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Journal of Fluency Disorders 29 (2004) 275–305

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Journal of  
**FLUENCY  
DISORDERS**

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# Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: personal accounts of South African individuals

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Received 25 September 2003; received in revised form 6 July 2004; accepted 7 October 2004

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## Abstract

The purpose of the study was to investigate the life experiences of a group of South African adults who stutter and the impact of stuttering on their quality of life. Participants were 16 adults with a mean age of 28.9 and ranging from 20 to 59 years. Methods involved individual interviews designed to explore the life domains of education; social life; employment; speech therapy; family and marital life; and identity, beliefs and emotional issues. Main findings of the study indicated that the majority of participants perceived their stuttering to have impacted on their academic performance at school, and relationships with teachers and classmates. Although their stuttering was not perceived to adversely influence their ability to establish friendships, people generally reacted negatively to their stuttering. Many felt that their stuttering did not have an adverse effect on their choice of occupation, ability to obtain work, and relationships with managers and co-workers, although it was perceived to influence their work performance and hamper their chances for promotion. Although the majority viewed their speech therapy experiences as being negative; more than half the sample believed that speech therapy had, nevertheless exerted a positive effect on their quality of life. Overall, stuttering did not appear to have influenced participants' family and marital life. Most participants felt that stuttering had affected their self-esteem and self-image, and had evoked strong emotions within them. Findings are taken to suggest the need to incorporate subjective feelings about stuttering into the clinical practice of speech-language therapy; to provide information and coping strategies for teachers and employers; and for further research.

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**Educational objectives:** After completing this activity, the reader will be able to: (1) describe and explain the perceived impact of stuttering on quality of life in terms of education; social life; employment; speech therapy; family and marital life; and identity, beliefs and emotional issues; (2) to interpret and utilize the subjective meanings that individuals attach to their stuttering to improve stuttering treatment, counseling and research.

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*Keywords:* Stuttering; Life experiences; South Africa; Quality of life

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## 1. Introduction

Although many people who stutter have written about their personal experiences of stuttering, very little systematic research appears to have been conducted regarding the perceived impact of this communication disability on quality of life (O'Keefe, 1996). The World Health Organisation (1993) defines quality of life as the perception of individuals of their positions in life in the culture and value system in which they live, relative to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by people's physical health, psychological state, level of independence, social relationships and their relationships to salient features in the environment (World Health Organisation, 1993). The experience of stuttering for the person who stutters may include negative affective, behavioral, and cognitive reactions, both from the speaker who stutters and the environment. This experience may also involve significant limitations in the individual's ability to participate in daily activities and a negative effect on the person's overall quality of life (Yaruss & Quesal, 2004).

O'Keefe (1996) believes that severe communication disabilities are likely to exert a negative impact on quality of life as they cause frustration for those individuals who experience them. The enjoyment of many of life's meaningful activities can be severely restricted when people attend to the manner of speaking more than the message it carries, which may be the case with stuttering. Consequently, communication disorders such as stuttering, are likely to exert a profound influence on the person at all stages of the life cycle. For example, during school-going age, studies have shown that children who stutter tend to perform slightly below average in school (Peters & Guitar, 1991). Although some school-age children who stutter are teased by peers and react by withdrawing from social situations, Peters and Guitar (1991) maintain that not all children who stutter are socially detached. Some are friendly, outgoing and sociable and gain support from their peers. With the advent of adolescence, Van Riper (1971) explains that making friends, especially with members of the opposite sex, may be difficult for the teenager who stutters. During adulthood, establishing intimate relationships may present unique difficulties for the adult who stutters (Ross, 2001). An additional factor of major concern to the adult who stutters is choice of occupation. According to Van Riper (1971), many people who stutter may strive for lower levels of achievement than their normally speaking colleagues due to low self-esteem and the overwhelming fear of failure.

With regard to speech therapy, Manning, Dailey, and Wallace (1984) reported that while a few of the participants in their study (aged 52–82 years) had experienced some degree

of success as a result of treatment later in life, the majority did not desire treatment at the time they were studied. Many adults who stutter report negative experiences associated with speech therapy (Louw, 1996, p. 46). Peters and Guitar (1991) explain that in many cases, stuttering forms a primary part of the adult's identity. It may be a part of themselves that they hate, a part on which they place many other troubles, a part they want to eradicate. And yet there are adults who stutter who would not consider receiving speech therapy for their difficulty. After years of emotional pain and anguish, these adults have grown accustomed to themselves as people who stutter and to consider therapy would imply rejecting themselves.

Manning, Dailey, and Wallace (1984) also examined the attitudes and personality characteristics of 29 people aged 52–82 years who stuttered, using five questionnaires. Results indicated that the vast majority of older stutterers perceived their stuttering as less disabling than when they were young adults. Furthermore, Leith, Mahr, and Miller (1993) administered self-report questionnaires to 67 people who stuttered in the United States, 27 from Finland, and 30 from Hungary. They found that treatment for stuttering was frequently frustrated by such attitudes and beliefs on the part of the stuttering person as denial, passivity, helplessness, guilt, shame, and anger.

Joss (1993) empirically assessed whether drawings were a viable method of reaching the thoughts and feelings of school-aged individuals who stuttered (age 8–12 years). Participants were able to produce iconic images of stuttering, and could both draw and describe these images. The predominant impression obtained, was that stuttering was viewed as an unpleasant experience (Joss, 1993). Pistorius (1994) subsequently investigated the conceptualization of adults and adolescents who stutter, of their stuttering. The images that were elicited tended to mainly reflect feelings of discomfort, restriction and anxiety (Pistorius, 1994). However, a criticism, which may be leveled against both these South African studies, is that they failed to take into account the influence of cultural differences.

In 1998 Corcoran and Stewart conducted a qualitative study, using in-depth interviews in which they investigated the experiences of adults who stutter. They found that suffering was the primary theme, which emerged from the analysis of the interview transcripts. Kathard (2001) carried out an exploratory study of the life history of a single participant in KwaZulu–Natal who stuttered. Critical events, turning points, identity issues, individual thoughts and emotions, and the community in which he lived received attention within a sociopolitical context. However, the use of a single case design precluded generalization of results to the broader population of people who stutter. More recently, St. Louis (2001) elicited from individuals who stutter, their life experiences with stuttering. Corcoran and Stewart (1998) mention that stories of people who stutter offer valuable insights into the meaning that stuttering has had over their life span and the personal meanings they have attached to it.

