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Abstract

This study describes the experience of childhood speech impairment (speech sound disorder) from the perspective of two young men and their mothers. Semi-structured interviews were conducted with the four participants, with questions framed around the *International classification of functioning, disability and health* (ICF; WHO, 2001) to gain a holistic understanding of life with speech impairment. Phenomenological analysis of the interviews revealed that the experience of speech impairment was associated with three key themes: (1) knowing, (2) having, and (3) doing. A core theme of 'battles' was common to all three themes (i.e. the battle for knowledge, the battle of having speech and associated difficulties, and the battle to do something to minimize the impact of the difficulties); however, the nature of the battles was different for participants, and was related to other life factors. This qualitative research provides valuable insights into the experiences of those living with speech impairment, and shows the importance of considering such information alongside quantitative research when making decisions in clinical practice.

Keywords

speech impairment, speech sound disorder, qualitative research, experience, International Classification of Functioning, Disability and Health (ICF)

I Introduction

Speech impairment is a high prevalence condition in childhood (Law et al., 2000; McLeod and Harrison, 2009), and residual speech errors may continue into adolescence and adulthood for some

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individuals. However, the nature of childhood speech impairment and associated difficulties with life activities change for individuals at different life stages, which may have implications for clinical management.

1 Speech impairment across different life stages

Speech impairment encompasses the terms speech sound disorder, articulation impairment, phonological impairment, and childhood apraxia of speech (CAS). Longitudinal studies of individuals with a history of childhood speech impairment provide valuable information about the type and longevity of difficulties that may be associated with the impairment, even when the articulation or phonological errors have apparently resolved. A landmark study was reported by Felsenfeld and colleagues (1992, 1994, 1995) in which the effects of childhood phonological impairment on educational, vocational and linguistic outcomes were demonstrated 28 years after individuals initially presented to clinic. For instance, those with a history of phonological impairment were more likely than a same-age control group to require remedial assistance at school, complete fewer years of formal education, and be employed in occupations with less reliance on communication skills.

Other studies have also investigated the association between speech impairment and a range of life activities across different life stages. McCormack et al. (2009) reviewed 57 of these studies in a systematic review of the literature from 1998 to 2008. Studies in the review reported speech impairment to be associated with difficulties in performing activities related to:

- learning and applying knowledge (e.g. reading, spelling, and mathematics);
- social interactions (e.g. negative peer relationships); and
- major life areas (e.g. education and employment).

At times, other factors were identified as contributing to the findings, such as co-occurring difficulties, severity of difficulties and persistence of difficulties. McCormack et al. (2009) concluded that the experience of speech impairment and of associated difficulties is unique to individuals, and is dependent on a range of contextual (environmental and/or personal) factors.

Longitudinal qualitative studies provide insight into the experiences of children and their families across different life stages, and consider the personal and environmental factors that may contribute to their experience. Brinton et al. (2005) have suggested that a long-term view of children with communication impairments is necessary to gain a detailed understanding of the complexity of impairments and the way in which they unfold over time. They presented the case of an individual with specific language impairment, which showed the range of difficulties he experienced throughout childhood and adolescence, starting with delayed expressive and receptive language skills, and progressing into academic difficulties in primary school and social difficulties in later school years. They concluded that 'there was nothing specific about his disorder' (p. 350), and praised the 'emotional, educational, therapeutic, and financial support provided by his family' to support his development at different life stages.

There are no such case studies of children with speech impairment. Thus, the complexity of speech impairment, and changes in the experience of those (individuals and families) living with speech impairment over time, is unclear.

2 Individuals' experiences of speech (communication) impairment

Information about the experience of individuals with speech impairment and their families is important in order to understand the perspectives of those experiencing the difficulty, their priorities and

goals for intervention (and for life), as well as the environmental and personal factors contributing to their unique context. Such information is necessary for clinical decision-making to ensure that timely and holistic intervention is provided for clients.

Qualitative studies provide descriptions of what the experience of a phenomenon is really like for individuals who live that experience; that is, to gain insight into their world. They enable an understanding of the way in which context influences experience (Damico and Simmons-Mackie, 2003). There is little research describing the lived experience of individuals with communication impairment generally, and with speech impairment in particular.

One study that has been conducted used questions and visual cues taken from the 'Speech Participation and Activity Assessment – Children' (SPAA-C; McLeod, 2004) to elicit the communication experiences of preschool children (aged 4–5 years) with speech impairment and their communication partners (McCormack et al., 2010). The participants in that study understood living with speech impairment meant encountering problems that then needed to be solved. They recognized three problems in their communication experiences: a speech problem experienced by the child, a listening problem experienced by communication partners, and the child's frustration arising from the speech and listening problems. Thus, the difficulties associated with communication impairment extended beyond the individual with the impairment to other family members.

Other studies have described school-aged children's view of their communication (Merrick and Roulstone, 2011) and views of speech therapy (Owen et al., 2004). Children in those studies were more likely to describe their own communication difficulties, than were the younger children, and also recognized the role of speech and language therapy in helping them develop their communication skills.

