. This finding is consistent with several other reports (JCIH, 2007; Rance, 2005; Teagle et al., 2010). ANSD may also occur in association with other syndromes or neurologic pathologies (Raveh, Buller, Badrana, & Attias, 2007) and family history of hearing loss (JCIH, 2007).

The majority (59.2%) of ANSD occurred in babies from the NICU with the remaining in well-babies. These findings are similar to other reports that also found that a substantial number of children with ANSD had risk factors related to NICU admission (Dowley et al., 2009; Sanyelbhaa Talaat, Kabel, Samy, & Elbadry, 2009). Korver, van Zanten, Meuwese-Jongejeugd, van Straaten, and Oudesluys-Murphy (2012) concluded that ANSD is likely more common in the well-baby population but that with current screening techniques, some children go undiagnosed. In the absence of screening using ABR, it is likely that some infants in the well-baby nursery will be missed through screening (Hayes, 2008).

Because of the many possible sites of dysfunction resulting in a diagnosis of ANSD (e.g., inner hair cells, synapse, auditory nerve), audiological profiles have been reported to be highly variable (Norrix & Velenovsky, 2014). Patients with auditory dyssynchrony have a wide range of hearing losses from normal to profound, as documented in several studies (Rance et al., 2007; Sininger & Oba, 2001). Similar to the conclusion from 16 studies reviewed by Roush et al. (2011), our study found that the majority of children had audiological results in the severe-profound range. Consistent with other research (Humphriss et al., 2013), our study showed that more than half of children showed variation in audiometric thresholds over time. All but one child in our cohort had bilateral ANSD, which is aligned with the results reported in larger studies (Berlin et al., 2010; Bielecki et al., 2012; Sanyelbhaa Talaat et al., 2009).

Previous research has shown that ANSD in many children can be associated with co-morbidities such as developmental delays, learning disabilities, attention deficit disorder, autism spectrum disorders, blindness, cerebral palsy, and motor disorders (Ching et al., 2013; Kirkim et al., 2008; Pelosi et al., 2013; Shallop, 2008; Uhler et al., 2012). These complexities can delay early diagnosis. More than 30.0% (7/22) of children in our study cohort had other disabilities which likely accounted for the average age of diagnosis of over one year (range 0.16 - 49.2 months). This is in contrast to the Ching et al. (2013) study that showed an early diagnosis of ANSD at an average age of 3.3 months.

There is increasing evidence that a substantial number of children with ANSD benefit from hearing aid fitting. ANSD guidelines (Feirn et al., 2013; Northern, 2008) recommend that amplification should be fitted as soon as ear-specific elevated pure-tone and speech detection thresholds are demonstrated by behavioral test procedures. By definition, the presence of otoacoustic emissions in ANSD suggests normal cochlear outer hair cell function and a subset of ANSD patients may exhibit neuromaturation, whereby ABR develops with age (Madden et al., 2002), thus a trial with hearing aids has been recommended as a primary management strategy (Clarin, 2014; Feirn et al., 2013). This study found that there was considerable improvement in aided thresholds and that the majority of children developed auditory skills. However, the literature is quite mixed with some studies showing improvement in speech perception (Roush et al., 2011) and others showing limited improvement in speech perception ability with hearing aids (Berlin et al, 2010; Rance, 2005). Like pure-tone thresholds, speech perception ability can be variable in this population and is difficult to predict from the pure-tone audiogram (Starr, Picton, Sininger, Hood, & Berlin, 1996). Our results for the group of children with hearing aids were not markedly different from those with CIs, pointing to the importance of a well-managed trial period with hearing aids for these children as recommended by Clarin (2014). In our study, the majority of children without other severe disabilities developed their auditory abilities, a finding that is supported by recent research by Ching et al. (2013) in a population-based study examining outcomes in children with hearing loss. That study showed that the presence of additional disabilities was a significant predictor of outcomes at age 3 years for children with hearing loss.

In our study, while almost all children were initially fitted with amplification, an examination of age of fitting showed that almost all received hearing devices after the typical recommended age of 6 months (JCIH, 2007). While this is partly due to a later age of diagnosis, the delay in amplification may also be explained by the characteristics of ANSD. Because ABR results for children with ANSD do not provide a valid estimate of behavioral thresholds, amplification decisions for these children can be challenging. Early hearing aid fitting for these children is highly dependent on reliable behavioral thresholds (Feirn et al., 2013; Norrix & Velenovsky, 2014). Some children with ANSD require more time for threshold determination (Cardon & Sharma, 2011) due to disabilities or medical conditions that include developmental delay. There is also evidence that, like the general population of children with permanent hearing loss, hearing may not initially be the first priority for parents of children who present other medical issues and/or a stormy neonatal course (Uus, Young, & Day, 2012).

Although conventional hearing aids improve sound audibility, there is research showing that they may not resolve temporal processing deficits in some children with ANSD (Rance & Barker, 2009). Some children may not experience the same benefits from hearing aids expected from those with typical sensorineural loss in whom temporal processing is relatively unaffected. This fundamental difference has implications for management and has led to discussions about the best option for affected children (Roush et al., 2011). In our cohort, all children who received CIs had severe to profound hearing loss, however, some authors (Berlin et al., 2010; Breneman et al., 2012) have recommended that children with ANSD should be considered for CI regardless of pure-tone thresholds, particularly when there is poor progress in speech and language development despite amplification. It has been proposed that CI can improve auditory temporal processing by stimulating the synchronous discharge of the auditory nerve (Humphriss et al., 2013; Rance, 2005; Shallop, 2008). In a recent systematic review (Fernandes, Morettin, Yamaguti, Costa, & Bevilacqua, 2015), the authors concluded that there is no difference in the hearing skills of children with ANSD and SNHL who use CIs with respect to speech detection, discrimination, and recognition of words and sentences.

Our findings related to communication development of the 17 children followed in rehabilitation showed that six had communication outcomes within the range expected for typically developing children, with another two children showing moderate language delays. Budenz et al. (2013)

studied children with isolated auditory neuropathy who developed speech and language skills at a level commensurate with their peers who had SNHL and CIs. It is important to note that our study included all children with ANSD including those with an additional diagnosis of cognitive or developmental disorders. Other studies of children with CIs (Cruz et al., 2012; Edwards, 2007) who have SNHL with additional developmental disabilities have typically reported poorer speech and language development compared to children with hearing loss alone. Rance and Barker (2009) compared speech and language outcomes between three groups of children: 1) children with ANSD after CI implantation, 2) children with SNHL after cochlear implantation, and 3) children with ANSD with amplification alone. They found no significant difference between any of the groups on any measure of language development. More recently, in a group of 47 early-identified children, Ching et al. (2013) found there was no significant difference in performance levels or variability between children with and without ANSD at age 3 years, both for children who used hearing aids and those who used CIs.

Our study adds to the growing understanding of the communication outcomes that can be expected from children with ANSD. Our work shows that more than 85.0% of children with ANSD were fitted with current hearing technology and achieved some degree of open-set speech recognition, while almost half either developed spoken language skills similar to their hearing peers or with moderate delays. Undoubtedly, there remain many questions about the management of these children, including the approaches that favor speech-language development, and how soon cochlear implantation should be recommended. Recent research suggests that electrophysiological measurements including electrocochleography (Santarelli, Starr, Michalewski, & Arslan, 2008) and cortical auditory evoked potentials may assist in characterizing auditory function and differences in speech recognition. These techniques may provide insight into the severity of the disorder and whether hearing aids are likely to be helpful (Cardon & Sharma, 2011; Neary & Lightfoot, 2012), which should assist with clinical decisionmaking for these children.