People who stutter express a vast array of psychological experiences associated with stuttering, including reports of challenge, triumph, and heartache (Ginsberg, 2000). Conture (2001), Conture (2004) and Conture, Walden, Arnold, Graham, and Karass (in press) believe that the psychosocial processes of people who stutter are complexly related to their speech production behavior. They maintain that speech-language pathologists need to consider the life context of people who stutter, for example, in terms of family and society. Such a perspective is likely to assist them in seeing the individual who stutters as a unique person, and as a functioning individual interacting with a number of people.

“The personal meaning that stuttering has for an individual must be woven into the ‘who am I?’ identity issue for it to be understood as an integral part of the life tapestry” (Kathard, 2001). Consequently, the purpose of this study was to describe the life experiences of people who stutter; the meaning they attach to their stuttering and its impact on various life domains at various stages of the life cycle, and its effect on their quality of life as viewed from their perspective. Specific life domains targeted included education, employment, social life, speech therapy, family and marital aspects, as well as identity, beliefs and emotions. This research project endeavored to expand and build on existing research by investigating the life experiences of people who stutter within the multicultural context of South Africa. Furthermore, the profession of speech-language pathology is primarily clinically oriented and it was envisaged that this research project would contribute to existing theory regarding subjective dimensions, which could supplement the therapeutic process.

## 2. Methodology

### 2.1. Participants

The study was located within a qualitative, small group research design, which incorporated interviews with 16 adults who stuttered. Participants were selected via non-probability, convenience sampling techniques, which prevented the generalization of results to the broader population of adults who stutter, but nevertheless generated rich descriptions of the personal meanings attached to stuttering and how it impacted on individuals in the real world. Participants were recruited from various sources, including Speakeasy SA Stuttering Association of South Africa, University of the Witwatersrand Speech and Hearing Clinic (Johannesburg) and personal contacts.

Participants were selected according to the following criteria:

*Diagnosis of stuttering:* Participants were required to have been given a diagnosis of stuttering by a speech-language pathologist, following a formal assessment, as this study focused on the life experiences of people who stutter and the impact of stuttering on quality of life.

*Language:* Participants were required to be competent in English in order to minimize the misinterpretation of the questions, as the interview was conducted in English.

*Age:* As this study focused on the perspectives of adults, participants were required to be over 20 years of age.

Table 1 shows age (mean age = 28.875 years; range from 20 to 59 years), race, employment history, and treatment history of participants. It should be noted that three of the persons who were unemployed were completing their tertiary education and three were seeking employment. Those who had received speech therapy at various intervals in their lives attended for periods ranging from two sessions to 10 years. Only four persons reported attending speech therapy at the time of the study. Participants reported that their stuttering severity fluctuated depending on the context, the audience to whom they were speaking, health status, fatigue, and their stress level and emotional state.

Table 1  
Demographic profile of participants ( $N = 16$ )

| Demographic factor   | Sub-group                    | Number |
|--|------------------------------|--------|
| Age  | 20–25                        | 7      |
|  | 26–30                        | 6      |
|  | 31–35                        | 1      |
|  | 36–40                        | 0      |
|  | 41–45                        | 1      |
|  | 46–50                        | 0      |
|  | 51–55                        | 0      |
|  | 56–60                        | 1      |
| Gender   | Male                         | 9      |
|  | Female                       | 7      |
| Ethnic group   | Black                        | 6      |
|  | White                        | 5      |
|  | Indian                       | 5      |
| Marital status   | Married                      | 2      |
|  | Single                       | 13     |
|  | Widowed                      | 1      |
| Educational level  | High school                  | 1      |
|  | Post matriculation           | 15     |
| Employment status  | Employed                     | 10     |
|  | Unemployed                   | 6      |
| Age at onset of stuttering   | Infancy                      | 3      |
|  | 5–11 years                   | 1      |
|  | 12–15 years                  | 11     |
|  | 16–20 years                  | 1      |
| Age at formal diagnosis of stuttering by a speech-language pathologist | 5–11                         | 6      |
|  | 12–15                        | 2      |
|  | 16–20                        | 3      |
|  | 21–25                        | 1      |
|  | 26–30                        | 3      |
|  | 31–35                        | 1      |
| Utilization of speech and language therapy                             | Received therapy             | 15     |
|  | Did not receive therapy      | 1      |
| Participants' ratings of the severity of their stuttering              | Manageable/recovered         | 1      |
|  | Mild                         | 3      |
|  | Moderate                     | 3      |
|  | Severe                       | 1      |
|  | Varies from mild to moderate | 5      |
|  | Varies from mild to severe   | 3      |

## 2.2. Research instrumentation

Interviews were used as the method of data collection in the present study, because the researchers felt that they were more suitable in terms of obtaining information regarding the personal accounts of the life experiences of people who stutter and the impact

of stuttering on quality of life. The researchers designed an original interview schedule since an extended literature search did not yield any suitable existing instruments, which met the specific needs of the study. The interview schedule comprised both closed and open-ended questions, with structured items supplemented with additional follow up questions. A copy of the schedule is set out in [Appendix A](#). The interview schedule was divided into seven sections including: Demographic Information; Education; Social Life; Employment; Speech Therapy; Family and Marital Life; and Identity, Beliefs and Emotional Aspects.

### 2.3. *Research protocol*

#### 2.3.1. *Pre-testing the interview schedule*

Prior to conducting the study, the interview schedule was pre-tested by using two people who stutter and who met the participant selection criteria but who did not participate in the research study. Amendments suggested by these two participants were incorporated in the final version of the interview schedule. For example, an item on defining stuttering and a question on finding a cure for stuttering were incorporated under the section on Identity, Beliefs and Emotional Aspects.

