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## Toward an Understanding of Acquired Hearing Loss in a Family: Narrative Play Format as a New Voice in Qualitative Methodology

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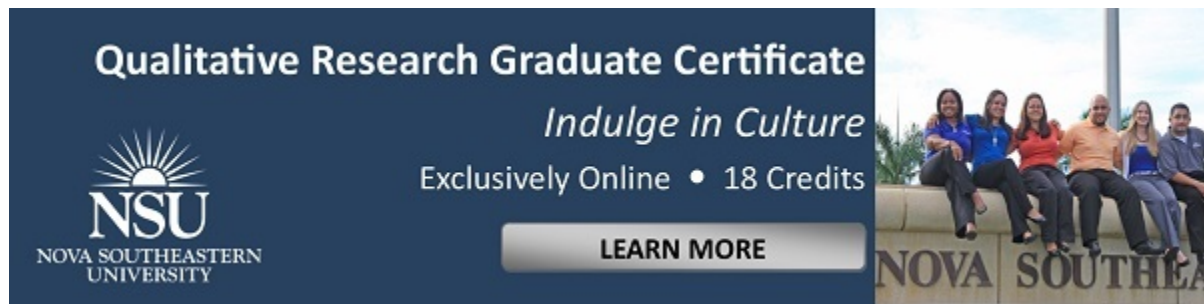
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### Abstract

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### Keywords

qualitative research

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# **Toward an Understanding of Acquired Hearing Loss in a Family: Narrative Play Format as a New Voice in Qualitative Methodology**

by

**Bruce A. Kent, Brett E. Furlonger, and Delwyn A. Goodrick<sup>±</sup>**

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## **Abstract**

This study examines how the reality of acquired hearing loss effects one family. Some consideration is given to the medical elements of the condition but the primary concern is with the psychological and social affects of hearing loss. The affects of the loss are revealed, by using systematic introspection in a narrative play format. This writing format is evaluated as the chronology of events, emotions, turning points and coping strategies are revealed.

## **Introduction**

Researchers who have reported the impact of acquired hearing loss in adults (Ramsdell, [1978](#); Knutson & Lansing, [1990](#); Rutman, [1989](#)) have identified that hearing loss primarily affects the individuals ability to communicate effectively, thereby significantly impacting on interpersonal interactions. Depression, anxiety, loneliness and social withdrawal have all been documented as symptoms of acquired hearing loss in adults. Rutman ([1989](#)) and Dineen ([1990](#)) both argue that acquired hearing loss can be more disabling than congenital hearing loss. Rutman considers hearing loss equal to the death of a significant other, retirement, relocation and the deterioration of physical health. Not only does this population suffer lifestyle changes, they may also have to change careers (David & Trehub, [1989](#)), and experience fewer options in the workplace (Reib, [1994](#)). People with acquired hearing loss often report that professionals seem to lack understanding and empathy and often confuse the treatment of those with acquired hearing loss with congenitally deaf people (David & Trehub, [1989](#); Woolley, [1993](#)). Bibby, Beattie and Bruce ([1996](#)) note that the recent literature seems to focus on five major issues that confront deafened adults. These issues illustrate their experiences: their sense of belonging, the role of feelings in dealing with hearing loss, the effects of hearing loss on communication and life style, their contact with professionals, and the coping strategies they develop. The present study revisits these issues, using an experimental writing format in an attempt to more effectively engage with the complexity of acquired hearing loss in a family.

## **Rationale for Approach**

There is some evidence that research within the social and behavioural sciences is experiencing a dual crisis of legitimation and representation (Lincoln & Denzin, [1994a](#)). Lincoln and Denzin,

two notable advocates of qualitative research term this crisis 'the fifth moment' ([1994b](#)). They indicate that "we are in a new age where messy, uncertain, multivoiced texts, cultural criticism, and new experimental works will become more common as will more reflexive forms of fieldwork, analysis and intertextual representation" (p.15). This crisis is reflective of postmodern critiques about the nature of knowledge and the purpose of research. One of the major arguments of these authors is that traditional research approaches negate the important role of the researcher in constructing the research account. In most standard forms of research presentation the author is invisible or represented as the objective third person. The 'sanitised', researcher-proof research account legitimates the conclusions drawn (Rosenau, [1992](#)). The underlying message is that the data (truth) will speak for itself. This is clearly not the case as all research accounts reflect limitations of methods, language, and choices by the researcher about what is important to include or leave out (Charmaz & Mitchell, [1997](#)).