There are no reports of adolescents' and adults' experiences of childhood speech impairment; however, there have been studies describing the experiences of individuals with a history of stuttering (also called stammering) (e.g. Anderson and Felsenfeld, 2003; Cream et al., 2003; Crichton-Smith, 2002; Hearne et al., 2008; Kathard, 2006). It may be expected that some parallels could be drawn between the experience of stuttering and the experience of speech impairment given both may be associated with no known cause, both may initially present in the childhood years and persist into adulthood, and both may be associated with difficulties in other life areas. However, research investigating the experiences of individuals with speech impairment is needed before comparisons can be made. According to research with individuals who stutter, they reportedly become aware of the impairment at school (Crichton-Smith, 2002), and as adolescents are motivated to seek intervention by the desire to complete life activities (e.g. further education or gain employment) rather than by the impairment (stuttering) (Hearne et al., 2008). It is currently unclear when individuals with a history of speech impairment first identify themselves as having difficulty, and why they seek intervention.

3 Parents' experience of speech impairment

At present, there are numerous studies that have investigated parents' reasons for seeking intervention and their experience of intervention services (e.g. Carroll, 2010; Glogowska and Campbell, 2000; Lyons et al., 2010; McAllister et al., 2011; Paradice and Adewusi, 2002; Watts Pappas and McLeod, 2009). Such research provides useful information to guide service delivery. However, considering parents' experience of life (i.e. raising a child with speech impairment), as well as their experience of intervention, is also important. Such research enables insight into the family context, the personal and environmental factors that influence their experience and the unique challenges they face, which is important for delivering family-centred practice. There are currently a limited number of studies that describe the experience of living with communication impairment from the perspective of parents

(e.g. Canary, 2008; Goldbart and Marshall, 2004; McCormack et al., 2010). The existing studies have focused on individuals with a range of disabilities (Canary, 2008) or with complex communication needs requiring augmentative and alternative communication (AAC) systems (Goldbart and Marshall, 2004), and reveal the many demands faced by parents of these children. Information about the experiences of parents of children with speech impairment would be useful in order to identify the demands they face and the additional support they require.

4 Research aims

Speech impairment is a high prevalence condition in early childhood, and may be associated with ongoing social and academic difficulties. There is growing awareness of the consequences of having speech impairment; however, no studies have examined the experiences of young adults diagnosed with speech impairment in childhood, and their families. Such information is important in the provision of holistic family-centred practice. Kovarsky (2008: 51) has suggested 'an exclusive reliance on objective data is at odds with the very nature of what it means to participate in the life world and how communication disorders manifest themselves'. She suggested the need for both experimental and qualitative modes of inquiry to gather evidence for clinical practice. The purpose of the current study was to describe the experience of living with childhood speech impairment and specifically:

- to gain insight into how two young men view their own speech impairment in terms of current difficulties and past experiences;
- to gain insight into the experience of being a mother of child with a history of speech impairment.

II Method

I Participants

The two focus individuals, Fraser and Tim (pseudonyms), were recruited through opportunistic sampling. Their families separately approached one of the authors, wanting to share their stories, after learning of her research. They were selected to take part in the current study because their cases were 'information rich' and gave 'insight about a phenomenon' (living with speech impairment) (Patton, 2002: p. 40). Fraser and Tim were provided with further written information before consenting to participate. They were asked to identify significant others who could also participate. Both identified their mothers, who subsequently agreed to be interviewed. Information about Fraser and Tim (in the following sections) was provided by them and their mothers in the interviews.

a Fraser (17 years): Fraser was the youngest of three children, all of whom were diagnosed with 'dyspraxia' (childhood apraxia of speech or CAS) during their childhood years. Fraser's father, uncle and cousins were also reported to present with characteristics of dyspraxia; however, this had not been clinically diagnosed. Fraser was first assessed by a speech language therapist (SLT) at 12 months due to feeding difficulties. He presented with minimal speech output as an infant, and attended early intervention (at 3–4 years) where he was taught to communicate using Makaton key word signing. He did not receive any direct speech and language therapy in early childhood due to the lack of services in the town where he lived. However, his mother had access to activities provided by an SLT for her older son in a town where they lived previously, and used these with

Fraser. Fraser received intervention with an occupational therapist to assist with balance and coordination, as well as fine motor skills. His non-verbal IQ was assessed by a paediatrician and found to be within the normal range.

At 5 years, Fraser commenced school at a mainstream primary school. He used speech (not signing) to communicate; however, his speech was unintelligible to peers and teachers at times, and his older sister was occasionally asked to interpret his message. An SLT provided Fraser's mother and school with activities to assist his speech and language development, and conducted 6-monthly reviews. However, he did not have regular direct intervention with the SLT and was unable to access any SLT services after he completed primary school.