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Reflective Practice in Speech-Language Pathology: Relevance for Practice and Education

La pratique réflexive en orthophonie : pertinence pour la pratique et l'enseignement

KEY WORDS

REFLECTIVE PRACTICE SPEECH-LANGUAGE PATHOLOGY PROFESSIONAL KNOWLEDGE THEORY AND PRACTICE ETHICAL PRACTICE

PROFESSIONAL PRACTICE

Abstract

As a profession, speech-language pathology appears to have become interested in reflection and reflective practice as important components of clinical practice and education. However, little systematic consideration of the potential value of reflective practice within the field has been undertaken. The purpose of this paper seeks to consider how reflective practice is relevant to contemporary speech-language pathology practice. Drawing on comprehensive and diverse theoretical literature, we suggest that reflective practice is a framework worthy of consideration because of its potential to: (1) foster the generation of knowledge from practice, (2) balance and contextualize science with patient care, (3) facilitate the integration of theory and practice, (4) link evidence-based practice with clinical expertise, and finally, (5) contribute to the cultivation of ethical practice.

Abrégé

En tant que profession, l'orthophonie semble en être venue à s'intéresser à la réflexion et à la pratique réflexive comme composantes importantes de la pratique clinique et de l'enseignement. Toutefois, la valeur potentielle de la pratique réflexive a reçu peu de considération systématique dans le domaine. L'objectif de cette publication est de considérer la manière dont la pratique réflexive est pertinente à la pratique contemporaine de l'orthophonie. En nous appuyant sur une littérature théorique exhaustive et diverse, nous suggérons que la pratique réflexive est un cadre qui mérite d'être considéré étant donné son potentiel de : (1) promouvoir la génération de connaissances à partir de la pratique, (2) équilibrer et contextualiser les données scientifiques par rapport aux soins des patients, (3) faciliter l'intégration de la théorie et de la pratique, (4) lier la pratique basée sur les données probantes avec l'expertise clinique, et enfin, (5) contribuer à la culture d'une pratique éthique.

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Introduction

The profession of Speech-Language Pathology (S-LP) has become interested in the concept of reflection and reflective practice as an important component of clinical practice and education. Yet to date, reflective practice has not been widely examined in the S-LP scholarly literature and it has only recently begun to be studied in any meaningful way (Caty, Kinsella, & Doyle, 2009; Hill, Davidson, & Theodoros, 2012). A reflective approach may be required as a standard for licensing and registration or can be adopted as a teaching strategy to facilitate clinical education. What remains unclear behind the call for the adoption of reflective practice is the essential question of 'why'? The rationale for integrating reflective practice into S-LP is difficult to elucidate given that the systematic consideration of its potential value is only beginning to occur in the field. This raises the question: What does reflective practice potentially offer to the field of S-LP, and more specifically, what can it offer to the contemporary practice of speech-language pathologists? Given the growth of interest in and the adoption of reflective practice in other disciplines (Mann, Gordon, & MacLeod, 2009), as well as increased calls for attention to reflective practice in the S-LP profession (Geller & Foley, 2009a; Geller & Foley, 2009b; Hersh, 2010; Horton, 2004), an examination of its value to S-LP is needed. In this paper, the relevance of reflective practice to contemporary S-LP practice is examined in an effort to provide justification for its adoption in clinical practice and education.

Objective

The objective of this paper is to critically examine the potential relevance of reflective practice to the field of S-LP. In order to meet this objective, a brief portrait of contemporary S-LP, especially in health care settings, is provided. This is followed by a short overview and the central part of this paper- a critical analysis of reflective practice. Through this analysis we suggest that reflective practice has the potential to contribute to the S-LP field through its capacity to: (1) foster the generation of knowledge from practice, (2) balance and contextualize science and patient care, (3) facilitate the integration of theory and practice, (4) link evidence-based practice with clinical expertise, and finally, (5) contribute to the cultivation of ethical practice. As we explore these ideas, we believe that their relationship to the contemporary S-LP workplace and their inherent implications for clinical practice and education will become apparent.

Contemporary S-LP

The contemporary workplace for speech-language pathologists (S-LPs) is an ever-changing one that is driven by political, economical, social, and technological forces (Lubinski & Hudson, 2013). For example, within Canada's evolving health care system, there are current demands for increased efficiency, cost-effectiveness, and quality improvement (Health Council of Canada, 2013). With current cost-cutting measures, S-LPs find themselves with fewer resources to respond efficiently to increasingly growing demands. In other words, they are being asked to 'do more with less'. This calls for innovative approaches. Further, S-LP practitioners are facing increasing requirements related to accountability for their service and the need to prove to third-party payers, employers, and clients that their services are measurable and costeffective. This means that there are increasing demands for S-LPs to use methods that are derived from evidencebased studies and to document functional outcomes. As interprofessional collaborative patient-centred practice is recognized as necessary for improving the quality of patient care in Canada (Barrett, Curran, Glynn, & Godwin, 2007), another important issue facing today's S-LPs is the need to work effectively with other professionals across different settings. All clinicians must develop strategies for working collaboratively in multi-professional and multispecialty teams. These expanded collaborations and their additionally increasing demands, often driven by politicoeconomical forces, not only affect S-LPs' professional practice, but also the preparation of S-LP graduates.

Socio-demographic trends also contribute to the changing landscape of S-LPs' clinical work (Lubinski & Hudson, 2013). For example, as the composition of the Canadian population is changing steadily (Statistic Canada, 2014), S-LPs are required to provide responsive and sensitive services to caseloads from more culturally and linguistically diverse populations. Moreover, an aging population (Statistic Canada, 2015) demands increased levels of service delivery and escalating healthcare costs, putting pressure on S-LPs to change the manner in which they deliver services (Lubinski & Hudson, 2013). With older individuals presenting with a variety of chronic health conditions affecting their communication, cognition, and swallowing, S-LPs also face an increase in the complexity of needs for this population. Confronted with these socio-demographic changes, S-LPs must examine their own education and experience, and seek to upgrade their knowledge and skills as needed, in order to provide competent care to these growing populations.

As for advances in technology, access to the Internet, particularly telepractice, offer S-LPs the opportunity to provide assessment and intervention services to rural areas, but also to various parts of the world (Dudding, 2013). There is also greater use of online and distance continuing education for working S-LPs and similar online and distance support for students who are on placements in remote areas. Such uses of technology extend the transfer of clinical knowledge and have the potential to improve access and quality of S-LP services. These technological advances inevitably call for the development of new skill sets and expanded capabilities from S-LPs and graduates alike, in order to facilitate appropriate and high quality services to individuals with communication, cognitive, and swallowing disorders.

In sum, the clinical workplace for S-LPs is a complex, dynamic, and rapidly changing environment, necessitating the ability of students and practitioners to learn new skills quickly. Many of these skills must be learned independently through a process of constantly reflecting on one's practice and seeking new opportunities for learning. In such changing conditions, ethical issues also may arise as clinicians are faced with conflicting demands and contradictory situations. This may require negotiating with an existing institutional work ethic and environment that may be conflicting with one's professional and personal values (Kummer & Turner, 2011). Thus, clinicians and student entering the field of S-LP require even greater "preparation, tools, and awareness" (Rose & Best, 2005, p.348) in order to successfully cope with this changing workplace. We propose that such "preparation, tools, and awareness" (Rose & Best, 2005, p.348) may lie in the understanding and recognition of the importance of reflective practice to achieve effectiveness in a complex work environment. In the following section, reflective practice will be briefly presented.

Reflective Practice: An Overview

There are many different conceptualizations and ideas about what constitutes the theory of reflective practice, as well as its purposes and applications. In their systematic review of reflective practice in health professional education, Mann et al. (2009) offer a useful way of conceptualizing the different reflective models by distinguishing between those focusing on the iterative process of reflection (i.e., Boud, Keogh, & Walker, 1985; Schön, 1983; 1987) and those that identify different levels of reflection (i.e., Dewey, 1933; Hatton & Smith, 1995; Mezirow, 1991; Moon, 1999). More importantly, Mann et al. (2009) point out a common premise to these models: the examination of experience through deliberation resulting in learning, which guides future actions. In terms of purposes and applications, reflective practice has been described as having different roles. More directly, reflective practice may be viewed as a way to link theory and practice, generate theory about practice, better understand the conditions under which practitioners work, develop professional knowledge and expertise, and improve actions in professional practice (Bolton, 2005; Greenwood, 1998; Honor Society of Nursing, 2005; Johns & Freshwater, 2005; Kinsella, Caty, Ng, & Jenkins, 2012).