Fine ([1994](#)) suggests that researchers who conduct research within the social sciences are 'working the hyphen'. She uses this phrase to indicate the interdependence of researcher and research participant and the ways in which they mutually influence each other within the research process. She suggests that researchers must better examine the relationship between the 'self' of the researcher and the 'other' of research participant. Researchers are encouraged to be more reflexive (Woolgar, [1988](#)) about their accounts of 'other' in particular when studying the experiences of different cultural groups. One's own experience; biography and purpose require exploration as all research accounts are built on interpretations of the researcher (Kleinman, [1991](#)). The area of deafness, similarly to culture, would also seem particularly amenable to the inclusion of reflexive analysis (Evans, [1998](#)).

In recent years there have been some notable examples of a turn toward more reflexive, iterative methodologies and on the fringe of these an acknowledgment of the role of the researcher's self within a research product not merely as the producer of the research product but as participant. (Ellis, [1993](#)). New textual and experimental forms include the use of poetry (Richardson, [1993](#)) dramatic plays (Ellis & Bochner, [1992](#)), split format narratives and 'layered stories' (Lather, [1995](#)).

These examples are evidenced broadly in the social science and humanities disciplines however there appears to be developments that challenge conventional designs in research in deaf education as well. For example as early as [1989](#) David and Trehub presented an article arising from questionnaires and interviews with deaf adults. The author does not claim that such portrayals are generalisable but rather that they facilitate readers' understanding of the emic (or insider) experience of deafness. Perry ([1996](#)) also extends rich descriptive qualitative information presented about 'others' and illustrates the use of the first personal narrative or storytelling mode in her lengthy article about her own story of hearing impairment. Janesick ([1994](#)) points out qualitative research has often been reported with little of the authors' reflections on the ways in which the material or experiences connect with or to their own life. Such reflections may be particularly relevant when exploring a topic area that the author/researcher has also experienced. Yet, such accounts have not always been welcomed by the academic community sometimes being labelled as self-indulgent thus invalidating the intensity of the author's personal experience (Mykhalovskiy, [1997](#)).

## **Implications for Practitioners**

We offer this example of systematic introspection (Ellis, [1991](#)) of a personal experience as a means of enhancing practitioners understanding of acquired deafness. There exists only a small body of research on acquired deafness in adults. Professionals, especially audiologists, physicians and counsellors working with this population, could benefit from information gleaned through a first person analysis of the topic. The value of such an analysis is evident in a provocative article by Stetten ([1981](#)) in which he recounted his own experience of going blind. The purpose of his article was to raise awareness among professionals of the importance of seeing behind the diagnosis to the individual's experience. He suggests that the ophthalmologist's attitude toward his blindness reflected their technical concern: "We are more interested in vision but have little interest in blindness" (p. 458). The experience Stetten recounts is clearly not confined to eye specialists; there is a tendency to privilege technical knowledge over personal knowledge and yet personal knowledge contributes to practitioners' diagnoses. The purpose of this article is to explore one potential new form of writing and research; one which utilises the researcher's experience as data. The objective and presentation is similar to Perry in that we are adopting this format as a valid and potentially instructive research 'tale' (Van Maanen, [1988](#)). We also discuss the contribution and challenge such reporting formats may entail. This style of presentation is not offered as a replacement of more traditional research forms: we support 'critical multiplism' (Shadish, [1993](#)) and the use of multiple methods while acknowledging inherent weaknesses in all methods. It is, however important to stimulate discussion and debate about the most appropriate and useful ways to gain an understanding of experience that is often not amenable to testing, survey methodology or experimentation (the 'gold' standard of research). This article seeks to make the first author's experiences salient through an acknowledgment of the embeddedness of the experience within his life. Firstly, it deals with a topic (acquired deafness) on which little has been written. Secondly it represents an attempt to delve into the newer forms of experimental writing discussed in emerging texts within the social sciences. Thirdly, while experimenting with a new form of representation we wanted to consider and problematise some of the issues which emerge from this 'new voice' in social science research.