#### 2.3.2. *Data collection*

After obtaining Ethics Clearance for the study from the University of the Witwatersrand Ethics Committee for Research on Human Participants as well as participants' informed consent to participate in the study, arrangements were made for personal meetings in order to complete the interview schedule. Individual interviews took approximately 1–2 h to complete and were conducted at the University of the Witwatersrand Speech and Hearing Clinic, and participants' homes.

### 2.4. *Transcriptions of audiotapes and field notes*

Although all participants were given the choice of expressing themselves verbally or writing down their responses, they all chose the interview option. Following each interview, the interviewer transcribed the audiotapes and supplemented these transcriptions with her field notes. Responses were subsequently analysed by the same person and checked by the second researcher.

#### 2.4.1. *Data analysis*

The qualitative data obtained from the interviews were analyzed in terms of content analysis. [Rosnow and Rosenthal \(1996\)](#) explain that content analysis is utilized to highlight common themes elicited in response to open-ended questions and describe them in a systematic and quantified fashion. In attempts to most fully understand the dataset, the person who conducted the interviews reiteratively read and re-read, participants' responses. Firstly, responses were categorized in terms of whether stuttering *did* or *did not* affect quality of life within the various life domains. Thereafter, recurring themes and sub-themes within each life domain were identified. As recommended by [Wilson \(1997\)](#), once the thematic classification scheme was established, an independent rater checked the classification of the

material, in order to enhance the inter-rater reliability of the classification scheme. Once agreement had been reached between the two raters, the various themes and sub-themes were quantified.

### 3. Results and discussion

Results are discussed in accordance with the sub-aims of the study.

#### 3.1. Education

##### 3.1.1. Perceived effects of stuttering on academic performance at school

Of the total sample of 16 participants, 6 reported that their stuttering exerted *no* effect on their academic performance at school, while 10 believed that their stuttering *did* negatively impact on their academic performance to a greater or lesser extent. In terms of the 10 participants who perceived their stuttering to have negatively affected their academic performance at school, various sub-themes emerged which included:

*Oral presentations*—This theme emerged in the responses of 8 out of the 16 participants. Blood, Blood, Tellis, and Gabel (2001) explain that educational settings place a major emphasis on oral communication skills focusing on public speaking and interactions in small groups.

*Others' lack of understanding of the participants*—Lack of understanding demonstrated by teachers and others was evident in the responses of two of the participants. According to Rustin, Cook, and Spence (1995) many people who stutter report that they have found the support and help received from an understanding teacher invaluable in their educational progress and personal growth. However, equally, there have been reports of unenlightened teachers who appear to have little or no understanding of the painful experiences of people who stutter. One of the participants explained the lack of understanding demonstrated by his teachers as follows: “*You weren't given the same opportunities as other children. They don't understand it – they aggravate it. They won't give you the chance to answer – because take extra time so you don't prepare*”.

*Reading aloud*—Reading aloud emerged in the responses of two of the participants. Peters and Starkweather (1989) state that reading aloud is an aspect of school life, which stresses fluency. Most teachers are not sure how to deal with a child who stutters during oral reading.

*Self-confidence*—This theme was evident in the responses of two of the participants. In terms of self-confidence, there is agreement among clinicians and researchers working with people who stutter that speech disorders may have adverse effects on self-perception and, particularly, on self-esteem (Bajina, 1995).

##### 3.1.2. Perceived effect on relationships with teachers

Table 2 illustrates the perceived effect that stuttering had on participants' relationships with their teachers. Out of the sample of 16 participants, 6 (37.5%) reported that their stuttering did *not* have any impact on their relationships with their teachers. They attributed this lack of impact to teachers' understanding them, and the fact that the participants were

Table 2  
 Perceived effect of stuttering on relationships with teachers ( $N = 16$ )

| Themes        | Sub-themes                      | Number    | Examples of quotes reflecting themes and sub-themes  |
|---------------|---------------------------------|-----------|--|
| Had no effect |                                 | <b>6</b>  | The teachers were fine.<br>No, at school – no discussions, you did what you were told. I didn't really communicate with the teacher. I wasn't quiet because of stuttering – I'm a quiet person.  |
|               | Teachers' understanding         | 4         | No, none whatsoever. Teachers were quite understanding about the whole thing.  |
|               | Treated normally                | 2         | I was treated as a normal person in class.   |
| Had an effect |                                 | <b>10</b> | Yes. I think so because I never spoke to them – they formed the opinion that I was not interested and that I didn't take initiative. To . . . a great extent, wait for you to talk, others rush you. You feel belittled, didn't feel like normal kids. Wouldn't know how to accommodate people who stutter – affect your self-image.   |
|               | Teachers' lack of understanding | 4         | Teachers didn't try and help because they didn't know why. They didn't bother finding out about stuttering – they actually aggravated it.<br>Teachers were not informed about speech and there were no facilities to do something about it.  |
|               | Pressure                        | 2         | My teachers . . . brought pressure on me – “What's wrong with you? Why are you stuttering now? I used to speak fluently, now I have a speech problem.<br>Yes. My English teacher forced me into situations. I was afraid of public speaking. She thought by forcing me – to get over it. She put pressure on me. For that fact I disliked her.   |
|               | Special treatment               | 2         | My mother is a teacher. I always got special attention from the teachers and other kids. I'm not sure if it was because of my status or my stuttering. I don't know if it was because of my speech, because they felt sorry to show concern.<br>Yes, because teachers tend to be more special treating towards you, more sensitive. This is not necessarily special treatment – it separates you from the class. |
|               | Belief/trust                    | 2         | An impatient teacher didn't believe in you. A teacher couldn't trust that there was a problem.   |

treated normally like other children. However, 10 (62.5%) of the participants stipulated that stuttering *did* affect relationships with their teachers. For 7 of these 10 participants, stuttering had a negative outcome on their relationship with their teachers, while 3 of the participants felt that stuttering had both positive and negative effects. “. . . Teachers . . . tend to be more special treating towards you, more sensitive. This is not necessarily positive. Positively: teachers were understanding, for example during speeches – I was placed in smaller groups. In negative way: special treatment – separates you from the class. Need a balance between the two”. In addition, negative pressure and special treatment from the teachers were viewed both positively and negatively.