The origin of reflective practice lies in the seminal work of Donald Schön who was influenced by the earlier work of reflective theorists such as philosopher John Dewey (1933). Dewey (1933) defined reflection as "active, persistent, and careful consideration of any belief or supposed form of knowledge in light of the grounds that support it and further conclusions to which it tends" (p. 9). Schön (1983) introduced the 'reflective practitioner' as an individual who uses reflection to revisit experience in order to learn from it, and to frame the "messy and confusing problems" (Schön, 1987, p.3) found in professional practice (Kinsella, 2007; Schön, 1987). In his writings, Schön (1983; 1987) has explored the different sources of professional knowledge and inquired about the kind of 'knowing' with which competent practitioners engage. He describes reflective practice as a form of inquiry by which practitioners make connections between general knowledge and particular cases when faced with problematic situations (Schön, 1987). Essentially, Schön's (1983; 1987) theory of reflective practice draws attention to what practitioners learn through reflection on experience in the context of unique and complex professional practices and consequently, considers how knowledge relevant for practice is generated from this experience.

Schön posits that technical rationality (i.e. the application of scientific theory and technique to the instrumental problems of practice) is important for professional practice, but suggests that it has been overemphasized (Kinsella, 2007; 2010). He contends further that there is a complementary and different kind of knowledge embedded in competent professional practice. In Schon's view, there is an epistemology of practice¹ that is displayed "in the artistic, intuitive processes which some practitioners do bring to situations of uncertainty, instability, uniqueness, and value conflict" encountered in practice (Schön, 1983, p.49). In other words, when S-LPs reflect on "what to do" in such situations, they draw from a broad repertoire of knowledge built from experience that can lead to successful outcomes. Thus, reflective practice is the process of surfacing, examining, testing, and refining the kind of practical knowledge that may yield effective professional interventions and learning (Argyris & Schön, 1992; Schön, 1983).

Relevance of Reflective Practice for S-LP

Clearly many variables contribute to becoming an effective S-LP practitioner. Most S-LPs would agree that these include such things as a sound theoretical and scientific knowledge base across multiple disciplines and areas of study, as well as good technical skills. Moreover, no one would refute that being an effective practitioner also requires the capacity to successfully manage complex contextual situations that arise in practice and to exhibit the requisite interpersonal skills that will occur as part of therapeutic practice. Therefore, we propose that reflective practice is important for S-LPs, and for the S-LP profession, because it offers opportunities for enhancing effectiveness in professional practice. We contend that reflective practice has the potential to directly influence S-LP practice in at least five ways. The areas of practice that are influenced by reflection include the practitioner's ability to: generate knowledge from practice, balance and contextualize science with patient care, integrate theory and practice, link evidence-based practice and clinical expertise, and cultivate ethically guided practice. Each of these critical areas will be addressed in the sections to follow.

Generating Knowledge from Practice

Reflective practice draws attention to the ways in which knowledge is generated through reflection on practice experience. For example, reflection on clinical situations, relationships, or organizational issues encountered in the workplace are potential sources of professional learning that become integrated into a practitioner's repertoire of knowledge, or 'practice-based evidence' (Gabbay & le May, 2011). Schön (1983, 1987) contends that the practitioner's everyday performance depends to a significant extent on knowledge derived from reflection on informal experiences in workplace. He posits an "epistemology of practice" in which professional knowledge is developed from the practitioner's process of "making sense of their professional experience" (Richardson, Higgs, & Abrandt Dahlgren, 2004, p.8). Further, one's epistemology is "revealed in the pragmatic competencies reflected in practitioner action" (Kinsella, 2007, p.105).

A number of scholars contend that professional knowledge gained through reflection on professional practice experience remains underutilized in the contemporary health care system (Beecham, 2004;

Gabbay & le May, 2011; Higgs, Titchen, & Neville, 2001; Kinsella, 2010). For instance, Gabbay and le May (2011) have called for greater attention to the ways in which practicebased knowledge is generated and how it ultimately contributes to professional practice. Others have suggested that it is important to make the tacit knowledge that informs professional practice explicit (Higgs, Richardson, & Dahlgren, 2004; Higgs & Titchen, 2001) and to contribute to disciplinary knowledge bases by sharing such knowledge in collective forms (Kinsella & Whiteford, 2009). In S-LP, such discussions are only beginning to occur. Beecham (2004) has directly suggested that it is urgent for S-LP as a profession to "understand what we do in practice; and that this needs to be theorized" (p.133). She argues that this is important because "without understanding, as a profession, what it is that we do, and why we do it, we will be subject to the enthusiasms and counter-enthusiasm of groups of therapists/academics owning different understandings of practice" (Beecham, 2004, p.133). In addition, the knowledge generated through reflection on practice is information that is important to explicitly share with students and less experienced practitioners; doing so serves as a potential contributor to effective decisionmaking in practice and supports the extension of students' knowledge (Dollaghan, 2007; Titchen & Ersser, 2001; van der Gaag & Anderson, 2005). Finally, attending to the significance of and making explicit the various forms of professional knowledge that inform clinical decision-making is important for interprofessional collaboration in that it enables communication amongst team members relative to the rationale for pursuing actions to meet the client's needs (van der Gaag & Anderson, 2005).

In sum, reflective practice has the potential to contribute to not only the individual practitioner's repertoire of knowledge relevant to practice, but to the profession. Indeed, if information gleaned from reflection is made explicit and considered collectively, it has the capacity to generate disciplinary knowledge that can continually serve the profession of S-LP. The knowledge generated through practice is also suggested to be of importance to efforts toward interprofessional collaboration in the context of clinical service provision.

Balancing and Contextualizing Science with Patient Care

In writing about the crisis of care in the helping profession, Swaby-Ellis (1994), a paediatrician, writes that: "[b]alancing the responsibilities of effectiveness, efficiency, and empathy will never be an easy task" (p. 94). In the same vein, Beecham (2005) and, more recently, Roulstone (2011) remind us that the S-LP profession faces diverse challenges

from dual commitments of being a scientifically-based profession, as well as a helping one. As outlined in Speech-Language and Audiology Canada (SAC, formerly CASLPA) Code of Ethics (2005), S-LPs strive for high standards by providing professional services and information that are supported through current scientific and professional research. They also hold in esteem the values of caring and respect in their daily professional practice (SAC, 2005); thus, S-LPs place importance upon building a positive helping relationship within the clinical encounter (Beecham, 2004). Given the dual commitments as a 'scientist' profession and a 'helping' profession, balancing sound discipline-specific knowledge with the capacity to manage the contextual and interpersonal aspects of clinical service provision is required for effective day-to-day S-LP practice (Hinckley, 2010). Nonetheless, coursework in S-LP has not always reflected both commitments. Historically, the focus on discipline-specific knowledge about normal and disordered speech, language, voice, swallowing, and communication processes has resulted in little information being shared about the special characteristics and processes of working with individuals with communication disorders and their families (Shahmoon-Shanok & Geller, 2009). Within the discipline-specific education of S-LPs, knowledge that is more relational, reflective, and experiential in nature has typically not been directly addressed (Beecham, 2004; Cruice, 2005; McAllister, 2005; Shahmoon-Shanok & Geller, 2009). According to Beecham (2004) an emphasis on rules and the application of procedures derived from discipline-specific knowledge can result in a narrowed and somewhat circular gaze by the practitioner on the nature of a person's communication disorder. This gaze may not permit the practitioner to appreciate and balance the helping relationship formed between a practitioner and client and the measurable symptoms of communicative breakdowns exhibited by this client-both of which underlie the S-LP clinical encounter (Beecham, 2004; 2005).