## **Data Generation and Collection: The Family and the Research**

The 'family' are the first author's wife and sons. The first author has a brother and a sister. The brother also has an acquired hearing loss while the sister remains unaffected. At the time of writing the first author was 41 years of age, married with two young children. The family are of European decent and live in the South Pacific. The desire to conduct first-person research by the first author grew out of a frustration with the way professionals had dealt with his condition and his questions. The desire then was to tell the story from the 'inside out', providing a depth of understanding never gained from stories told about acquired hearing loss from the 'outside in'. Over a six-month period he visited, interviewed and recorded his family's responses to his questions. Each of his siblings and their wives and were asked to complete a questionnaire asking them about their knowledge of the history of the hearing loss and the effects of it on their lives (Alpiner & McCarthy, [1993](#); Spitzner, Leder, & Giolas, [1993](#)). These responses were read by the first author and provided a basis for constructing a 25 question semi-structured interview. The first author, his siblings and their partners undertook the two-hour interview. Building on this data, the first author and his wife, each wrote an extended report of their own experiences of

the effects of acquired deafness and their developing relationship. From these reports the narrative was constructed by transforming the separate accounts into a dialogic mode of narration.

### **Data Processing: Presentation of the Narrative**

This presentation of the personal experience of acquired deafness has been developed jointly between the 3 authors. It utilises a 'narrative play' format (Ellis & Bochner, [1992](#)), which is a style adopted to better portray the interconnectedness of stories within a family. The narrative play format creates the effect of a performance with the purpose of allowing the reader to connect with more than words. Potentially the reader can envision facial expressions, movements, gestures, tones, and inflections in the actors' voices, feeling the passion of the performers (Ellis & Bochner, [1992](#)). The authors follow Ellis and Bochner ([1992](#)) in presenting the story of Bruce and Wendy's adjustment to deafness and recount the reconstructed chronology of events including emotions, turning points, and coping strategies. Bruce and Wendy presented their reflections independently; the dialogue that follows was jointly constructed from the transcripts. The categories were chosen after the text was transcribed and discussed among the authors. As Ellis and Bochner ([1992](#)) observe, personal narratives bridge the dominions of public and private life. Extending the bridge analogy suggests that the foundations must be anchored in both domains, that the construction involves scaffolding and that the final structure may be extended, renewed or replaced. In addressing the context of acquired hearing loss the first author found reviewing the literature validated his experience of hearing loss. In this sense the public domain provided a foundation point from which to explore, categorize and develop a sense of coherence of the private domain. The affirmation of experience crystallized the themes considered in the semi-structured interviews and the initial writing. The collaborative writing process supported the construction of the personal narrative - the author engaged with an audience and the audience in turn entered the authorship.

### **The Cause of the First Author's Deafness**

Bruce's deafness is caused by otosclerosis that is the second stage of the two stage otospongiotic-otosclerotic disease. Essentially the biochemistry of the inner ear causes the bone structure to soften and cease to pass sound vibrations to the nerve endings in the cochlea. The chemical change can also affect the cochlea and in the case of endolymphatic hydrops the fluids in the cochlea may pass from one chamber to another causing a temporary but complete hearing loss. In 90% of cases the onset of the disease is between 15 and 45 years of age (Jerger & Jerger, [1988](#)). There is no standard medical treatment although restorative surgery (a stapedectomy) may improve hearing and sodium fluoride is frequently used to stabilise the bone degeneration. The trigger of the disease may be an autoimmune process with genetic or hormonal determinants (Causse, et al., [1989](#)).

### **History of Our Deafness and Treatment**

*Bruce:* My brother David and I have followed the typical pattern of Otosclerosis - a gradual decline in hearing until in the later stages endolymphatic hydrops occurs. We have both had

stapedectomy operations but neither of us feel we have received any benefit from them. However I did not suffer the intense physical pain that my brother David did.