The findings from Table 2 suggest that teachers’ understanding of the participants and of the nature of stuttering was viewed in both a positive and negative light, with some participants reporting that stuttering had no appreciable influence on the student–teacher relationship. These findings support the view expressed by Rustin, Cook, and Spence (1995) who believe that the majority of teachers are understanding, sympathetic individuals who are motivated to help their students. Teachers’ lack of understanding of the nature of stuttering was emphasized by one of the participants in the present study who stated “*In standard 1 – I moved to a new school and I was asked the 3 times table and I didn’t (couldn’t) answer because of my stuttering so they put me back in grade 2 for the year*”.

### 3.1.3. Perceived effects of stuttering on relationships with classmates

Out of the total sample of 16 participants, 3 (18.75%) reported that their stuttering exerted *no* affect on their relationships with their classmates, although 13 (81.25%) of the 16 stated that stuttering *did* have an effect on their relationships with their classmates. Where participants felt that stuttering had affected their relationships with their classmates, the main theme that emerged related to teasing which was mentioned by 6 (37.5%) participants. The negative impact of classmates teasing children who stutter was vividly reflected in the account of one of the participants of her experiences, “*I still remember them – it hurts*”. However, another participant viewed the issue differently, “*Before they know you, they tease, they talk behind you, then I tend to be more stubborn I don’t care what they say. I was dependent on myself. Stuttering made me independent*”. It seemed that this particular participant described his experiences as having both negative and positive consequences. Acceptance or rejection of the peer group is important for the school-age child, and “teasing becomes a major social crisis for the child who deviates from the norm” (Starkweather & Givens-Ackerman, 1997, p. 52).

## 3.2. Social life

### 3.2.1. Impact on social life in terms of establishing friendships

More than half, that is 9 (56.25%) out of the 16 participants reported that their stuttering *did not* have an impact on their social life in terms of establishing friendships; however 7 participants felt that it *did* exert an effect, either positively or negatively. Analysis of the responses revealed five emerging themes including: fear of talking, positive gains, others’ understanding of stuttering and of people who stutter, and teasing.

*Fear of talking*—This theme appeared the greatest number of times. Of the 16 participants, 6 (37.5%) mentioned fear of talking. The implications of fear of talking was depicted by one of the participants who mentioned, “*In the beginning onset of trying to make friends you worry what happens if I make a fool of myself. ‘She stutters she’s strange’. Hard to make that step. As you get older you cope with it better, you hide it better, it becomes easier. I would rather avoid it – prefer people to introduce me. It’s scary*”. Hayhow and Levy (1989) explain that fear is believed to be a central component of stuttering. People such as strangers, those who are in authority and people who ask direct questions may all be feared.

*Positive gains*—Of the 16 participants, 2 (12.5%) explained that stuttering had a positive influence in terms of their relationships with others. “*I actually gained out of it. Before, I used to be loud and a big mouth; then I spoke less, was quiet – got to know people on a personal level. Then I realized it’s not a major hassle to be quiet*”.

*Others’ understanding of stuttering*—It was felt by 2 (12.5%) of the 16 participants that this factor exerted an influence on the establishment of friendships and social relationships, which is also likely to affect quality of life.

*Teasing*—Although the theme of teasing emerged in only one instance, it has relevance in terms of establishing friendships that can in turn impact on quality of life. The finding regarding teasing lends support to the view of Dalton (1994) who maintains that people who are dysfluent may be teased or simply not listened to and it may be difficult for them to establish friendships.

### 3.2.2. Participants’ perceptions of people’s reactions to stuttering

Out of the sample of 16 participants, 6 (37.5%) viewed people’s reactions to their stuttering as being negative, 7 (43.75%) participants perceived others’ reactions in both a negative and positive light, 1 participant felt that people’s reactions to her stuttering were generally positive, and 2 participants reported a neutral reaction from people in response to their stuttering. In line with these findings, many studies show that listeners attribute negative attitudes toward stutterers (Collins & Blood, 1990; Silverman & Paynter, 1990), even when listeners have been speech-language pathologists (Lass, Ruscello, Pannbacker, Schmitt, & Everly-Myers, 1989). However, in contrast with these studies, Crowe and Walton (1981) found generally favorable attitudes expressed by fluent speakers towards people who stutter.

One of the participants in the current study highlighted the profound impact of listeners’ reactions by commenting, “*People can use it (stuttering) as a weapon to put you down, put pressure on you so they can look better than you growing up*”. Another participant reported, “*When I met a person who stutters – I felt uncomfortable – it was quite a shock to me – so I know how others feel – that’s quite amusing*”.

The following themes emerged with regard to participants’ perceptions of people’s reactions to stuttering:

*Listeners’ facial expressions and emotional reactions*—Perceived adverse feelings and reactions of the listeners, which occurred in 18.18% of the responses, included: laughing, embarrassment and helplessness; shock; lack of caring; nervousness and being frightened and awkward. In 7.27% of the responses, participants mentioned never knowing what was in listeners’ minds. These reactions were confirmed by Turnbridge (1994) who states that

often people will adopt a kind of trance-like look in order to pretend that nothing unusual is occurring. In terms of dealing with these types of unwanted situations, one participant stated, “*Situations have to be handled – where others laugh – few incidents at meeting (at work)/restaurant*”. In this respect [Guitar \(1998\)](#) explains that many advanced stutterers control their environments carefully in order to avoid situations in which they are likely to stutter. Other perceived negative reactions emerged in the themes of avoidance and discomfort in 10.9% of the responses. These findings are consistent with the research literature which explains that fluent listeners may attempt to avoid or limit conversation with stuttering partners and desire more social distance between themselves and stutterers ([McKinnon, Hess, & Landry, 1986](#)).

*Patience*—The issue of patience emerged in 14.54% of the responses. In terms of listeners demonstrating patience one of the participants explained that generally in the past people “*were impatient – not now*”. This point brings to the fore the positive attitudes that some listeners may have developed towards stuttering. Positive attitudes were also expressed by another participant, “*actually they’ll wait for me to finish what I’m saying and until I respond*”. However, in most instances participants emphasized the lack of patience displayed by listeners. This finding is consistent with the view of [Jonas \(1977\)](#) who referred to the impatient looks on other people’s faces when he had trouble getting a word out.