Several authors, such as Taylor (2008), have begun to emphasize that a caring and empathetic practitioner responds effectively to the interpersonal needs of their clients and his/her family. Reflective practice and the learning that occurs through reflective processes have the potential to allow practitioners to attend to such affective and relational dimensions that frequently occur in clinical encounters and to develop a repertoire of appropriate ways to respond to challenging interpersonal situations. In the midst of delicate interpersonal interactions, such as in a context of cross-cultural communication or discussing the clinical diagnosis, the interpersonal knowledge base derived from reflection on the therapeutical relationship can contribute to the artfulness of selecting appropriate attitudes, tone, and words. Taylor (2008) suggests that such ways of responding can reduce practitioner and patient anxiety, allow for the sharing of critical information, and support clients in feeling that they are both cared for and respected as individuals. Indeed, reflective practice encourages practitioners to continually learn through reflection on their relational encounters in practice. This would include those related to affective, emotional, and inter-subjective domains of one's practice, as well as those of more traditional domains such as speech, language, and general communication processes. In this way reflective practice may contribute to a more humanistic and flexible approach to care, and in doing so, assist practitioners to engage in a reflective dialogue with the patient and his/her family members to foster improved communication.

In sum, effective S-LP practice can potentially be strengthened by blending several types of knowledge. Bringing together scientific knowledge with knowledge derived from reflection on the care of the client, mitigates the risk of practitioners applying an approach that does not fit the unique needs of clients. This issue is of current relevance as the S-LP profession gives more attention to the 'clinician effects' such as their ability to create therapeutic alliances with clients (e.g., Bernstein Ratner, 2005; Manning, 2010), and to person-centeredness in determining outcomes of intervention (e.g., DiLollo & Favreau, 2010; O'Halloran, Hersh, Laplante-Lévesque, & Worrall, 2010). Reflective practice offers the practitioner the potential to consider the unique relational, contextual, and emotional needs of the client and family while simultaneously seeking to balance and contextualize these concerns with the scientific approaches to practice.

Integrating Theory and Practice

Supervisees and supervisors alike often perceive a lack of coherence between the theoretical knowledge they learn as part of their professional education and what is expected from them in practice (Carozza, 2011). This has classically been described as the *theory-practice gap* (Allmark, 1995). This gap has been widely documented and referred to, most notably in the nursing professional education literature (e.g., de Swardt, du Toit, & Botha, 2012; Gallagher, 2004; Hatlevik, 2012; Rafferty, Allcock, & Lathlean, 1996). In S-LP, Ferguson (2007) has identified the theory-practice gap as one of the most prevalent challenges for professional education. The transfer of theoretical knowledge to a workplace setting is not a straightforward undertaking, in part because of differences in context, cultures, and modes of learning (Eraut, 1994), and in another, because of the different forms of knowledge required for professional practice (Higgs et al., 2001). This gap is also confounded by the reality that no two patients are the same and that the most advanced clinical service requires the ability to adapt, adjust, and seize emergent therapeutic opportunities when they occur.

An underlying assumption of the theory-practice gap is that theory² can transfer into practice in a straightforward manner. More directly, this underlying premise assumes that the language of abstract theoretical knowledge articulates precisely with that of clinical experience (Gallagher, 2004; Rafferty et al., 1996). Such a view, however, underestimates the dynamic and contextually-bound nature of practice situations. While effective practice needs to be informed by formal theory, the complex and ever changing nature of practice also necessitates the development and understanding of other kinds of theories relevant for professional practice (Eraut, 1994; Higgs et al., 2001; Kinsella, 2007). For instance, through reflective practice, practitioners develop theories of action (Argyris & Schön, 1992), or private theories (Eraut, 1994), those derived from lived experience that can then inform professional practice.

Argyris and Schön (1992) have suggested that professional effectiveness involves practitioner theories of action, which are comprised of what they refer to as *theories-in-use* and *espoused theories*. They contend that the theories-in-use which practitioners use in everyday practice are revealed in practitioners' actions and behaviours- for the most part, these are tacit and unconscious. Espoused theories, on the other hand, are more explicit and represent what practitioners' say about what they believe about practice; they represent the conscious theories that practitioners hold.

Both theories-in-use and espoused theories may be seen to correspond with what Eraut (1994) has referred to as "private theories" (p.59). Eraut (1994) contrasts "private theories", or "ideas in people's minds which they use to interpret or explain experience" (p.59), with "publicly available theories" or "systems of ideas published in books, discussed in class, and accompanied by a critical literature which expands, interprets, and challenges their meaning and their validity." (p.59). According to Eraut (1994), putting public theories into use involves an interpretive effort that gives them a contextual and specific meaning; that is, it involves a process of theorizing on the part of the practitioner. This process of theorizing involves the practitioner reviewing, through reflection, his or her private theories in a dialectical manner with publicly available theories (Eraut, 1994). From this perspective, the reflective practitioner is viewed as a theorist of his/her own practice

and individual decision-making is a reality of practice based on experience and knowledge. But, when other levels of consideration and discussion through social reflection specific to decision making are possible, it will likely enhance future practice and the practioner's private theories. This collective point of view further posits reflective practice as an important vehicle through which publicly available theories are mediated through practitioner's private theories to shape action in professional practice.

Along similar lines, Hartlevik (2012) noted that reflective skills act as a mediator between one's practical skills and theoretical knowledge, thus, contributing to practitioners' perception of coherence between the two. Similarly, de Swardt et al. (2012) noted that guided reflection appeared to assist in clarifying theoretical and practical experiences and subsequently facilitated understanding of the connection between the two. In other words, new clinical learning derived from guided reflection becomes assimilated into one's repertoire of active knowledge. The supervision process in S-LP offers many opportunities for engaging in such reflective learning.³ In sum, by serving as a mediating vehicle between abstract theory and the particulars of unique clinical situations, reflective practice has the potential to facilitate integration between both the theoretical and practical components of clinical experiences and ultimately contributes to the development of professional expertise (Benner, Tanner, & Chesla, 2009; Dreyfus & Dreyfus, 1986a).

Linking Evidence-Based Practice and Clinical Expertise

For over two decades, the evidence-based practice movement has devoted considerable effort to making research evidence accessible, available, and transferrable to clinical practitioners. Recently, a greater emphasis has been placed on the need to integrate practitioners' clinical expertise with research evidence (Graham et al., 2006; Greenhalgh & Wieringa, 2011). In S-LP, Roulstone (2011) has argued that research evidence and expertise are both required for evidence-based practice to occur. Reflective practice is essential in the development of expertise (Benner, 2001) and, therefore, may have direct implications for S-LPs in fostering the judicious use of research evidence.

Originating from a group of physicians and medical educators at McMaster University, the evidence-based practice movement arose from the need for physicians to easily access evidence for clinical decisions while caring for patients (Evidence-Based Medicine Working Group, 1992; Sackett & Rosenberg, 1995). Evidence-based health care was originally defined by its proponents as "the conscientious, explicit, and judicious use of current best external evidence [i.e., from systematic research/clinically relevant research] in making decisions about the care of individual patients" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p.71). A systematic approach to evidencebased care was articulated along the following lines: (1) transform information need into a question, (2) search relevant information, (3) critically appraise the information found, (4) apply the findings of the search, and (5) evaluate and assess the outcomes (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). A later description of evidence-based care integrated the best external evidence together with individual clinical expertise and consideration of patients' preferences and values (Guyatt, Meade, Jaeschke, Cook, & Haynes, 2000; Sackett et al., 2000).

In practice however, this new description notwithstanding, the emphasis in "evidence-based" approaches remains primarily on scientific research evidence that focuses on levels of evidence, research literacy, and the critical appraisal of scientific literature. Yet as Sackett, one of the originators of the term points out, "even excellent external evidence may be inapplicable to or inappropriate for an individual patient" (Sackett et al., 2000, p.72). In the context of S-LP, a primary focus on external evidence without reflection in and on practice might be seen to entail risks. In this vein, Dollaghan (2007) contends that the emphasis on scientific or external evidence has overshadowed the consideration of clinical expertise. Sackett et al. (1996) have cautioned that "neither alone is enough" (p.72). Without current best evidence "practice risks becoming rapidly out of date", and without clinical expertise "practice risks becoming tyrannized by external research evidence" (Sackett et al., 1996, p.72). A lack of balance between evidence and reflection on clinical experience (which informs clinical expertise) has the potential to result in ineffective and inappropriate care for patients.