In addition to his speech impairment, Fraser was identified with literacy difficulties at school (reading and spelling were below the level expected), and at age 12 he repeated the first year of secondary schooling (year 7) due to difficulties with academic activities and problems with peer interactions. His mother chose to move Fraser to a new secondary school at this time due to 'severe bullying' that he was experiencing.

At the time of the current study, Fraser was 17 years old and in year 11 at secondary school. He reported ongoing difficulties with reading, spelling and auditory memory. Fraser's speech was completely intelligible; however he presented with residual articulation errors (such as substitution of [f] in place of 'th' and [w] in place of 'r') in conversational speech. Fraser was completing his secondary school qualifications with a combination of academic and vocational subjects, expressing particular enjoyment of graphics (drawing and design) and circus subjects (stage design and lighting). He indicated a wish to work for an international circus when his schooling was completed.

b Tim (23 years): Tim was the youngest of a family of nine children. There was a history of stuttering in his father's family; however, there was no history of other speech or language difficulties. At the age of 3;6 years, Tim attended speech and language therapy due to 'poor tongue movement' and 'difficulties with pronouncing words'. His mother was provided with activities from the Lindamood Phoneme Sequencing® Program (Lindamood-Bell, 2011) and Tim was required to practise a range of sounds (including /f, l, k/). Intervention was discontinued after approximately 6 months as Tim was uncooperative, and then experienced a period of 'childhood depression' when his older brother (aged 5 years) passed away.

Tim commenced primary school at 5;6 years, instead of 4;6 years, as his mother did not feel he was ready 'language-wise or emotionally-wise' to commence earlier. At school, he experienced 'learning difficulties' and his mother returned to the SLT when Tim was 6 years old. The SLT diagnosed Tim with 'auditory discrimination impairment', and he received direct intervention with the SLT for approximately six months. His mother reported that his initial difficulties with confusing speech sounds and confusing letters improved. However, he continued to have occasional difficulty planning what he wanted to say and coordinating speech movements when speaking quickly. During the remainder of his schooling, Tim continued to experience difficulty with mathematics and literacy, but achieved adequate literacy levels to complete all levels of formal schooling.

Tim was 23 years old and completing a traineeship in broadcast journalism at the time of the study. He reported ongoing difficulties with 'mispronouncing' words, particularly polysyllabic words, and noted getting 'tangled' or 'tongue-tied' when he was talking too quickly. Similarly, his mother reported: 'when he's speaking slowly, it's quite clear and ... when he's speaking fast, immediately it becomes a little bit hard to catch some of the words.' Tim described and presented with residual articulation errors (e.g. metathesis) when producing multisyllabic words (e.g. 'specific', and 'particularly') during the interview and when producing tongue-twisters (e.g. 'She sells sea shells by the sea shore'; Haber and Haber, 1982) during a brief informal assessment following the interview; however, his speech was completely intelligible.

2 Procedure

Three semi-structured interviews were conducted: one with Fraser and his mother (90 minutes), one with Tim (30 minutes), and one with Tim's mother (40 minutes). Two of the three interviews were conducted face-to-face, and one (with Tim's mother) was conducted over the telephone due to distance. The duration of each interview was dependent on the number of participants being interviewed at one time, and their other commitments.

The interviews comprised open-ended questions, which enabled participants to offer a range of responses regarding their experiences, and to expand on key aspects when prompted. Interviews followed a conversational style of questioning, in accordance with the established protocols for in-depth qualitative interviewing (Minichiello et al., 2008). A fixed set of questions was not used; instead, participants were asked questions regarding key topics, and the content of subsequent questions was influenced by their responses. The development of key topics was guided by the *International Classification of Functioning, Disability and Health* (ICF; World Health Organization, 2001). The ICF is a framework that recognizes health as resulting from an individual's ability to participate in everyday life, as much as from being medically/physically 'well'. Furthermore, it recognizes the role of personal and environmental factors in facilitating health and well-being. Thus, it is useful for describing and understanding a health condition, such as speech impairment, in a more holistic way. Topics (and sample questions) are presented in Table 1.

Interviews were audio-recorded, then transcribed verbatim by the first author. Interview transcripts were sent to the participants for review. Participants were invited to make changes to their transcript (e.g. additions and deletions) to ensure that the transcript accurately reflected their thoughts and experiences and to assure them they could not be identified in transcripts. Occasional modifications were requested to increase the clarity of the respondent's own comments, but no information was deleted.

Ethical approval for the research was obtained from the Charles Sturt University Ethics in Human Research Committee.

3 Data analysis

This research took a phenomenological approach in that the researchers were interested in understanding the essence of the experience described by individuals with speech impairment and their families (van Manen, 1990). Phenomenology is a methodology that may comprise a range of data collection and analysis methods (see, for example, Cream et al., 2003; McCormack et al., 2010; Plexico et al., 2005). In this study, interviews with key informants were the chosen data collection approach, and thematic analysis was the chosen form of analysis. The analysis involved repeated readings of interview transcripts in order to identify content that directly related to the experience of living with speech impairment (i.e. the phenomenon). This analysis was inductive, so themes and patterns emerged from the data rather than being imposed prior to data collection (Patton, 2002).