A further difference in our treatment has been the use of diuretics to control my hydrops; a procedure which has been relatively successful to date. I do not know why this was never offered to David. Otosclerosis has genetic determinants, yet neither David nor I received any genetic counselling over the three decades we have been treated by specialists.

For nearly 20 years I had been lead to believe my deafness was nerve deafness and never provided with a prognosis other than a vague comparison to Beethoven. My brother David and his wife Ngaire had similarly nebulous medical explanations, when any were offered. In fact I was 33 years old before I was told the actual name of the condition and that my brother was in the same situation. We both felt that we were treated as 'ears' rather than people!

## **A Spoiled Identity**

*Bruce:* I first became conscious of my own hearing loss around the age of 16 when I realised that it was more difficult to hear on the telephone with my right ear than my left. Despite having uncles who were deaf and a brother who was by now wearing a hearing aid, my own hearing loss seemed trivial and not worthy of any mention.

I functioned well amongst my peers, performing leadership functions in my youth group and generating fun and mischief for others. No one had trouble communicating with me. I had never seriously considered being deaf and felt I was the same as everyone else until one day my hearing loss was thrust into focus in a very painful and humiliating manner.

As part of my teacher-training course I had to present a video recorded lesson of myself, teaching children. During this lesson I had to ask some students to repeat their responses. When the tape was reviewed in my college class the lecturer queried the repetition. "Anyone could hear that!" I recall feeling belittled and vented my anger and shame on my motorcycle, by fast and reckless driving on my way home. From that time on I became more aware that I had noticeable difficulties, but still refused to accept that I was having problems with my hearing. I felt I wasn't like my brother David. He needed hearing aids and visits to medical specialists. He often didn't fully understand what was said and people had to make a more conscious effort to talk with him. I wasn't like that. It was only in a few situations that I didn't completely hear everything but these situations were exceptional and excusable.

Over a five-year period, while at college, I had come to know Wendy (my future wife) quite closely as we had a similar circle of friends. While she was always aware of my hearing difficulties they did not become problematic until we married.

*Wendy:* Bruce's hearing difficulty first became apparent to me during telephone conversations when he was about 17. Sometimes he appeared to have difficulty hearing me although I mistook some pauses in conversation as him thinking before talking. He seemed reluctant to talk on the telephone but I rationalised that as a personal idiosyncrasy. He had a reputation for being vague in his responses but I thought at the time that may have been due to him not fully hearing details.

Because his deafness was not significant in those days, the prospect of having a deaf spouse wasn't an issue and, tending to be optimistic by nature, I also thought his hearing may not get worse. I was aware of Bruce's brother David's deafness but wrongly thought that their deafness



was due to different causes. Even if I had been fully informed of the facts I don't think that deafness would have changed my desire to marry Bruce.

After we married, attempted discussions about Bruce's hearing loss was met with denial and hostility. I recall being a little frightened at the end of one particular discussion about his deafness when Bruce vehemently stated, "I hate, abhor and despise deafness " and then angrily refused to communicate further.

*Bruce:* The different responses after our marriage were probably due to the depth of involvement which only comes through being intimately involved with a person over a period of time. It is quite different to know about deafness in your partner and to actually live with that day after day, year after year. For example, routine communication such as, Wendy having difficulty talking to my 'deaf' side or my back when we were in bed. It is probably the difference between "knowing" information and "understanding" through direct experience.

*Bruce:* At age 21 I finally felt I had to get specialist advice. After the tests were conducted the specialist told me that I had the same problem as Beethoven. Apart from fitting me with hearing aids he said there was nothing else that could be done and in the long term my hearing would continue to deteriorate. I remember at the time that he could have achieved the same result if he had hit me with a brick and taken my wallet. I was stunned and depressed because there was no cure, just a future of declining competence.

## **Facilitating Change**

The spouses of hearing impaired people may not share the same perceptions of the condition or means of dealing with it. Hallberg and Barrenas ([1993](#)) examined the perspective of spouses living with hearing impaired males. They identified two core findings: the husband's reluctance to acknowledge hearing difficulties and secondly the impact of hearing loss on the intimate relationship. They suggest that the "male's tendency to deny and reject hearing difficulties is driven by his striving to protect a positive self image and to avoid being defined as a deviant; that is being an abnormal person" (p. 257). Repeatedly they found confirmation of the male's fear of being inadequate, abnormal or 'deviant'- the strong denial was intended to avoid the stigma of deafness.