Sackett et al. (1996) state that "[e]xternal clinical evidence can inform, but never replace, individual clinical expertise, and it is this expertise that decides whether the external evidence applies to the individual patient at all and, if so, how it should be integrated into clinical decisions" (p.72). This point is consistent with the rigour versus relevance dilemma which Schön (1983) notes practitioners face in their everyday work lives. Should practitioners rigorously apply external evidence in practice, even when it appears not to be working, or should they be concerned with relevant and useful actions in context, by reflecting on the situation in order to respond in creative and relevant ways? Despite the emphasis by Sackett et al. (1996), Dollaghan (2007) and others (e.g., Benner, 2001; Schön, 1987) on incorporating clinical expertise into evidencebased decision-making, this dimension of the evidencebased care movement has received little attention in the literature to date in S-LP.

In terms of discussions relating to clinical expertise, both Benner (2001) and Schön (1987) point out that practitioners require a capacity for reflection in order to develop their clinical expertise. Through such reflective effort, clinicians enhance their ability to respond in relevant ways in the midst of complex professional practices. The capacity to engage in reflection can contribute to S-LPs' professional expertise, inform their capacities to integrate external evidence into practice and respond to the complexities of practice and the needs of the clients. As a consequence of these actions, reflection may then serve to assist practitioners in negotiating the indeterminate zones of practice for which no clear trajectory of evidencebased outcomes exist (Dreyfus & Dreyfus, 1986b; Mamede, Schmidt, & Penaforte, 2008; Moulton, Regehr, Mylopoulos, & MacRae, 2007; Schön, 1987).

Cultivating Ethical Practice

Reflective practice also has a role to play in the cultivation of ethical practice in S-LP. Ethical practice has been defined as 'conscious consideration' of daily activities that enable practitioners to identify the values that lead to their decisions and further actions (Chabon & Morris, 2005). Ethical questions and opportunities for reflection about them occur in S-LP practice on an everyday basis (Chabon & Morris, 2005; Stewart, 2007). Therapists often reflect on questions such as: "What should I do?", "What is the right thing to do?", "Is this fair?". Unfortunately, choosing the 'right thing' or the 'fair thing' to do is not always easily achievable. Ethical codes of conduct, such as SAC's (2005), can provide guidance to help solve ethical issues, though such codes cannot and do not provide specific guidance for those 'grey' or complex ethical issues that occur in everyday practice (Eadie & Charland, 2005). Eadie and Charland (2005) state that "ethical decisions require consideration of a number of factors" and that "speech-language pathologists must not only follow their professional codes of ethics, but they must look beyond the rules and regulations and identify ethical elements within daily practice" (p.27). Ethical situations in clinical practice are complex and involve many layers that the process of reflection can presumably help to unveil.

According to Chabon and Morris (2005) and Stewart (2007), an ethically guided practice consists of one in which consideration is given to the values at stake in decision-

making and professional judgment (Chabon & Morris, 2005; Stewart, 2007). Reflection has been depicted as a means for the practitioner to become aware of distortions and errors in assumptions, and to uncover the values, interests, and normative standards that underpin them (Brookfield, 1990; 1995; Kinsella, 2001). Confronting unsettling situations that provoke discomfort in practice are recognized as an opportunity for reflection and ethical exploration (Chabon & Morris, 2005; Kinsella, Park, Appiagyei, Chang, & Chow, 2008; Nisker, 2004). Thus, reflection may be seen as being essential to the cultivation of ethically guided practice (Chabon & Morris, 2005; Stewart, 2007). In contrast, missed opportunities to reflect on these dimensions may result in decreased awareness of practitioner values and assumptions and how these will shape practice. This failure can also lead to misreading of ethical issues or miscalculations in ethical judgments and may then prevent practitioners from adequately thinking about and justifying their decisions and actions (Chabon & Morris, 2005). Reflection is, therefore, a critical action that has the potential to inform competent practice and permit ethical decisions to be made within each given clinical encounter.

In summary, the cultivation of an ethically guided practice requires a reflective approach which involves, but is not limited to, the ability to examine one's personal values and beliefs and assess how they impact one's actions in the workplace (van der Gaag & Mowles, 2005). Further, reflection provides an intrinsic resource for the practitioner to develop their capacity to understand particular contexts and relationships and the ethical issues that may arise from them (Eadie & Charland, 2005). Consequently, a reflective approach not only offers the potential for practitioners to identify the values that guide their decisions in practice, but also to inform their capacity for ethical reasoning and decision-making in everyday S-LP practice (Chabon, Morris, & Lemoncello, 2011; Kenny, Lincoln, & Balandin, 2007; 2010).

Conclusion

Reflective practice is a theory that attends to the centrality of practitioner experience in the generation of knowledge that is directly relevant to his or her practice. Although reflective practice has become recognized as an essential dimension in the development of professional expertise, and while research on it is beginning to emerge in other health care professions, it has yet to be integrated into the literature in any meaningful way in the field of S-LP. In this paper we have argued for the relevance and importance of reflective practice to contemporary S-LP practice. Today's S-LP workplace is a rapidly changing one, thus, necessitating the ability of practitioners to learn

new skills quickly. In this complex environment, ethical challenges also abound. Reflective practice offers a rich opportunity for learning in professional practice, as well as for developing knowledge that is essential to achieve effective and ethical practice in such a complex environment. In other words, reflective practice is critical to ensuring that the S-LP profession remains responsive to contemporary societal needs so as to ultimately achieve the best outcomes for the people it serves. In particular, it was argued that reflective practice has the potential to generate professional knowledge, balance and contextualize science with patient care, facilitate the integration of theory and practice, link evidence-based practice with expertise, and to cultivate ethical practice. Although further research is warranted, it is clear that reflective practice provide a rich framework that has the potential to advance professional practice and education in S-LP in a number of ways with benefits to not only the practitioner, but also to those whom the profession serves.

End notes

¹*Epistemology* is a term referring to how knowledge is constituted and which encompasses philosophical questioning about the origin, nature, and validity of knowledge (Finlay & Ballinger, 2006; Titchen & Ersser, 2001). Schön's *epistemology of practice* is a conception of knowledge that takes full account of the tacit knowledge or "knowing-in-action" making up the competence that practitioners sometimes display in complex clinical situations (Schön, 1995). In other words, this is critical knowledge that might not be captured in research results formulated in textbooks or published papers (Schön, 1995).

²For the purpose of this article, 'theory' refers to 'theoretical knowledge' which can be found in textbooks and which is typically taught through formal education activities.

³More details on how to facilitate reflection and the development of reflective skills in the context of supervision and clinical education can be found in the writings of Baird and Winter (2005), McAllister and Lincoln (2004), and Schaub-de Jong (2012), among others.

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Declaration of interest

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Authors' Note

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Language ENvironment Analysis (LENA) with children with hearing loss: A clinical pilot

Le système LENA (Language ENvironment Analysis) chez des enfants ayant une perte auditive : une étude clinique pilote

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Abstract

The provision of an enriched learning environment is widely advocated to facilitate language acquisition for children with hearing loss. In recent years the Language ENvironment Analysis (LENA) system was designed to collect information in a child's environment via a child-worn recording device, to acoustically analyze the listening/linguistic environment and to analyze variables such as child vocalizations, conversational turn taking, and adults words spoken to a child. This pilot study was undertaken in a clinical program to examine the feasibility of implementing the LENA system as part of the clinical program. Two full-day language recordings using the LENA device were collected for five children with hearing loss enrolled in a listening and spoken language program in a Canadian pediatric hospital. Overall, parents felt that the device was easy to use and that it could be incorporated into the home environment. Useful information was collected about the child's acoustic environment and about exposure to spoken language in the home. Based on the results of this pilot study, the LENA device has been implemented as a clinical tool to assist in coaching families about their child's learning environment.