*Listeners completing sentences/words of people who stutter*—In 9.09% of the responses, participants conveyed intense dissatisfaction with the fact that people tended to finish their sentences for them. One person described how he tried to manage such situations, “*I over-cloud him, try to dominate him – so he would probably finish off sentences but I try to control the conversation*”. According to [Turnbridge \(1994\)](#), when most people are confronted by a stutterer who is having difficulty with speaking, they will finish the word or sentence for them. This reaction on the part of the listener is normal, although it may be annoying to the person who stutters.

*Understanding or lack of understanding*—In 5.45% of the responses, participants felt that listeners demonstrated understanding, for example, “*Now people are more accepting of disabilities and have more knowledge*”. Similarly, 5.45% of the responses revealed that people displayed a lack of understanding, as reflected in the comment: “*Little understanding on stuttering even from professionals*”. This finding was not unexpected as [Whaley and Parker \(2000\)](#) explain that fluent speakers are often unaware of the profound impact that stuttering has on the lives of people who stutter.

*Telephone calls*—Another area of concern in terms of listeners’ reactions, appeared to be telephone calls, which appeared in 5.45% of the responses. One lady recounted her telephonic experience in a humorous light, “*When I spoke on the cell phone and stuttered the other person said to me: ‘you are breaking up on the phone’ (cell phone), I was amused*”. According to [Leith and Timmons \(1983\)](#) one of the most commonly feared talking situations amongst people who stutter is speaking on the telephone.

Although participants in the present research highlighted the negative reactions people demonstrated toward their stuttering, they also remarked, in 5.45% of the responses, about the positive experience of acceptance by other people. [Starkweather and Givens-Ackerman \(1997\)](#) explain that one of the most striking effects on stuttering is that of the accepting listener.

Table 3  
Cultural views or beliefs regarding people who stutter ( $N = 6$ )

| Theme                      | Ethnic group | Number | Verbatim comments  |
|----------------------------|--------------|--------|--|
| Being left out in the rain | Black        | 1      | Once I heard my grandmother: ‘when you were a baby we took you out in the rain – rain dropped on you and you started stuttering’. You know Black people are superstitious. If Black people don’t understand something, give their own meaning. I never really believe in it. I never really had those beliefs. |
| Personality stereotypes    | White        | 1      | The more Westernized movies on TV – the guy who stutters is “stupid”, “introverted” – stereotypically – not a true message.  |
|                            | Indian       | 1      | Some say you are not very intelligent. Indian community: ‘you are stuttering you are a weird person, something major wrong with you’.  |
| Tickled                    | White        | 1      | I was tickled under my feet – that’s what caused it. ‘Cried until no breath – cold water was poured on me’ – that’s what caused it.  |
| Heredity                   | Indian       | 1      | The hereditary issue – like my dad had it for a while.   |
| Psychological factors      | Indian       | 1      | Yes, they (Indian community) think stuttering is psychological. They think I was abused when young, physically abused by parents when young.   |

Note: Responses do not total 16 as this item was not applicable to all the participants.

### 3.2.3. Cultural beliefs regarding people who stutter

In total, 6 out of 16 participants reported the existence of cultural views/beliefs regarding people who stutter. Table 3 indicates that within the sub-group of 6 participants (1 Black, 2 White and 3 Indian) who perceived their culture as having particular views or beliefs regarding people who stutter, factors surrounding the causes of stuttering emerged. Firstly, the theme of being left out in the rain was mentioned by a Black participant as being a cause of stuttering. This finding was also documented in a study undertaken by Platzky and Girson (1993) who investigated beliefs and attitudes of Black South African indigenous healers to stuttering. Secondly, personality stereotypes were described by a White participant as well as an Indian participant. These stereotypes included being ‘stupid’, ‘introverted’, ‘not very intelligent’, ‘weird’ and having ‘something major wrong with you’. According to Ham (1990) informants in his study viewed people who stutter as being less adequate and often characterized by poor adjustment. A third theme that emerged as a causative factor of stuttering was being tickled. This belief was described by a White participant who recounted childhood memories of tickling being a superstition associated with stuttering. Heredity was another theme mentioned by an Indian participant. This factor has been discussed in the literature. For example, Guitar (1998) maintains that, compared with nonstutterers, stutterers are more likely to have family members who stutter. More recently, Fox (2003) also highlighted the role of heredity in stuttering. An Indian participant identified psychological factors as being linked with stuttering.

### 3.3. Employment

#### 3.3.1. Occupational categories and influence of stuttering on choice of occupation

In total, 4 (25%) out of 16 participants perceived that stuttering *had* influenced their choice of occupation. However, 12 participants felt that it did *not* exert any impact. According to Peters and Starkweather (1989) in many professions fluent speech appears to be a ‘must’ and a ‘merit’, and therefore, often people who stutter let stuttering influence their career choice. Themes that emerged in terms of the influence of stuttering on participants’ choice of occupation included decrease in speaking demand, lack of sympathy and fear.

#### 3.3.2. Perceived effect of stuttering on ability to obtain work

Table 4 demonstrates the fact that, 8 (50%) out of 16 participants felt that their stuttering did *not* influence their ability to obtain work, as one of the participants explained, “*Speech has always been an issue in my own mind not in others*”. However, four people believed that stuttering did exert an effect in terms of obtaining work. A participant who at the time was completing his engineering degree anticipated that in future his stuttering would affect his ability to obtain work, “*It would after I finish my technikon studies. I wouldn’t be a teacher/lecturer. I realize that in engineering you need to talk. Companies would want someone who communicates well – so it would. Communication is the first thing*”. In line with these findings, Hurst and Cooper (1983) maintain that fluent speakers evaluate