*Bruce:* I was fitted with a hearing aid but refused to wear it. It epitomised the deficiency. If I had to wear 'that thing' I would be acknowledging that I was not normal - that I had a handicap.

*Wendy:* I consider I have always had a practical and somewhat simplistic view of deafness often saying "if a hearing aid will help then wear one!" This attitude was divergent from Bruce's and for many years our different perspective's stayed in the "too-hard-to-deal-with basket". I wanted Bruce to seek medical advice concerning the prognosis, treatment or management of his condition but he was reluctant to do this thinking the only help being offered was 'to hang one of those things on my ears'.

## **Understanding the New Identity**

Thomas ([1988](#)) suggests that successful rehabilitation of adults with acquired hearing loss demands in-depth knowledge of the person affected - their attitudes and feelings towards their hearing loss, how they coped with it in their everyday lives and the effect it has on their personal



well-being. An individual's sense of personal identity and well-being implies a social relationship. By its nature deafness is "peculiar in that it is social from the beginning .... it strikes at the heart of social interaction" (Jones, Kyle & Wood, [1987](#), p.16).

*Bruce:* Most of the time I could get by and I had developed a range of strategies to cope with difficult situations. Within a conversation I would typically ask a lot of questions to avoid being questioned and also avoided quietly spoken people. When teaching I structured work environments to suit my condition and would set up small group work rather than large group lessons.

I still felt happy talking to a large group such as an assembly as there were usually few, if any, questions from the audience. I think at times, I reinforced the perception that I was a vague and reflective person, in order to cover my lack of hearing and response to questions. I continued to have a serious problem with the thought of wearing a hearing aid as I knew it would set me apart as different or more precisely as deficient. It was not part of my current image. How would I appear as a teacher if I wore a hearing aid? Hearing aids and deafness to my mind were associated with old age and incompetence!

*Wendy:* I felt additional pressure by having to cope with supporting him in social situations. Out of love and loyalty I wanted to protect him (and probably myself) from embarrassment and shame by answering for him. However this became increasingly difficult because I didn't want to appear to be a domineering wife with a pathetic husband unable to answer questions for himself. For a considerable time Bruce had a hearing aid but was unable to bring himself to wear it until we went overseas where he was unknown. Later visits to medical professionals both public and private in New Zealand and London were unsatisfactory and essentially they seemed to do little more than fit new hearing aids.

*Bruce:* I began to think I would wear a hearing aid if I had a 'new start' in an environment where no one knew me and I didn't have an established image to live up to, or so I promised my wife! I got the 'new start' by moving to London but struggled with my new image. A continued decline in hearing finally compelled me to wear a hearing aid; I was now dependent on one whether I liked it or not. But I felt obvious and odd having to wear one.

The sense of stigma was very strong. Consequently I disguised my "problem" and continued to hide the fact that I was deaf. I would not tell anyone of my condition and became very sensitive about my hairstyle as I attempted to keep enough hair over the ear to hide a hearing aid.

*Wendy:* Bruce's unreasonable defensiveness and inability to deal effectively with deafness frustrated me. For example, only I was allowed to cut his hair, and not being expert this created stress every time. He worried about having long enough hair to cover his hearing aid, and I worried about the limitations of his fine hair to cover the aids and how I was going to meet his stringent expectations.

*Bruce:* Another effective way to hide the deafness was to avoid social contacts that might lead to discovery, in part exacerbated by living in a new country. I no longer had an established network of friends and family around me who knew my condition. It was easier to simply not make new contacts. By doing this I failed to develop what could have been useful networks of contacts for support and employment.

Although my wife was patient and loyal, she couldn't understand why I refused to accept my hearing loss and be 'up front' with people. Any in-depth discussions about deafness resulted in

her feeling frustrated with my non-acceptance and attempts to conceal my real motivations and emotions while I continued to anguish over not being able to identify any solution to my problem.

*Wendy:* Bruce still demanded secrecy about the true situation and I was very uncomfortable with the deception, but I also began to avoid some social situations in order to avoid this issue.

