



The experiences of living with a sibling who stutters: A preliminary study

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ABSTRACT

Stuttering impacts on the child in a variety of ways, notably in terms of communicative impairment and psychosocial impact. In addition, the stuttering disorder has a holistic impact, affecting those with whom the child who stutters lives. Within the family constellation, the closest person to the individual who stutters is often their sibling. This study investigated the experiences of fluent siblings of children who stutter to examine the impact that stuttering may have on their lives. A mixed methods research design incorporated qualitative semi-structured interviews and quantitative questionnaires. The results of the qualitative investigation revealed four aspects of children's lives that were affected by having a sibling who stuttered: the relationship between siblings, the impact on the fluent sibling, the impact on the parent relationship with both children, and the impact on the sibling's relationship with others. Findings revealed that siblings of children who stutter exhibited strongly negative emotions, and differing levels of responsibility associated with their involvement in the actual stuttering management programme. Furthermore, for the fluent sibling, secondary to having a brother or sister who stuttered, communication with and attention from their parents was variable. The results of the quantitative component of the study revealed children who stutter and their siblings demonstrated significantly greater closeness, and concurrently, increased conflict and status disparity than did the control fluent sibling dyads. The parents of the experimental sibling dyads also demonstrated significantly greater partiality towards a child, namely the child who stuttered, than did the parents of the control sibling dyads.

Educational objectives: The reader will be able to: (1) identify the themes associated with having a sibling who stutters; (2) identify how the quality of the sibling relationship differs between sibling dyads that do and do not consist of a sibling who stutters; and (3) discuss the clinical implications of the results with regards to working with children who stutter and their families.

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1. Introduction

Children who stutter (CWS) experience more than just the observable typographical features of part word repetitions, whole word repetitions, sound prolongations, inaudible blocks, or audible blocks (Manning, 2010; Ward, 2006). Their stuttered speech can be viewed in terms of several interacting components: presumed etiology, impairment in body function, affective, behavioural, and cognitive reactions to stuttering, the environment, limitations in communication activities, and restrictions in participation (Yaruss & Quesal, 2006). The stuttering disorder is also likely to have an even more holistic impact, affecting those with whom the CWS interacts, such as parents, siblings, friends, extended family and teachers.

Treatment approaches for young children who stutter usually necessitate a significant amount of family involvement. Therapy strategies are provided by the clinician in the clinical setting; however the suggested therapy techniques are implemented at home in the context of the family environment (Millard, Nicholas, & Cook, 2008; Yaruss, Coleman, & Hammer, 2006). Efficacy data supportive of a beyond-clinic parent–child interaction therapy (Millard et al., 2008), comprised of six sessions of clinic-based therapy and six sessions of parent-led home based therapy, yielded significantly reduced stuttering frequency in preschool children (Millard et al., 2008). In addition, experimental data for early stuttering treatment compared two treatment approaches which both employed parent administered procedures (Franken, Kielstra-Van der Schalk, & Boelens, 2005). Results indicated that the stuttered behaviour frequencies and overall stuttering severity ratings decreased for both treatment groups. Franken et al. also showed that therapy positively affected parents, given that treatment acceptability and satisfaction were rated positively by the parents themselves (Franken et al., 2005).

The impact of stuttering and stuttering therapy on the siblings of CWS and the subsequent quality of the sibling relationship has to date not been thoroughly explored. It has been suggested by Bank and Kahn (1982) that siblings follow a particular relationship life cycle. In early childhood, they provide a constant source of companionship; during the school years, they extend themselves to others external to the immediate family; and during adolescence, siblings demonstrate ambivalence regarding their relationship but still confide in and advise each other to a considerable extent (Seligman & Darling, 1997). Siblings, in general, share the majority of time with each other, especially during childhood, and siblings often spend greater time with each other than with their parents (Dodd, 2004). It has been suggested that the emotional ties between siblings are second only to those between children and their parents (Furman & Buhrmester, 1985), and that these sibling relationships are unique in terms of their power and dynamism (Young, 2007). Despite these findings, there has been more research and more clinical focus on the relationship between the parents and the CWS than on the sibling relationship (Young, 2007).

The impact of living with a sibling with a health condition has been explored in the context of other disabilities such as autism (Rivers & Stoneman, 2003; Wolf, Fisman, Ellison, & Freeman, 1998), Down's syndrome (Cuskelly & Gunn, 2006; Wolf et al., 1998), diabetes (Hollidge, 2001), epilepsy (Mims, 1997; Rossiter & Sharpe, 2001), cerebral palsy (Pit-Ten Cate & Loots, 2000), and spina bifida (Bellin, Kovacs, & Sawin, 2008). Concerns of non-disabled siblings have included: over-identification, embarrassment, guilt, isolation, loneliness and loss, resentment, increased responsibilities, pressure to achieve (Russell, Russell, & Russell, 2003), social stigmatisation (Moore, Howard, & McLaughlin, 2002) and bullying (Boer & Dunn, 1992). Furthermore, there have been reported difficulties in the development of self-identity (Moore et al., 2002), as well as frustration at the lack of education and information regarding the disabled sibling's needs (Harris, 1994). Positive implications have also been described by siblings, including such attributes as increased maturity and insight, tolerance, pride, advocacy, loyalty, strength and resilience (Russell et al., 2003). Notably, it has been found that when a child lives with a sibling with a disability, their feelings are comparable to the parental feelings yet, as children, their concerns are rarely heard (Barr, McLeod, & Daniel, 2008). Despite the presence of disability in one member of a sibling relationship, the very nature of being siblings (e.g., being relatively close in age, schooling and social circles), predisposes them to having shared social experiences and shared life impact.

Barr et al. (2008) explored the experiences and impact of a speech impairment on siblings in the context of a family-centred practice therapy. One of the key tenets of family-centred practice is the focus on the family as the collective client, in contrast to the singular child. This form of therapeutic practice incorporates the interconnected nature of family relationships and therefore proposes that therapeutically the focus is not exclusively on the child, but may be on the entire family. Findings from the qualitative interviews conducted with the siblings of the child with the speech impairment and their parents during the family-centred therapy, identified four areas of impact. These areas included the impact on the sibling relationship, the impact on the sibling's relationships with others, the impact on the sibling themselves, and the impact on the relationship between the parent and sibling. A positive relationship was found between the sibling and the child with the speech impairment. Specifically, when others were present, the sibling tended to interpret and speak for the child with the speech impairment in order to protect them from being misunderstood and potentially embarrassed. Siblings described several personal difficulties including jealousy and concern about their sibling with the speech impairment. In addition, there were several modifications within the relationship between the parent/s and the sibling reported, with the siblings reporting that parents spent an unequal amount of time with them due to the requirements of caring for the child with the speech impairment (Barr et al., 2008).

The current study sought to add to the literature with respect to the experiences of siblings of children with communication disorders by exploring these areas of impact from the point of view of the siblings of children who stutter. To place these sibling reactions in the context of the entire family system, the perspectives of parents and the child who stutter were also examined. Specifically, the purposes of the present study were to investigate: (a) the themes which exist regarding

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