Each interview was analysed separately; however, constant comparative analysis was conducted to identify commonalities and differences among them (Patton, 2002). The comparative analysis enabled recurring patterns in the data to be identified, which then enabled the data to be categorized into themes in a meaningful and accurate way. Initially, the transcripts from the focus individuals were compared to one another, and the transcripts from the parents were compared. Next, the transcripts from each family member were compared (e.g. Tim and his mother, and Fraser and his mother). Finally, the four interview transcripts were compared, and participant checking was conducted to ensure that the meaning assigned to statements and phrases was not taken out of the intended context.

Table 1 Key topics for interviews

ICF component	Topics	Sample questions
Body functions	Description of individual's speech / impairment (childhood impairment and any current concerns)	How you would describe your (child's) speech?
Activities and participation	Description of impact of speech impairment on: <ul style="list-style-type: none"> • Learning and applying knowledge (listening, attention, literacy, mathematics) • General tasks and demands (undertaking tasks, handling stress) • Communication (speaking, using non-verbal strategies, receptive language, conversation) • Interpersonal interactions and relationships (forming relationships, relating with family, friends, teachers, strangers) • Major life areas (school education, work) • Community, social and civic life (play, sports, hobbies) 	I'd like to find out more about how your (child's) speech impairment affected your (his/her) ability to communicate with other people. Could you talk about this? Can you talk a little about how your (child's) speech impairment may have affected your (his/her) education? Are there particular skills that you (he/she) found difficult to learn? How do you think your speech impairment may have affected your (child's) participation in social activities and the community?
Environmental factors	Description of: <ul style="list-style-type: none"> • Support and relationships (family, friends, peers, health professionals, teachers) • Attitudes (family, friends, peers, health professionals, teachers) • Services accessed, systems and policies (health, education and training) 	Can you talk about your experiences of accessing speech and language therapy services? Can you talk about how the attitudes of others may have influenced your (child's) experience of a speech impairment? And access to services?
Personal factors	Description of factors including personality, interests, and family history	

The trustworthiness (or rigor) of the findings in the current study was ensured through gaining data from more than one source (e.g. the focus individuals, and their mothers), comparing the data sets (triangulation) to check the consistency of information collected with different participants, checking of understanding of the data with participants, and using detailed extracts in research reports to ensure authenticity of the descriptions of participants' experiences and the themes drawn from the data (Minichiello et al., 1999).

III Results and discussion

I The experience of speech impairment: Knowing, having, doing

This research used a phenomenological framework to understand the experience of childhood speech impairment, as described and understood by two young men with a history of childhood speech impairment and their mothers. The phenomenological analysis saw the emergence of three

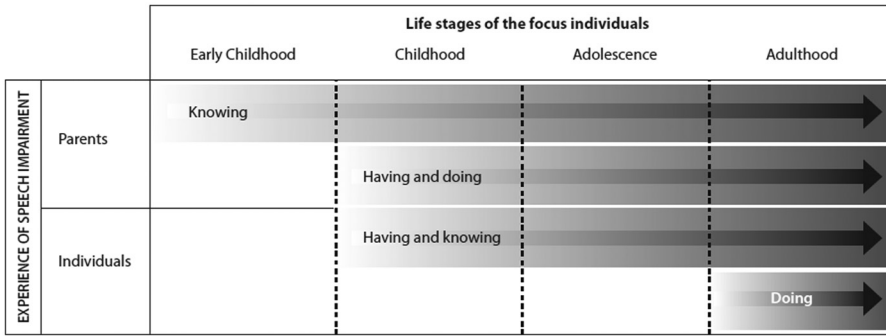


Figure 1 The experience of speech impairment from childhood to adulthood, according to individuals with speech impairment and their parents

Notes: Individuals and parents described the experience of speech impairment in terms of the same three themes (knowing, having and doing), but at different life stages

themes related to the experience of speech impairment: ‘Knowing’, ‘having’, and ‘doing’. In the first theme, *knowing*, participants reported being aware that a problem existed. In the second theme, *having*, participants described the nature of the speech impairment and difficulties associated with the impairment. In the third theme, *doing*, participants identified how they managed the speech impairment and associated difficulties. These three themes were common to both the young men and their mothers’ descriptions of living with speech impairment; however, the themes emerged at different life stages for both groups (see Figure 1).

2 Knowing

Participants described their identification of speech difficulties using terms such as being ‘aware’, ‘recognizing’ and ‘knowing’. For the mothers, knowledge of a problem with their son’s speech emerged in early childhood (e.g. prior to school) (see Figure 1). For Tim’s mother, her awareness that Tim ‘wasn’t speaking properly’ resulted from her knowledge of typical (or proper) development, most probably through comparing Tim to his typically developing older siblings. For Fraser’s mother, her recognition of a speech impairment resulted from her knowledge of atypical development. She was able to identify characteristics similar to both Fraser and his older brother who had been diagnosed with dyspraxia, which meant she ‘picked it [Fraser’s speech impairment] up straight away’. Thus, personal factors (such as positive family history) played a role in initial identification.