Abrégé

L'apport d'un environnement d'apprentissage enrichi est largement préconisé pour faciliter l'acquisition du langage des enfants ayant une perte auditive. Au cours des dernières années, le système LENA (Language ENvironment Analysis) a été conçu pour recueillir des informations à propos de l'environnement d'un enfant par l'intermédiaire d'un appareil d'enregistrement qui est porté par l'enfant. Ce système permet d'analyser acoustiquement l'environnement d'écoute/ linguistique et d'analyser des variables, telles que les vocalisations de l'enfant, le tour de parole en conversation et les mots utilisés par les adultes avec l'enfant. Cette étude pilote a été amorcée dans un programme clinique pour examiner la faisabilité de l'implantation du système LENA dans ce programme. Le langage de cinq enfants ayant une perte auditive et qui étaient inscrits au programme d'écoute et de langage oral d'un hôpital pédiatrique canadien a été recueilli pendant deux journées complètes à l'aide de l'appareil LENA. Dans l'ensemble, les parents ont eu le sentiment que l'appareil était facile à utiliser et qu'il pourrait être incorporé dans l'environnement de la maison. Des informations utiles quant à l'environnement acoustique de l'enfant et son exposition au langage oral à la maison furent recueillies. À partir des résultats de cette étude pilote, l'appareil LENA a été implanté comme outil clinique afin d'encadrer les familles quant à l'environnement d'apprentissage de leur enfant.

LANGUAGE ENRICHMENT ANALYSIS CHILDREN HEARING LOSS LANGUAGE ACQUISITION LANGUAGE ASSESSMENT

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Introduction

Language sampling is widely used in clinical assessment and research programs for collecting information regarding a child's spontaneous speech and language in an unstructured environment. Language sampling typically involves eliciting one sample of a child's utterances over a short duration in a developmentally appropriate interaction. Formal language analyses typically require a sample of 100 continuous utterances that are judged to be representative of the child's expressive language. However, obtaining a typical language sample from a child during a speech-language pathology evaluation or intervention session can be a challenging task, and it is unclear if the sample collected is truly reflective of the child's language abilities. Various factors can interfere with obtaining a valid natural language sample including the presence of new people, unfamiliar surroundings, the materials used, the topic of conversation, as well as child factors such as fatigue and lack of interest.

Through an influential study that involved extensive and long-term language sampling in the home setting, Hart and Risley (1995) drew attention to the dramatic consequences that a young child's family and learning environment have on language acquisition. In their 3-year longitudinal study of 42 children, the investigators showed that children's verbal abilities were highly related to the amount their parents talked to them in the early years. Socio-economic status was also an important predictor of language abilities. Furthermore, at age 9 years, the academic abilities of children in this study were related to how much their parents talked to them in their first three years. In addition to these important findings, this study highlighted the value of collecting extensive language experiences in naturalistic environments.

In response to these findings, a new Language Environment Analysis system (LENA) was developed in 2004 through the LENA Foundation to help overcome some of the difficulties involved both in obtaining representative data from young children and in conducting detailed analyses of language samples (http://www.lenafoundation.org). The LENA system was specifically designed to allow data collection of continuous speech over an extended period in a natural environment for children ages two months to six years. Accordingly, the system offers a means of acquiring a more representative sample of a child's language abilities. The LENA system comprises two distinct components: the recording hardware and the processing software. The LENA Digital Language Processor (DLP) is a small, lightweight digital recorder that fits into the front pocket of specially designed LENA children's clothing and permits up to 16 hours of

audio recording. The recording is subsequently uploaded to a computer for processing through the language analysis software. The processing software analyzes the language environment and provides the user with numerical and graphical data. Details regarding the specific environmental and linguistic components that are analyzed are provided in the methods section of this paper. In addition to the different data analyses that the LENA software can provide, normative data are also available and allow for comparison of a given language sample with typically developing peers. Normative data based on 2,682 hours of recordings for children 2 to 48 months of age with normal hearing and typical development are available in a LENA Foundation technical report (Gilkerson & Richards, 2008).

LENA has been used in several applications to examine language acquisition including with pre-term infants (Caskey, Stephens, Tucker, & Vohr, 2011) and children with autism spectrum disorders (Dykstra et al., 2013; Oller et al., 2010; Xu, Gilkerson, Richards, Yapanal, & Gray, 2009). The system has been found to be useful in identifying important factors influencing language development (Xu et al., 2009; Zimmerman et al., 2009), and in providing feedback to parents (Suskind et al., 2013). These studies suggest that LENA helps parents learn more about their children's learning environment and their own spoken language interactions with their children.

Given the importance of the auditory learning environment for young children with hearing loss, who are developing spoken language, LENA recordings can potentially contribute important clinical information. Research examining the acoustic and linguistic environments with this population of children is beginning to emerge. Aragon and Yoshinaga-Itano (2012) used the LENA technology to examine the language environment of 10 children with hearing loss in Spanish-speaking homes in Colorado and to compare their environments to those of children with hearing loss in English-speaking homes as well as those with normal hearing in Spanish- and in English-speaking homes. These researchers showed that the learning environments for children with hearing loss from Spanish-speaking homes and normal hearing Englishspeaking children were relatively similar in terms of the LENA variables analyzed (e.g., child vocalizations, adults words, conversational turn taking) whereas children with normal hearing in Spanish-speaking homes had access to less language-rich learning environments. The authors suggested that the LENA system was useful in helping parents understand their child's access to language in realworld environments

In a study that compared adult input to 22 children with hearing loss who were receiving intervention and 8 children with normal hearing, VanDam, Ambrose, and Moeller (2012) found adult word counts and conversational turns to be comparable. Using the LENA recorder, Vohr (2013) has recently reported a positive association between children's auditory and linguistic environment at home and receptive and expressive language skills measured at school age. Taken together, these studies suggest promising applications of the LENA device not only as a research tool but also as a clinical tool to assist with education and coaching in family-centred intervention programs for children with hearing loss.

The pilot study described in this report was conducted in collaboration with the Children's Hospital of Eastern Ontario Audiology Clinic. The clinic had recently acquired a LENA system and the clinicians were interested in potentially adopting the technology as an assessment and parent guidance tool. The clinicians were therefore interested in exploring the feasibility and utility of these devices and whether parents would accept the recording device when it was incorporated into the intervention program. In addition, we felt it was important to collect preliminary information in the clinical setting prior to starting a larger-scale clinical study in the therapy program. This study had two main objectives: 1) to explore the feasibility of collecting meaningful language samples with the LENA system through a clinical program, and 2) to describe the vocalizations and speech productions of a group of children with hearing loss. We were interested in investigating the practicality for parents, ease of using the recording device, and whether the device was functioning during the planned recording times. Specifically, we sought to examine parents' ability to use the device correctly, turn it on and off accordingly, and pause recordings during naptime, car rides, water activities, and other instances that are inappropriate for recording. Data collected from the recordings were also used to analyze and describe the children's vocalizations and adults' speech. Specifically, for this study, the auditory environment, child vocalizations, conversational turn taking, and adult word counts were analyzed through the LENA software program.

Methods

Participants

Participants were recruited through the Children's Hospital of Eastern Ontario Audiology Program. The hospital services a population of approximately 1 million and is the regional diagnostic center for all children who undergo newborn hearing screening. The Program offers publicly funded early intervention services emphasizing listening and spoken language development to all children of preschool age with hearing loss. The inclusion criteria for this study were a permanent hearing loss, as well as English and/ or French spoken in the home so that the sample could be collected in the home environment. The Research Ethics Boards of the Children's Hospital of Eastern Ontario and the University of Ottawa approved the study. Parents signed a written consent form for participation in the study.

All eligible families were informed of the study by their clinician and given the option to participate. Seven parents initially gave consent to be contacted about the study. Although all seven initially agreed to participate, one family later informed investigators that the time commitment would be too great for the family at the time. Another family who initially enrolled in the study was unable to continue due to timing difficulties, leaving five participants contributing recordings for the pilot study. In accordance with ethics procedures, these two families were not questioned further about their reasons for declining to participate in the study.