Table 4  
Perceived effect of stuttering on ability to obtain work ( $N = 16$ )

| Themes            | Sub-themes                                 | Number   | Examples of verbatim comments reflecting themes and sub-themes  |
|-------------------|--|----------|---|
| Exerted no effect |  | <b>8</b> | No I think of other things influencing my ability.<br>No problem with this job.   |
|                   | Interviews were not problematic            | 2        | I was fortunate I was fine in interviews.   |
|                   | Employment agency helped                   | 3        | Not at all. With personnel agency it worked out. This is my first vacancy job.  |
|                   | Allaying fear through disclosure           | 2        | No. I’m up front with them because I need to know and believe that the school believes in me. Introduce it to the kids and principal. I always like to make things known. It takes away fear. |
|                   | Patience                                   | 1        | Mostly people in business situation are not impatient.  |
| Exerted an effect |  | <b>4</b> |   |
|                   | Interviews were problematic                | 2        | Yes   |
|                   | Personal contacts                          | 1        | Yes   |
|                   | Others interpret stuttering as nervousness | 1        | Many people interpret stuttering as nervousness.  |

Note: Responses do not total 16 as this item was not applicable to all the participants.

people who stutter as being less employable. Various sub-themes emerged regarding the perceived effect of stuttering on participants' ability to obtain work, namely interviews (25%), employment agents (18.75%), allaying fear through disclosure (12.5%), personal contacts (6.25%), patience (6.25%), and the interpretation of stuttering as nervousness by others (6.25%). Attending interviews was a sub-theme with which participants had negative associations. For example, *"at times if not adequate at interviews you lose them given eloquence"*. In addition, one person commented how therapy helped him during interviews, *"Since therapy, when I go to an interview I introduce that I stutter and to some level I can control it"*.

### 3.3.3. Perceived effect of stuttering regarding performance at work

Out of the sample of 16 participants, 6 (37.5%) felt that their stuttering *did* affect their performance at work. One lady recounted her negative experiences on the job which adversely affected her work performance, *"When I worked for 6 months, I had a terrible boss – she told me: 'No it's not a problem once I get into it it'll be fine'. She tried to 'fix my problem in a few days'. She used to phone clients and ask them how my speech was. I went home and cried. It pushed me back. You grow from it even through the bad experience"*.

In contrast, 6 (37.5%) other participants reported that their stuttering *did not* affect their performance at work, *"No, my performance at work is very good, hasn't affected my performance, I received an award"*. One of the participants explained the positive aspects of stuttering, *"In accounting side – wouldn't lose client because I stutter, didn't affect performance. You can use stuttering in your own advantage – people become more sensitive – use it to your own advantage for example in conflict people more soft towards you"*.

Three of the 16 participants conveyed mixed feelings regarding the influence of stuttering on their work performance. Similar findings were documented by [Silverman and Zimmer \(1982\)](#) who reported that the majority of persons in their study tended to consider that being a stutterer limited their chances of vocational success. However, two females who replied that being a stutterer had had a positive effect on their vocational success explained that, due to their stuttering, they worked harder to succeed and felt that they had achieved their goals.

### 3.3.4. Perceived effect of stuttering on relationships with supervisors or managers at work

The results from this study revealed that 7 (43.75%) out of 16 participants reported that their stuttering *did* affect their relationships with their supervisors or managers at work. One individual commented, *"Yes, I don't talk to them and I'm very quiet. When they talk to me my friend talks for me, they form opinions that I'm an innocent little girl"*. Half the sample reported that stuttering *did not* affect their relationships with their supervisors or managers. In contrast, [Joss \(1997\)](#) found that many stutterers in her study believed that their supervisors' evaluations of their job performance had been unfairly biased because of their stuttering behavior.

The themes that emerged with regard to participants' perceptions of the effect of stuttering on their relationships with supervisors or managers at work included avoidance of the

stutterer, being given special attention, supervisors conveying acceptance and understanding; and supervisors completing the sentences of the employee who stuttered. Furthermore, the issue of advertising stuttering also emerged in terms of employees explaining to their supervisors and managers that they stuttered.

### 3.3.5. Perceived influence of stuttering on relationships with colleagues or co-workers

Five (31.25%) of the 16 participants felt that their stuttering *did* influence their relationships with colleagues or co-workers, as one person stated, “*They usually take charge to do stuff. I’m more in the background, for example don’t go talk to people – because I worry about the initial contact. For example I think I won’t be able to say this*”. Just over half, i.e. nine participants felt that their stuttering did *not* have an influence on their relationships with colleagues or co-workers. One person explained, “*No, I don’t think so. Even if it did I am so insistent on saying it over and over again until they get it. People may misconstrue what you say – use other phrase – but I say over and over what I mean until the person gets it*”.

### 3.3.6. Perceived impact of stuttering on chances for promotion

Out of the total sample of 16 persons, this section of the interview did not apply to 8 (50%) participants due to the fact that at the time of the study they were not in line for a promotion. Two (12.5%) people believed that their stuttering did *not* impact on their chances for promotion while 6 (37.5%) felt that their stuttering *did* have an impact. Making telephone calls was viewed by one of the participants as a negative factor impacting on his chances for promotion, as he explained, “*Yes. I used to deliver pizza and to be promoted to a managerial position one had to make phone calls and quickly take orders and because of the stutter I wasn’t comfortable to take orders over the phone – under stressful conditions*”. Another participant felt that her boss viewed her work performance poorly which impacted on her chances for promotion, “*She (my boss) wouldn’t promote me as in her mind I wasn’t good enough – she gave me that impression because of the stuttering*”. These findings provide support for the views of Peters and Starkweather (1989) who maintain that a number of employers are unwilling to promote a person who stutters even though the person is able to interact with great effectiveness.