*Bruce:* Periodically I returned to various specialists while living in London and twice had to upgrade my hearing aid as my hearing deteriorated.

I hoped that they might provide me with some direction to solve the problems that I faced. But their advice was always very similar to that which the first specialist had given me, my hearing would probably decline, and they could only provide bigger and more powerful aids.

## **Growing Apart**

A couple form a dynamic dyad in which they jointly establish and maintain a common culture within the family structure (Rice, [1984](#)). They may have to cope with a disjuncture in the personal growth rates of the partners (Vash, [1981](#)) due to disability and be forced to review their shared culture and future goals. Progressive hearing impairment demands that the person consider future options and objectives (Sanders, [1993](#)). Woolley ([1991](#)) notes, "the deafened person looks to medicine for a cure to problems which are seen as stemming from faults in the ear. When the cure is not forthcoming, the deafened person experiences a further loss-that of hope" (p. 223).

As with any serious disability, both the individual concerned and the family may become handicapped. Or, as several people repeated to Vash ([1981](#)), "Disability is one hell of a test of love"(p.66).

*Bruce:* After five years in London I had become bored with my job and the issue of my reluctance to accept my deafness had begun to seriously threaten our marriage. Conversely Wendy enjoyed her work but was very frustrated that I had not come to terms with my deafness, and wanted some space to think about our future together. I decided to return to New Zealand to see if I could settle down and re-establish myself. I had only planned to take three months to do this but it became a year before Wendy felt comfortable enough to leave London for New Zealand.

*Wendy:* The matter was highlighted when Bruce returned to New Zealand a year ahead of me to get re-established. I was not sure at that point if he would ever be able to accept the consequences of deafness. I was giving up hope that Bruce would ever be able to accept and adjust to his hearing loss. I missed the old Bruce who used to be so light-hearted and was now at times depressed and angry.

## **An Identity Challenged**

The building and maintenance of identity including career identity is an important developmental stage. A hearing disability can, however, threaten the successful development of identity particularly when individuals are faced with a hearing community who may hold negative stereotypes about deafness (Taylor & Bishop, [1991](#)).

*Bruce:* My 'new start' resulted in me disguising my deafness again, thinking it would spoil my career prospects. Naturally, once I was established in a teaching job, I couldn't then disclose my loss because I had already created the 'hearing teacher image'. Except for a few trusted friends and family (whom I felt accepted my condition without me having to conform to unspoken expectations) I confided in no others.

I did not discuss my deafness with colleagues because I felt that the public admission of 'weakness' would jeopardise my job. I considered that in general teachers were not particularly good at keeping confidences.

*Wendy:* I doubt that Bruce would have chosen a different career, but I think he would have advanced further in mainstream education if he had normal hearing. He kept a low profile and declined positions of responsibility to maintain the pretence of normality.

*Bruce:* The degeneration of my hearing was unrelenting and in due course I experienced a very complete incidence of what is known as endolymphatic hydrops (a total but temporary loss of hearing). I was hospitalised for five days while receiving treatment.

Now my deafness was becoming unavoidable. But what was I to do? No one seemed to offer any realistic possibilities that would meet the practical requirements of my family and my own personal needs of feeling worthwhile and stimulated. I adopted a functional coping mode to simply get by each day. Future plans seemed futile because I didn't have much hope of functioning effectively.

A lack of hope, an underlying sense of anxiety and frustration at repeatedly exploring what seemed like dead-end options were constant emotions. An awareness of my deafness and its consequences (not to mention the possibilities of sudden and total loss) were always in my thoughts.

*Wendy:* I also felt a sense of fear as I had to consider the prospect of becoming the primary earner in the family - a fear that was heightened with the birth of children. When Bruce was hospitalised with a complete hearing loss due to hydrops I was 4 weeks pregnant with our first child and felt very vulnerable.

I also felt some resentment against the way in which his reservations about his genetic legacy had played a part in delaying our decision to have a family (Bruce was by then 39 and I was 36). I wanted to see Bruce freely acknowledge his deafness without embarrassment or shame. I did not want him to feel apologetic or weak admitting his disability. I felt this potential change in attitude, and decided to work towards improving communication between ourselves and others. Finally, because his problem could not be avoided any longer we discussed it with close friends and our specific fears about the long-term impact of his hearing loss.