Table 1 shows the clinical characteristics of the five participants in the study. The children included two males and three females, ranging in age from 2.4 to 5.8 years at data collection. All but one child (L=06) had undergone newborn hearing screening. The children ranged in age from 3 months to 2 years, 8 months at identification of hearing loss. Two children had congenital or early onset sensorineural hearing loss (less than 6 months) while the remaining three had delayed onset loss. All children had bilateral hearing loss and two of the five had a documented progressive hearing loss. Severity of hearing loss ranged from mild to profound dB (based on better ear puretone average at 500, 1000, and 2000 Hz) at the time of recording. All children used binaural hearing aids except one child, who wore a unilateral cochlear implant combined with a hearing aid in the contralateral ear. No child presented with other known disabilities. The children did not undergo a formal cognitive assessment but there were no clinical concerns about developmental or cognitive development for any of the children. All children received auditory-verbal therapy regularly, (weekly or bi-weekly) in the Audiology Program and all were in English-speaking homes. In an auditory-verbal intervention approach, parents participate directly in clinical sessions with their child, where the primary goal is to teach parents how to develop their child's listening and spoken language abilities by integrating language into the child's natural learning environments. Parents are therefore coached extensively on how to provide an optimal and quiet learning environment and are

ID	Age	Sex	Onset	Age at Identification (years, months)	Age at HA Fitting (years, months)	Progressive HL	Current dB HL-PTA (better ear)	Etiology
L-01	2-4	F	Late onset	1-4	1-6	Yes	66.7	Familial
L-02	2-8	F	Congenital	0-3	O-11	No	26.7	Familial
L-03	5-8	Μ	Early onset	0-10	1-10	No	31.7	Familial
L-04	3-4	F	Late onset	2-8	2-9	No	70	Genetic
L-06	3-9	Μ	Late onset	1-10	HA: 1-10 Cl: 2-5	Yes	120	Unknown

Table 1. Clinical characteristics of children

Key: HA: hearing aid(s); Cl: Cochlear implant(s); HL: Hearing loss; PTA: Pure-tone average; early onset: < 6 months

provided with specific techniques to develop their child's listening skills and to facilitate oral language development (Estabrooks, 2006; Fitzpatrick & Doucet, 2013).

Procedures

The families were asked to commit to two to three recording days over a two-month period. At study enrolment, one of the researchers, a speech-language pathology graduate student or the clinician providing services to the child, explained proper wearing and functioning of the LENA Digital Language Processor (DLP) to the parents, including asking parents to have the child wear the recorder in the special LENA clothing. Parents were also provided with an instruction sheet to guide them in using the device and with contact numbers in case further assistance was required. Parents were informed that they had the option of requesting that sections of the data be deleted if they were uncomfortable with exposing certain information from home on the particular recording day. The children wore a LENA DLP device on their recording days.

All of the recordings were collected in the child's home environment. The data collected from the LENA DLP device were analyzed by downloading the recordings to a computer where a specialized LENA software program automatically performed the analysis. The quality of the recording was examined to determine if the device was being worn correctly. In addition, parents were asked to complete a daily activity log on their child's recording day as well as a brief written feedback questionnaire at the end of the study. The purpose of the brief eight-item questionnaire was to collect parents' comments regarding ease of use, their child's response, and any difficulties encountered. In addition, parents were asked to comment on whether the recording day seemed to represent a typical day for the child and family. Parent responses were summarized qualitatively.

Recordings included all vocalizations produced by the child wearing the DLP and all externally-sourced sounds and speech activity within an approximate 4-6 foot radius. This unobtrusive approach to data sampling permitted the collection of naturalistic full-day recordings from the child's home language environment.

The LENA system processed and allowed for extensive analyses of the samples. The analyses provided key language environment statistics related to the child's auditory environment, child vocalizations, conversational turns, and the number of adult words spoken on the recording day. All data collected from the recordings were compared to normative data collected for typically developing children with normal hearing provided by the LENA Foundation (http://www.lena-foundation.org). The LENA Foundation normative database provides information according to age categories (2 months to 48 months of age) based on 32,000 hours of recording on 329 children in English-speaking households in the United States. A full description of the English data collection process is found in a LENA Foundation technical report titled "Natural Language Study" (Gilkerson & Richards, 2008).

Following the recordings and analysis, the clinician providing services to the child, in consultation with the graduate student when technical expertise was required, provided feedback to the parent during a regular therapy session. This involved interpreting the LENA data and sharing the results of the recordings with the parent. Details about the specific information captured by the LENA program are provided below.

- Auditory environment: Auditory components captured by the LENA DLP in the home environment and described by the LENA Foundation include:
 - Television/electronic devices: the number of minutes or hours that a child is exposed to television/electronic devices during the recording period.
 - Noise: the number of minutes or hours that rattles, bumps, and other non-human signals are captured during the recording period.
 - Silence and background noise: the number of minutes or hours that a child is exposed to silence, quiet, or vegetative sounds during the recording period. The latter include common sounds such as laughing, burping, and coughing. Sounds fall in this category if they are under 32 dB SPL.
 - Meaningful speech: the number of minutes or hours that a child is exposed to distinguishable speech (babble, words, and protophones (squeals, raspberries, etc.) during the recorded time period.
 - Distant speech: the number of minutes or hours that a child is exposed to speech produced from six feet away or more.
 Over-lapping speech in child and adult conversations during the recording is also included in this category on the basis that the adult's speech is not available to the child during these periods.

- Child vocalizations: the number of vocalizations produced by the child during the recording period. Vocalizations consist of continuous speech segments (e.g., babble, words, or pre-speech sounds).
- Conversational turns: the number of conversational turns, or vocal interactions between the adult and the child where one speaker initiates and the other responds within five seconds. These interactions can include a variety of vocalizations including cooing, babble, and words.
- Adult words: the number of adult words spoken to the child during the recording period.

Data collected for this study

Two 16-hour samples of continuous data were collected from each participant, resulting in a total of 132 hours of recordings for analysis. Participant L-O6 provided three recordings; however, for the purpose of this study, consistent with the number of data points for the remaining children, only the first two recordings were used. Following data extraction from the LENA recorder, characteristics of the auditory environment, adult word counts, child vocalizations, and conversational turns were analyzed and compared across participants and between the two recordings for each participant. Given the small number of children, all analyses are presented descriptively.

Results

Auditory environment

Results for the auditory environment are provided below in accordance with the categories that are analyzed by the LENA software. The auditory environment is divided into five categories in the LENA software: 1) TV and electronic sounds, 2) noise, 3) silence and background noise, 4) meaningful speech, and 5) distant speech. For the presentation of results, we have combined the first three environmental sounds categories.

TV/electronic sounds, noise, and silence

Figure 1 shows the amount of time in minutes and seconds that TV and electronic sounds (combined), noise, and silence and background noise (combined) were captured on the first recording for all participants. Only data from the first day are presented due to the similarity between the first and second recordings. Data across each of the categories are similar among participants. Exposure to television ranged from 20 minutes (3rd percentile according to LENA normative data) to 1 hour, 20 minutes



Figure 1. Auditory environment for each child (recording day 1 data)

(8th percentile). The amount of noise captured by the LENA system ranged from 26 minutes (3rd percentile) to 39 minutes (4th percentile). Exposure to silence and background noise varied from 6 hours, 25 minutes (40th percentile) to 8 hours, 8 minutes (53rd percentile). Examination of the parents' activity log (sheets) suggested that the increased amount of silence and background noise observed for participant L-02 may potentially be explained by the fact that the child is one of the younger participants in this study, and as a result spent more time sleeping than the other participants (according to parents' activity log). Overall, these five children spent most of their day in a quiet listening environment without interference from electronic devices or noise.

Meaningful and distant speech

Information concerning the amount of exposure to meaningful and distant speech is presented in Figures 2a and 2b. Figure 2a shows how much of each recording the LENA processing system interpreted as meaningful and distant speech across the five participants. This group of children spent a median of 3:35:45 hours (Interquartile range [IQR]: 2:54:10, 4:09:30) exposed to meaningful speech. Figure 2b shows a comparison for meaningful and distant speech for each individual child. The discrepancy noted between distant and meaningful speech for participant L-01 can be explained by the fact that the caregiver carried the recorder around near the child, however, not always close enough for the LENA system to interpret input as meaningful (i.e., close proximity speech). This deviation from the recommended use of the LENA clothing explains why distant speech is much more elevated than meaningful speech. Information from the parent activity log sheets indicated that L-03 and L-06 were wearing snowsuits during part of the recording. This may have affected how the LENA system analyzed the data with respect to meaningful versus distant speech.