## 3.4. Speech therapy

### 3.4.1. Previous speech therapy for stuttering

Out of the sample of 16 participants, 15 (94.75%) reported that they had had speech therapy for their stuttering at various intervals in their lives, ranging from periods of 2 sessions to 10 years, while 1 person stated that he had never attended speech therapy. A somewhat disquieting finding was that out of the 15 participants who reported that they had undergone speech therapy, only one participant viewed speech therapy as being helpful in terms of enhancing fluency. The remaining 14 (87.25%) participants perceived speech therapy as non-helpful, as reflected in the comment, “*I went two years ago for one or two months and I wasn’t improving*”. In a study conducted by Silverman and Zimmer (1982) the majority of participants reported that during elementary school through high school their therapy experiences were generally not perceived to be helpful as they did not really

understand what exactly therapy was supposed to accomplish. However, after high school, therapy was regarded as helpful as the choice to attend therapy was theirs alone, and they were better able to understand the nature of therapy, their role and what might and might not be accomplished. Further negative sub-themes, which emerged from the current study, in terms of speech therapy included frustration, anger, lack of carry over to real life situations, lack of belief/trust between therapist and client, boredom and hatred towards therapy. One of the participants in the current study explained that she went to speech therapy out of curiosity. She mentioned, “*I don’t really need it, I wasn’t as bad as others. I lived with this thing most of my life, so I have learnt to control it*”. Hence future research needs to compare persons who have received speech therapy and still stutter with those who have undergone therapy but no longer stutter.

Four participants reported that they attended other forms of treatment for their stuttering in addition to speech therapy. Three people mentioned that they attended speech and drama, of which two related positive experiences associated with this activity. “*Speech and drama was very good for me, it was a confidence booster*”. One of the participants attended various elocution lessons, psychotherapy, hypnotism, numerous workshops on stuttering, and speech therapy in South Africa and abroad.

#### 3.4.2. Impact of speech therapy on quality of life

Table 5 shows that despite holding negative opinions of whether therapy helped them become more fluent, 8 (50%) of the participants nevertheless expressed the view that speech therapy *did* exert a positive effect on their quality of life while three people viewed speech therapy as having both positive and negative effects. Three participants mentioned that speech therapy had had *no* effect on their quality of life. One of the participants who reported that speech therapy had had a positive influence on her quality of life explained, “*It’s good, lucky my mom brought me when it first started when I was small*”. From analyzing the participants’ responses in terms of speech therapy exerting a positive effect on quality of life, a sub-theme that emerged in 37.5% of the responses was that speech therapy was helpful, “*Speech therapy did help me cope with some situations. I still use the techniques I learnt in therapy*”; “*After therapy I could control my speech*”. Another participant stated, “*Everything must have helped at the end of the day, now when I speak to you I have less blocks*”. Improvement in quality of life due to speech therapy was another sub-theme, “*it really added to my life*” which appeared in 37.5% of the responses. The sub-theme of confidence and self-esteem also appeared as a positive effect of speech therapy in relation to quality of life in 18.75% of the responses, as one of the respondents claimed, “*Therapy boosted my confidence. The speech therapist built me up to handle situations, for example job interviews*”. Another participant explained: “*In terms of quality of life therapy makes you more sure of yourself because if you do get stuck you have something to fall back on which gives you better peace of mind*”. These words highlight the sub-theme of something to fall back on which occurred in 12.5% of responses. Further, sub-themes that emanated from the theme of speech therapy exerting a positive effect on quality of life included viewing and understanding stuttering in an improved light (12.5%), and identification with others (6.25%). These findings are similar to those documented by Yaruss and Quesal (2001) who maintain that improvements in fluency often increase a speaker’s sense of confidence and ability to communicate freely.

Table 5  
Impact of speech therapy on quality of life (N = 16)

| Themes                                 | Sub-themes                                   | Number   | Examples of verbatim comments reflecting themes and sub-themes  |
|--|--|----------|---|
| Exerted a positive effect              |  | <b>8</b> |   |
|  | Helpful/improved quality of life             | 6        | It helped a lot because I know my stuttering was worse than now.<br>The therapy definitely improved quality of life. In terms of quality of speech it helped a lot.   |
|  | Enhanced confidence and self-esteem          | 3        | Improves your self-esteem – makes you feel positive and confident.  |
|  | Something to fall back on                    | 2        | You learn coping skills, you learn a technique – psychologically you fall back on it.   |
|  | Identification with others                   | 1        | Therapists will also tell you about others in therapy – you are not alone – which helps.  |
|  | Changed view and understanding of stuttering | 2        | They changed the way I thought stuttering was, to a better perspective. It wasn't as bad as I thought it was.<br>What I have learnt from therapies is the reason I stutter is that I try to talk fast then people don't hear me . . . so I should talk slower to be more eloquent when I speak . . . You need to relax and take things easy not to stutter. |
| Exerted a positive and negative effect |  | <b>3</b> |   |
| Positive effect                        | Stopped stuttering                           | 1        | When I was young – 14–15 years old – I went to therapy and stopped stuttering for 6 months to a year.   |
|  | Friendship and trust                         | 1        | I went to speech therapy and became friends with the therapist. It became more of a friendship to build trust again in speech therapy.  |
|  | Hope   | 1        | It gave me some hope, knowing I was learning techniques to help me.   |
| Negative effect                        | Mistrust and breach of confidentiality       | 1        | During grade 4–6 the speech therapist broke my confidentiality . . . so I did not trust a speech therapist ever again . . . A part of me is still wary of speech therapists.  |
|  | Frustration                                  | 1        | I became frustrated towards the end of therapy.   |
| Exerted no effect                      |  | <b>3</b> |   |
|  | Attended therapy for a short period          | 2        | No impact whatsoever because I only went four times.  |
|  | Helped only in terms of fluency              | 1        | In terms of quality of life there wasn't much difference – I'm still the same person. It did help in terms of fluency, I didn't need the therapy to improve my quality of life, just in terms of fluency.   |

*Note:* Responses do not total 16 as individual participants mentioned more than one theme.

### 3.4.3. Techniques or strategies used by participants for coping with stuttering

Findings showed that 13 (81.25%) of the 16 participants reported that they employed techniques or strategies to help them cope with their stuttering. Of the 13 people who reported that they were using techniques or strategies to assist their stuttering, 2 participants mentioned that they were not using the techniques all the time, depending on who the listening audience was, “*If I’m with friends and feel comfortable I won’t use any technique I’ll just be natural*”. This finding is consistent with the research literature, for example, according to Stewart (1996) speech therapists have found that speech therapy programs for adult stutterers can bring about major increases in fluent speech in the clinic, but these changes seem temporary and when subjected to external pressures the fluency breaks down. Numerous stutterers have shown an unwillingness to use fluency-enhancing techniques, despite positive reactions from normal listeners within their environment.