Personally, I was very worried about becoming the primary income earner and having less time to be a mother to my young children. I was also very worried about Bruce's self esteem if he was forced onto welfare as a 'sickness beneficiary'.

*Bruce:* The sense of despair finally forced me to seek outside help. Wendy and I met with some old friends and shared our problem. Wisely, our friends directed us to address our worst fears of unemployment and possible loss of income. The loss of income would have meant problems with paying the mortgage and planning a secure financial future for our children.

## **Moving Forward**

The degree of inter-relatedness of the family members and the impact of self-validation from family relationships is important in ameliorating communication difficulties and their consequences. Family relationships are challenging; where there are unexpected crises such as a disability the family unit must attempt to integrate the new situation so that a healthy relationship can be maintained (Goldenberg & Goldenberg, [1991](#)). Sanders ([1982](#), [1993](#)) indicate that acquired deafness is a family problem, since those close to the person who experiences a sudden loss of hearing also experience considerable anxiety and apprehension.

*Bruce:* Together, we worked through the problems and faced these fears. The experience left my wife and I with a glimmer of hope and some renewed options. One result of this was that I began to actively investigate the possibility of combining my teaching with my deafness. To my surprise I discovered that in the area of deaf education a hearing loss was not seen as a deficit.

Learning of the possibilities of teaching the deaf provided me with significant hope. At last there were attractive prospects. To be given the opportunity to actually begin teaching in Deaf Education removed a lot of anxiety about providing for my family and it also started to affirm the beginnings of my new identity. I felt I could once again engage in meaningful study and practice, be accepted in a social grouping and therefore have a sense of personal worth and efficacy.

*Wendy:* Thankfully, his eventual move into deaf education reduced a lot of my fears and instigated many positive changes in Bruce's attitudes. He became more open to admitting his deafness to others and talked more freely about his unique communication needs.

He then became more relaxed about meeting new people and less anxious about his work environment. I believe his fear of being found out and feeling inadequate greatly reduced and I suffered fewer pressures as a result.

### **Further Challenges**

*Wendy:* One of the biggest tests to our 'new attitude' to deafness came when our 2-year-old son contracted Meningitis. It was a challenging time because of the nature of the illness. Not only is meningitis life threatening but children who recover are often left with a hearing loss. Bruce was terribly shocked when told the diagnosis after having seen his son drift into a coma. What made it worse was that Bruce had attended a seminar that morning at the National Audiology clinic during which they had discussed the serious effects of this condition on children's hearing. We both started to feel our dreams and hopes for our son slipping away. While we had adjusted to Bruce's deafness we did not want our son to be deaf.

Our son did finally recover, but the event was a profound shock to us both and again challenged our understanding of what deafness meant to our family.

*Bruce:* It was such a challenging time for me because of the sudden and extreme nature of the illness. At the time we had to face getting Andrew to the emergency room and finding someone to look after our other son Matthew. I was nearly overwhelmed by the frantic nature of trying to get an ambulance, getting to hospital, and seeing him get a lumbar puncture.

When the preliminary diagnosis was made I felt stunned and sank back into a chair groaning and exclaiming "Oh no!". I felt weak kneed, faint and experienced the most intense feelings of fear. I

had time that night to reflect on the possible loss of language Andrew may experience and what might have to be a massive shift in our care-giving roles for him.

### **Reflections on the Impact of Acquired Deafness**

*Wendy:* There are still areas in both our lives that remain affected by deafness. The occasional onset of endolymphatic hydrops still causes difficulty and we have had to adopt routines that permit regular communication of daily matters. During these times our children watch television while we talk about household business that without deafness would typically be discussed while engaged in another activity. We have also had to buy certain items of technology such as flashing lights, fax, intercoms, baby-alarms and telephone answering machine.

Overall, I think deafness has made Bruce more reclusive in nature. Prior to the onset of severe deafness he could be the life and soul of the party always with an opinion and would participate actively in lively discussions, especially on controversial topics. Now he avoids this type of group discussion and many social events. On the occasions when we do attend a social gathering he tends to avoid the mainstream of conversation and endeavours to interact on a one-to-one basis.