As shown in Figure 1, Tim and Fraser both spoke about their knowledge of speech impairment developing later. When Tim was asked to recall first noticing the speech difficulties he had described, his response related to his recollection of attending speech and language therapy in later childhood:

Tim: I did have trouble talking ... not so much talking, but pronouncing my words, and I did have speech pathology assessments when I was about six, seven, eight, nine ...

Similarly, Fraser’s first awareness of his speech impairment related to his commencing school and having difficulty ‘getting on with kids’. He described the realization that others didn’t understand and didn’t care what he was saying:

Fraser: There were very few that actually tried to understand, and they would be closer friends. The rest of them just didn't really care – they'd just walk away.

Thus, environmental factors (such as the attitudes of others, and the services accessed) played a role in the individual's initial identification of impairment. However, it's likely that personal factors (such as age and self-concept) also contributed and, as they grew older, knowledge of their speech impairment was based more on experience and insight than feedback from others:

Tim: When I talk quick, that's when you get all tangled and have difficulty expressing, and I know, I know, I'm conscious of it.

The realization of communication difficulties in later (rather than early) childhood, which was reported by the individuals in the current study, may be related to the development of self-concept during childhood. Researchers have suggested young children are unable to perceive their own difficulties due to unrealistic self-concept, but that self-concept develops as children age and begin comparing themselves to others in their environment (Marsh and Shavelson, 1985), such as when they commence school. Previous research with children of different ages who experience communication impairments supports this view. For instance, McCormack et al. (2010) found most pre-school children with speech impairment were happy about the way they talked and did not perceive communication breakdowns to be a result of a speech problem. However, Owen et al. (2004) found that children with communication impairments attending mainstream primary school were aware of their specific communication difficulties and the way this affected other aspects of their life (e.g. friendships). Similarly, Crichton-Smith (2002) interviewed adults who stuttered and reported that first recollections of stuttering were associated with communication breakdowns in social settings, particularly at school.

3 Having

Participants described the experience of having speech impairment in terms of 'difficulties', 'problems' or 'trouble' they previously had, or currently have. Tim and Fraser described their difficulties in terms of the speech sound errors they made, but also the other life activities that were affected. That is, they described the impaired body functions and the impact on everyday life (see Table 1). For instance:

Fraser: I still have a lot of trouble with pronouncing words. Even small words, I still have trouble with doing it. And I still mix up words when I'm actually saying it out in a class ...

Their mothers described difficulties they observed their children experiencing; however, they also described the difficulties they experienced (as parents) through having a child with speech impairment, that is, the third party effects of speech impairment (see Scarinci et al., 2009). Fraser's mother reported attending a support group for parents of children with dyspraxia, but soon realized that many of the parents had children with other developmental disabilities, while 'I just had dyspraxia.'

4 Doing

Participants described the experience of doing something to manage the speech impairment and associated difficulties. Both Tim's mother and Fraser's mother described the experience of seeking

help for their children's speech impairment when they were aware of the problem (see Figure 1). This incorporated taking their children to the SLT and then doing exercises and activities with them at home/school:

Tim's mother: The sort of work that I was doing with him when he was a child – you might know how hard it is to do with a child ... getting them to lick the lollipop, poking the tongue out and getting him to do all those sorts of things.

In contrast, Fraser and Tim both described their development and use of informal strategies to help manage their speech impairment and associated difficulties, which began when they became aware of their speech impairment. For instance, Tim had recognized that when he slowed down his speech rate, he spoke better and was better understood, while Fraser used a range of visual (and mnemonic) strategies to assist with literacy-based tasks that he found difficult. Both had found ways to manage the teasing or bullying they received, by either walking away ('shrugging it off') or fighting back:

Fraser: Now I walk away from it [bullying] – I learn it from the past. If it's verbal ... I do it back to them or I walk away. If it's physical, well there's nothing I can do. So I have to stand there – either get hit myself or fight back. And after a while I started to fight back and it started to work.

Fraser acknowledged the help provided by a clinic that his mother had taken him to, but hadn't actively sought assistance since then. However, Tim had begun to actively seek out further intervention for his speech in order to succeed in his chosen career. For Fraser and Tim, their mothers' support was an environmental factor that facilitated their receiving help; however, the lack of available services was an environmental factor that acted as a barrier:

Tim: It wasn't until I got this career at the beginning of this year that I thought, 'OK, I might want to work on trying to access or trying to get some speech coaching' ... so that's why I've been looking, but unfortunately I haven't been finding anything. Because everyone's retired or they're like not in [town] or somewhere else ... too far away ... so I've been trying to do it myself and the problem is with myself I don't really know how good I'm going or what to improve.