Child vocalizations

Figure 3 shows the number of child vocalizations collected from each participant at each of the two recordings. The number of vocalizations from participant L-01 is substantially lower than the total vocalizations recorded from the other children. As noted above, this is likely explained by the fact that participant L-01 did not agree to wear the special LENA vest that typically houses



Figure 2a. Amount of time spent in meaningful and distant speech across children



Figure 2b. Comparison of time (two recordings) spent in meaningful and distant speech for each child



Figure 3. Number of child vocalizations on each recording day

the recorder but rather the child's mother carried the LENA DLP around in proximity to the child. As a result, the LENA DLP was unable to capture all of the child's vocalizations. Both recording samples collected from each participant were similar with respect to the vocalization counts captured. When compared to LENA normative data for typically developing children, all recordings with the exception of L-01 are between the 77th and 98th percentile with a maximum difference of 8% between the first and second recording.

Conversational turns

Figure 4 displays the number of conversational turns that occurred between the caregiver and child. Consistent with Figure 3, both recordings obtained from each participant are quite similar in the number of conversational turns captured by the LENA DLP. The difference in conversational turns between recording day 1 and recording day 2 ranged from 30 conversational turns for L-06 to 228 turns for L-04. There were less than 100 conversational turn differences between recording days for all children except L-06. The small differences noted between the first and second recordings further suggest that the recording days represent a typical day in the participant's life. Norms available for conversational turns situate all applicable recordings between the 85th and 99th percentile for typically developing children (LENA norms) with a maximum difference of 5% between the first and second recording.

Adult word count

Figure 5 shows the number of spoken adult words captured by the LENA DLP on each recording day. With the exception of the recordings from participant L-O2, all recordings were at the 99th percentile compared to LENA normative data. For L-O2, recording data on day one was at the 55th percentile and recording two was at the 77th percentile.

Parent Questionnaire Information

Parent questionnaires were returned for all five children and all reported that the LENA device was easy to use.



Figure 4. Number of conversational turns on each recording day



Figure 5. Number of adult words spoken to child on each recording day

LENA FOR CHILDREN WITH HEARING LOSS

However, for all children, parents also noted that their children either always or occasionally had a negative reaction to wearing the LENA clothing and this seemed to be one of the most challenging aspects for parents when using the recorder. None of the parents reported that using the device affected how they interacted with their child. Three parents also commented that it was necessary and in some cases challenging to organize family schedules to use the device for an extended period only in the home environment. These parents noted that this requirement impacted typical routines and in two cases resulted in a sample that was not representative of a typical day in their child's life. One parent positively commented that the LENA results confirmed that peak speech time for the child was in the afternoon and was pleased that this time coincided with the child's typical scheduled rehabilitation therapy appointment compared to a previous schedule of a morning appointment. One parent also indicated that she would appreciate receiving information about her child's daycare environment through use of the LENA system. For two children, parents indicated that they would definitely use the device again if requested by their therapist while the three other parents indicated they would maybe accept to use it.

Discussion

The purpose of this study was to examine the overall feasibility of using the LENA system as part of a clinical intervention program for preschool children with hearing loss. We were particularly interested in investigating the practicality for parents in a clinical program including how easy it was for parents to use the recorder, and whether parents would be able to use the device during the allotted recording times. In addition, this pilot project enabled us to describe the vocalizations and speech productions of a group of young children with permanent hearing loss receiving therapy in a listening and spoken language program.

Overall, LENA was found to be a useful tool for collecting naturalistic language samples from these young children. Parents were able to operate the device and reliable information regarding the child's home language and auditory environment was captured. Based on parent reports, the LENA device seems to have been easy to operate. However, parents also reported that their children either always or occasionally reacted with hesitation to wearing the LENA vest. Therefore, consideration of clothing, for example, familiarizing the child with the clothing (vest) by having him or her wear it for a period of time or incorporating the device into the child's own clothing might be useful to facilitate use of the device and ensure more accurate data collection. As the results demonstrate, when the device is worn correctly in a specially designed clothing item, the LENA system captures data representative of the child's auditory and language environment. In this study, parents first introduced the LENA vest to their child at home and one option might be for the child to first have an opportunity to use it in the clinical situation with both the therapist and parent during enjoyable play activities.

In a few cases, recordings were not completed on the anticipated day due to unplanned events in the family's everyday life. For this pilot project, we opted to limit recording to the home setting, and it is possible that it will be easier for parents to carry out the recording when there are no restrictions on the recording environment. Expanding the recording to multiple settings outside the home will also permit data collection that is more representative of typical daily activities for some children. Parents' comments confirmed this concern as they reported that the requirement to collect recordings in the home made the activity slightly more challenging to coordinate with their everyday schedules. Other important limitations of this study include the small sample size and the short time period over from which the recordings were collected. Finally, we did not specifically collect socioeconomic data on the families; however, these families all attended regular therapy sessions and as such were well informed of the importance of providing an enriched auditory and language environment for their children. Therefore, our findings from this small group may not be transferable to other program settings. It would therefore be useful to replicate this study on a larger scale and with a more diverse sample in future research.

These data indicate that LENA can provide useful information for clinicians to assist them in providing feedback to parents about their child's language learning environment. Based on information from LENA recordings, clinicians can offer parents' suggestions to further enrich the learning environment for the child. We did not collect comments in a systematic format from the clinicians involved in the clinic where the study was carried out. However, the pilot project laid the foundation for use of the LENA system such that it is currently being integrated more broadly into the auditory-verbal therapy program as a clinically useful tool for collecting extensive language samples and coaching families about the need for a stimulating language learning environment.

This is one of few studies that have investigated use of the LENA system with young children with hearing loss. Our findings, similarly to those of Aragon and

Yoshinaga-Itano (2012), suggest that the LENA system has useful applications for children with hearing loss in spoken language programs. In our study, all data that were appropriately collected, (child wore device in LENA clothing) were found to be within normative data for the LENA system. As noted, these children were all enrolled in an intensive therapy program with a focus on listening and spoken language since diagnosis. Therefore, parents had specifically received guidance regarding the importance of enriching the auditory environment by reducing background noise and received ongoing coaching related to exposing their children to good spoken language models. These data suggest that these children are in optimal learning environments. The findings regarding the environment can be used to reinforce parents' efforts to provide an enriched environment for spoken language development. For example, clinicians were able to visually demonstrate to parents which home situations and times of the day resulted in more (or less) adult talk and/or child vocalizations. Using this information, parents can be encouraged to capitalize on these time periods to provide an abundance of meaningful interactions and to teach new linguistic information such as vocabulary and grammatical structures. For children with hearing loss, the information about the auditory environment, particularly the presence of electronic sounds and noise, can be particularly useful in showing parents how much time their child spends in a listening context where there is less than optimal acoustic stimulation due to background noise.

Our results for this small sample are aligned with the positive results reported in a recent study for adult word counts and conversational turns in a larger group of children with mild to severe hearing loss from high socio-economic levels (VanDam et al., 2012). As noted, a sample that reflects a more diverse clinical population may yield different results in terms of the learning environment. For example, Aragon and Yoshinaga-Itano (2012) found that on average, children with hearing loss in English-speaking homes obtained higher scores on child vocalizations, conversational turns, and adult word counts than Spanish-speaking children with hearing loss. However, these authors also reported that conversational turns and adult word counts for this disadvantaged sample of Spanish-speaking children with hearing loss were higher than those recorded in Spanishspeaking homes of children with normal hearing. Based on these results, the authors suggested that early intervention services assisted parents of children with hearing loss in providing stimulating learning environments.

In addition to measurement in the home environment, LENA has the potential to be used in a variety of other settings by different caregivers interacting with the child. LENA can also be used to help measure the effectiveness of a treatment program in increasing the child's vocalization and in improving the learning environment, for example, by collecting pre- and post- therapy language samples. It also provides a tool for clinicians to explore the optimal time of day for treatment, and to identify settings and times of the day in which the child is most engaged in language and listening. As a tool to guide parents of children with hearing loss, LENA offers opportunities to teach parents about optimal acoustic environments and to encourage and reinforce parents' efforts in providing enriched language settings for their children's learning.

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