Interestingly, even simple actions have been affected - for example Bruce modified his laugh, as opening his mouth and laughing vigorously caused his hearing aid to whistle loudly. I miss his old laugh and would like to see him put his head back and have a really good laugh as he used to in the past.

*Bruce:* Deafness has been a formative element in our family. All the family have lived for decades with incomplete and erroneous information. My wife has had to adapt to a different role not of her choosing and the impact of acquired deafness continues to make its presence felt, despite our accommodations to its effects, in our family.

### **Data Analysis: Emerging Issues From Experimental Writing Formats**

The complexities of acquired deafness call for new methodologies that attempt to explore the experience. We support the continued development of methods and strategies to explore deafness and welcome discussion of the efficacy of such approaches. Nearly two decades ago Schön ([1983](#)) introduced the notion of the reflective practitioner into academic discourse. One of the core components of his theory was that professionals have experiences that are often messy, unstructured and difficult and which cannot be resolved by recourse to theory; such experiences form an important part of professional development and understanding.

We believe these new forms of writing research commend themselves to practitioners working within the field of deafness. As practitioners hear the stories of their clients they form a composite knowledge base that influences their work and their understandings of that work. However, practitioners have often been discouraged from using their experience in clinical settings to guide the development of understanding and have usually been encouraged to turn to conventional views of empirical research (Eisner, [1991](#)). This story captured the first author's voice at a moment in time and he considers the narrative play format provided an appropriate medium to share the story. In personal terms, the process has been an important step in the construction of a sense of self. More importantly, the story is acknowledged as capturing an

experience shared by others confronting a similar condition. This confirms the quality of the work and indicates the utility of the methodology for practitioners. The collaborative construction of the narrative play format demanded that the private domain be exposed to critical scrutiny as it was documented. The assessment of 'reasons and evidence' commented on by Conostas ([1992](#)), was intrinsic in the methodology employed. The methodology thus enabled the telling of a story with a strong authorial presence while also employing collegial reflexivity (Seale, [1999](#)).

### **Trustworthiness: Ourselves as Experimental Subjects and Our Experiences as Primary Data**

The presentation of these newer forms of experimental writing raise a number of considerations for authors and participants. A number of ethical dilemmas are inherent in work of this nature as the research participant (and author) is no longer anonymous within the account. Tensions are intrinsic in the use of personal narrative as a bridge between public and private domains. By sharing an authentic voice the author may generate aesthetic public appeal but also privilege a particular view (Seale, [1999](#)). Publication of the authentic voice may also jeopardise the private self. A future revision of the story would require renegotiation of the boundaries of public and private domains. This highlights the necessity of sensitivity to ethical practice and the on-going necessity of consultation in the evolving writing process.

The rich and descriptive narrative can expose not only the participant but also those that are connected with the participant, in this case the spouse, the brother, workplace colleagues and so on. Negotiation of ethical principles not only with the co-researcher but also with those implicated by the story may be important considerations.

Bruce's story of his deafness has proceeded through a number of iterations. The secondary authors did not alter Bruce and Wendy's words but modified their presentation. We are aware of the limitations of any written piece that attempts to capture the feelings associated with acquired deafness as in parts the narrative seems disjointed and truncated however we have attempted to maintain the integrity of the narrative as originally presented. Interestingly, Ellis and Bochner ([1992](#)) have expressed similar difficulties in their personal account.

This article has involved an extended conversation between the authors about the experience, reflections on the experience, appropriate methods and terms to write the experience. This afforded Bruce with the opportunity to reflect upon his deafness within his family, and to portray that experience in the way he chose, rather in a way that was driven by the researchers. At the same time the dialogue between the authors enhanced the expression and quality of the voice and the understanding of all participants. This example of a narrative play format is offered as an encouragement for others to engage in a similar process of encapsulating private voices in the public domain." The potential benefits of involving research participants in writing 'themselves' rather than interpreting on their behalf are empowerment, a deeper self-knowledge and a depth of understanding perhaps not achievable by those who were not part of writing the experience.

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