Personal factors, such as age and readiness to receive help, could also act as facilitators or barriers. For Tim, having insight into the difficulties he experienced and the way this might impact on his career as a broadcast journalist led him to 'do' something (e.g. seek intervention or assistance) as an adult to minimize the impact of speech impairment on his life goal. This finding is consistent with findings reported by Hearne et al. (2008) in a study of adolescents who stutter. They found adolescents needed to feel ready in order to seek intervention, and often were motivated by reasons such as going to university or starting work. They reported that having a stutter was not in itself a sufficient reason to seek help.

5 Battles in the experience of speech impairment

Participants described the difficulties they encountered as a result of their experience of speech impairment (knowing, having and doing), and as a result of the interaction between speech impairment and other life factors. Thus, a core theme of 'battles' (common to the other three themes) was

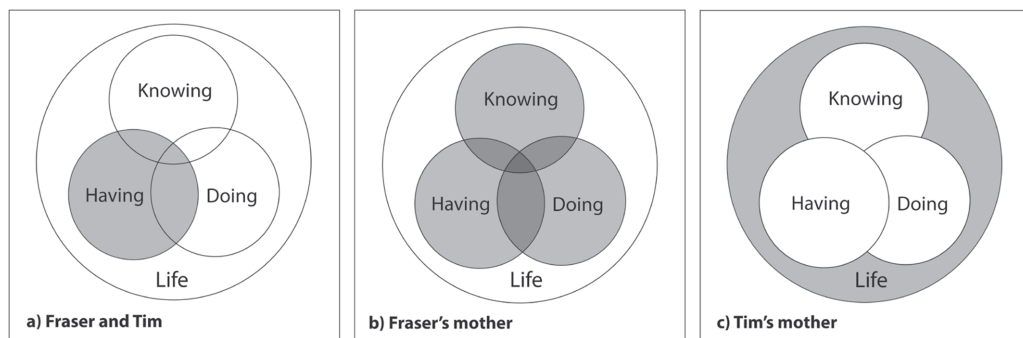


Figure 2 Battles in the experience of living with speech impairment

Notes: The shaded areas show the domains in which participants identified key battles. Fraser and Tim experienced battles associated with having speech impairment. Fraser's mother experienced battles with her quest to know more about her son's difficulties, with having a son who had difficulties, and with trying to do something to assist her son. These occurred within her life experience. Tim's mother experienced life battles, with a large family and with the death of her son (Tim's brother), which impacted on her experience of her son's impairment

found to emerge. The battles of living with speech impairment were experienced and described differently by the participants (see Figure 2). For Fraser and Tim, the experience of having speech impairment (rather than knowing or doing) was their main battle. For Fraser's mother, each component of her experience of speech impairment (knowing, having, and doing) presented unique challenges and combined to make life 'hard'. For Tim's mother, life was already 'busy', and this made the experience of speech impairment an additional (and secondary) challenge. In the sections that follow, the battles experienced by the young men and their mothers are described and illustrated using excerpts from the interviews.

a Battles: Tim and Fraser: For Fraser and Tim, the greatest battles in their experience of speech impairment were related to having speech impairment (rather than knowing or doing) (Figure 2a). They both described the experience of having speech impairment in childhood in terms of difficulty producing sounds and words, and therefore having a message misunderstood, and both identified their speech difficulties as continuing. As they progressed beyond childhood, both began to perceive that having speech impairment meant having a range of difficulties, and not just difficulty producing speech sounds. They described how these difficulties had impacted on their lives, such as preventing their involvement in some extracurricular activities (such as debating), or leading them to avoid some people and situations for fear of being 'ridiculed':

Tim: I found that through high school people that did well academically, they'd come and talk and I couldn't really talk to them because they'd be like 'What're you saying?' [and I] just felt bad because they just said ... oh whatever. So that's probably what affected me psychologically ... in high school, but ... other than that I could speak to any of my family obviously but some people I went to school with, I would just try and avoid ... or avoid specific topics 'cause I wouldn't know what to say ... or don't know much about the topic or just feel that I might stuff up ... just be ridiculed pretty much.

Both Tim and Fraser described negative social interactions (such as teasing and bullying), although the degree and frequency of social difficulties varied for both. For instance, Tim's mother reported that Tim was a popular child, despite his speech impairment, while Fraser's mother

identified that he ‘had been bullied severely’. Thus, some of the battles they experienced with having speech impairment were due to environmental factors, such as the attitudes of others.

Both parents also identified that having speech impairment meant their sons experienced frustration, particularly as young children. However, their different reactions to the experience of having speech impairment appeared to be related to personal factors, such as personality and reactivity. Fraser’s mother recalled Fraser often came home ‘het up’ (frustrated and angry) about things, and she attributed his distress and frustration to the bullying that he was experiencing at school. In contrast, Tim’s mother reported that he withdrew from situations:

Tim’s mother: Frustration was in his life ... it was never a big tantrum. He would just take himself away – exclude himself ... He never used to come to me distressed in not being able to be understood ... I would say possibly there would be a withdrawing before the distressing came about.

The range of difficulties reported by Tim and Fraser, and their mothers, is consistent with research showing the association between speech impairment and a range of academic, social, emotional and vocational activities across the lifespan (McCormack et al., 2009). In the current study, the range of difficulties experienced by Tim and Fraser became more apparent as they progressed from early childhood into later childhood and adolescence. Brinton et al. (2005) described a similar evolution of difficulties in a case study of a child with language impairment. In their study, the child presented in childhood with a highly specific language problem; however, as he matured, his language difficulties became more pervasive and extended into many areas of his life.

b Battles: Fraser’s mother: Fraser’s mother experienced battles with her quest to know more about her children’s difficulties, with having children who had difficulties, and with trying to do something to assist them (see Figure 2b). Obtaining knowledge about her children’s difficulties was an ongoing battle, due to the lack of information publicly available, and the lack of recognition of impairment labels being used:

Fraser’s mother: Whatever information I gathered from here, I then would take it back to the speech pathologist in [town] and go ‘This is what it’s [dyspraxia’s] about ...’ And he’d still say, ‘Oh no, but ... it’s just a general term for whatever ...’ You’d be in this limbo of ... [thinking] ‘Well, what really is it?’

Similar themes have been raised in research with other parents of children with CAS (Miron, 2010) and parents of children experiencing a range of disabilities (including some with speech/language impairment) (Canary, 2008). For instance, in Canary’s study, some of the adults identified their children’s disability as a ‘puzzle that they have not solved’ (p. 448). They continued trying to understand the disability, and relied on professionals to provide them with more information to assist this process. Similarly, McAllister et al. (2011) found parents of children with speech concerns relied on other professionals (e.g. teachers, doctors) to identify or confirm their concerns about the existence of speech impairment.

For Fraser’s mother, the battle to obtain knowledge was caused by conflicting information and advice being provided by these other professionals. The identification and management of dyspraxia (more so than articulation or phonological impairment) is an issue within the profession still (Miron, 2010). However, failure to diagnose CAS may have consequences in terms of the intervention, funding and support provided to children and their families, resulting in parents having to ‘fight’ to have access to specialist services, such as speech and language therapy (Paradise and Adewusi, 2002: 263).

Obtaining information from other professionals was not the only battle Fraser's mother encountered in her battle for knowledge. As her children progressed from early to later childhood, obtaining information from them about the difficulties they were experiencing at school was also a struggle, due to the 'effort' required from Fraser (or his siblings) to communicate what had happened and the 'time' required from her to listen to their story:

Fraser's mother: I was a pretty stressed out mother ... And your brain has got to work all the time. The boys would come home ... I don't know which one it was, Fraser or [his brother], but I remember ... one of them came home really, really upset and really stressed and tears pouring and everything ... I don't know which kid it was ...

Fraser: It might have been me ... I remember one time where you [mother] were out the front and I was crying, but I wouldn't tell you what happened to me.

Fraser's mother: Yeah, because it wouldn't come out. I mean, he didn't want to [tell] – that was one thing, because it meant the effort of having to tell me ... but I don't know which kid it was this time, but they came home and they were really, really upset. And it took over an hour to find out what the story was ...

This quote also reveals the battle experienced by Fraser's mother in having multiple children with dyspraxia, and with the multiple roles she had taken on for each child: interpreter, protector, advocate and case manager. She spoke of being tired and 'stressed out', but also isolated and alone in her experience. She reported doing speech and language therapy programmes at home with Fraser and then visiting the school each day to do the programmes there. Fraser's mother described the battle she experienced in trying to coordinate all of the information and programmes she was receiving from the numerous professionals involved in her children's care:

Fraser's mother: You've got the paediatrician saying 'this is what you do with this' then you've got the occupational therapist [saying] 'you do this with that,' the speech pathologist [saying] 'you do this with that,' But not once did they all sort of get together and say 'well, if these things are all happening, what exactly are we doing?' It was me in the middle trying ... 'OK, I'll take that advice because I think that's appropriate, so I'll take that advice, that advice, that advice – because it's working.' And then you find that doesn't work, 'OK, I'll go back to that one ...' So you've got this constant juggling all the time ...

c Battles:Tim's mother: For Tim's mother, the main battles she encountered were challenging life situations which affected her ability to balance knowing, having and doing:

Tim's mother: Being number nine in a large family, he [Tim] didn't have to learn to speak because speech was done for him. I was aware of that but also my life at that stage was extremely busy because ... there was an eighteen month old son ahead of him [Tim] who had serious heart conditions and he died at five.

While she was 'highly aware' that Tim had difficulties with speech, other life factors (i.e. the health and medical needs of Tim's older brother) impacted on her ability to do more to assist Tim (see Figure 2b). As her awareness of the impact of speech impairment on Tim's everyday life activities developed, Tim's mother felt 'guilty' that she didn't do more, but she acknowledged the life battles that contributed to this inability to assist (e.g. being 'busy' and having 'other stuff going on'):

Tim's mother: He was always slower on that [literacy development]. And you see once again guilt comes in, that horrible word, and thinking ... he could get away with it 'cause there was so much other stuff going on and he managed ... I can remember though I was saddened by that comment when he said to me about all the stuff that he had in his brain that he couldn't get it out, that he couldn't express it and ... I realized, he couldn't express it even in a family time ... 'cause we were so busy and we would move on ...

Battles to balance life factors and the task of raising children with communication impairment were also identified by parents of children using AAC in the study by Goldbart and Marshall (2004). In their study, parents described feeling worn down due to the demands on their time and energy, socially isolated due to the lack of support for the difficulties they were managing, and/or guilty for not having put enough time into working with their children.

For Tim's mother, additional difficulties were associated with Tim's lack of cooperation in intervention, due to his age and other family (life) factors:

Tim's mother: So anyway we did try those [therapy activities]. But also I'm not quite sure whether ... when [brother] died, Tim actually went into a childhood depression, I could say, when I look back on it. He ... he switched off for a while.

These findings are consistent with previous research which has described the influence of a range of factors related to services (e.g. waiting lists and cost), families (e.g. illness, time and work commitments), and children (e.g. readiness to participate) on the ability of families to access and engage in speech and language therapy (e.g. Goldbart and Marshall, 2004; McAllister et al., 2011). For instance, the parents in Goldbart and Marshall's (2004) study reported that professionals did not always understand or acknowledge the demands on their time and energy. The findings from the current study reinforce the need for therapists to provide sufficient knowledge, support and direction for families to make informed decisions about intervention and to enable participation, but to be aware of family goals and priorities outside of speech and language therapy.

6 Discussion of the method

This study was the first qualitative investigation of the experience of speech impairment from early childhood into early adulthood, and semi-structured interviews with two individuals was chosen as the most appropriate method to obtain detailed descriptions and understandings of individual experiences. It is acknowledged that there are limitations to such research, namely the inability to transfer findings based on two individuals to the wider population of individuals with speech impairment. In particular, there were a number of significant contextual factors that may have impacted on the experiences of the two individuals in this study and their mothers (e.g. family size, family history, ill family members). However, the methodological approach used in this study was chosen due to the depth, rather than the breadth, of data that could be collected. The qualitative design fulfilled this purpose, by enabling a deeper understanding of the experience of speech impairment from the perspective of the two individuals and their parents, and by highlighting the similarities and differences in experience that may exist among individuals with a diagnosis of speech impairment. The aim of this study was to describe experiences of childhood speech impairment and it is acknowledged that participants' descriptions were therefore reliant on their memories

of experiences. Triangulation of data sources was used to ensure consistency of data for participants.

7 Future research

Speech impairment is a heterogeneous condition and the context of all individuals and their families are unique. In the current study, the ICF (WHO, 2001) proved a useful way of exploring the range of difficulties that may be experienced by individuals with childhood speech impairment, but also the contextual (environmental and personal) factors that may contribute to their experience and the battles they encounter. It enabled an understanding of the similarities and differences in experiences between families, and among family members, and the way in which life interacts with speech impairment to influence those experiences. Further research with a larger number of participants would be useful to determine whether the experiences, and battles, described by the participants in this study are consistent with those of other individuals with speech impairment and their parents. Further research with individuals of different ages, or with the same individuals at different points throughout their lives would also be useful to understand how their perceptions and descriptions of the experience of living with speech impairment change over time.

IV Conclusions and implications for practice

Individuals with speech impairment and their families provide valuable insights into the experience of living with impairment. There is a need for research and clinical practice to consider such qualitative information alongside quantitative data in order to have the most socially significant and ecologically valid evidence on which to base clinical decision-making (Kovarsky, 2008). In the current study, participants described the experience of speech impairment in terms of knowing that an impairment existed, having an impairment, and doing something to address the speech impairment and associated difficulties. Their descriptions have implications for service delivery, and provide evidence of the need to modify clinical practice.

First, awareness of the speech impairment occurred at different times for parents and individuals, which may have implications for timing of intervention. Furthermore, the impairment was identified as being associated with a range of difficulties, which present differently at different life stages. Intervention, then, needs to be holistic and extend beyond the early years. For children and adolescents, the focus of intervention should be expanded beyond 'traditional' therapy aimed at improving impaired skills (such as articulation or language) and focus instead on quality of life (Brinton et al., 2005).

A focus on quality of life could extend to family members as well as individuals with communication impairments (Arkkila et al., 2008). The parents in the current study identified themselves as experiencing battles, as well as their children. They reported distress with observing their children's struggles, and occasional difficulty communicating with their children. They also described feelings of guilt, isolation and fatigue. Hence there is a need to support families as well as individuals in SLT intervention.

Finally, results from the current study reinforce the need for therapists to involve individuals with speech impairment and their families in decision-making about intervention goals and to provide intervention that will have real-world effects. Thus, engaging in true family-centred intervention should remain a goal for SLT clinical practice (Crais et al., 2006; Watts Pappas and McLeod, 2009).

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