Of the 13 of 16 participants who mentioned strategies, the following strategies were described: varying the speaking rate (38.46%), changing words or phrases (30.77%), advertising stuttering (23.08%), taking a deep breath (23.07%), avoiding certain words (15.38%), avoiding eye contact (7.69%), and avoiding certain situations (7.69%). Thus one participant reported that, “*If you speak on the phone and you think you’re going to stutter – tell them, that’s useful. Learning to accept it, let people know you stutter it helps a lot*”. Body language also emerged as a strategy (23.07%). Another participants remarked, “*I feel more comfortable not looking in the person’s face but looking aside to form an image. I talk in pictures to express myself*”. These findings were not unexpected as Miller (1982) states that all fluency-based programs have in common, decreased speech rate, fewer stress contrasts and continuous breath flow, which allow stutterers more time to co-ordinate their systems of respiration, articulation and phonation for speech production. Breitenfeldt and Lorenz (1999) explain that stutterers usually try many ways to hide the fact that they stutter. This creates tensions within the person who stutters and communication is difficult as often stuttering is increased. Advertising lifts the burden of trying to be fluent and a stutter-friendly environment can be created.

Strategies that were perceived by 9 (51.25%) participants to be easy, and helpful, included Easy Relaxed Approach (ERA) and Easy Relaxed Approach Smooth Movement (ERASM), shortening sentences, changing words/phrases, using airflow, interjections/filler sounds, light contacts, advertising, and deep breathing. Techniques that were regarded as difficult and non-helpful by three people, included airflow, rehearsing and deep breathing. In line with these findings, Andrews, Craig, Feyer, Hoddinot, Howie, and Neilson (1983) conclude that five treatments, namely prolonged speech, precision fluency shaping, rhythmic speech, airflow therapy, and attitude change tend to produce significant benefits.

## 3.5. Family and marital life

### 3.5.1. Perceived influence of stuttering on relationship with parents

Out of the sample of 16 participants, 7 (43.75%) reported that their stuttering *did* exert an effect on their relationship with their parents while 9 (56.25%) stated that their stuttering *did not* influence their relationship with their parents. From analysing the responses of those persons who believed that their stuttering had had an effect on their relationship with their parents, the following sub-themes emerged:

*Impatience* (18.75%), *lack of understanding* (18.75%) and *completion of sentences* (12.5%)—“My mom constantly finishes my sentences for me and when I mention it to her she doesn’t understand that it doesn’t help me”. In line with these findings, Guitar (1998) maintains that stressful adult speech models, defined by speech rate, polysyllabic vocabulary, complex syntax, and/or a multilingual environment, are factors that may trigger or maintain dysfluency in children.

*Participants’ stuttering had been painful for parents* (18.75%)—“My parents were very hurt and sad as it was a surprise”.

*Parents expected less of the stutterer than his/her siblings* (6.25%)—“They always had less expectations, far less expectations than for my brothers and sisters”.

*Parents paid more attention to the child who stuttered* (6.25%)—“They started paying more attention to me”.

Upon analyzing the responses of those persons who believed that their stuttering had *not* influenced their relationship with their parents ( $n = 9$  of 16 participants), the sub-themes of *support* (12.5%) and *being treated like other family members* (6.25%) were found, “My parents weren’t wealthy but they still sent me to England for therapy, it was very expensive. They made every effort to help”.

### 3.5.2. Perceived effect of stuttering on relationships with siblings

Out of the sample of 16 participants, 8 (50%) felt that their stuttering had *only positive* effects in terms of their relationships with their siblings, while the other 8 reported that their stuttering exerted *both positive and negative* effects in this regard.

*Positive effects*—Participants mentioned receiving support (12.5%), being encouraged to develop their expressive abilities (6.25%), the development of close relationships (6.25%), demonstration of understanding (6.25%) and patience (6.25%).

*Negative effects*—Themes included jealousy and competition (6.25%), suggestions given regarding speaking (6.25%), pity (6.25%), impatience (6.25%), lack of belief and trust in one another (6.25%), lack of understanding (6.25%) and embarrassment (6.25%).

The inextricable link between positive and negative effects was highlighted in the following response of one participant: “Say I stutter, they always teased you, it was like a joke. I have a very witty family who say very witty comments. It wasn’t offensive I took it as a joke”. According to Peters and Guitar (1991), members of the family play a part in children’s social and emotional development. On the one hand, the child’s brothers and sisters provide a wide support system. On the other hand, the child’s resentment at having to share his/her mother’s attention may provoke feelings of anger, aggression, and guilt. If these feelings are punished or ignored, they may provoke temporary disfluency, or they may make stuttering more severe.

### 3.5.3. Perceived impact of stuttering on relationships with spouses or partners

Ten (62.5%) of the 16 participants felt that their stuttering exerted *no* negative impact on their relationship with their spouse or partner, while the remaining 6 participants reported that the stuttering impacted both positively and negatively.

*Positive effects*—Positive reactions included: demonstrations of patience (6.25%), support (6.25%), and understanding (6.25%), showing awareness of stuttering (6.25%) and explaining this condition to others (6.25%).

*Negative effects*—Negative sub-themes which emerged, included frustration (12.5%), withdrawal (6.25%), lack of belief or trust in the stutterer (6.25%), embarrassment (6.25%), a need to remedy the problem (6.25%), lowered self-esteem (6.25%), lack of understanding (6.25%) and discomfort (6.25%).

### 3.5.4. *Influence of stuttering on decision to have children*

Within the sample of 16 persons, only 2 reported that they had children, which may have been related to the age profile of the sample. Both of these participants stated that their stuttering had *not* influenced their decision to have children. One of the two spoke about the fear associated with the fact that his children might stutter, however this fear did not influence his decision to have children. The issue of fear was reported in a study by [Boberg and Boberg \(1990\)](#) which revealed that many couples feared having children who would also stutter and were apprehensive about being stuttering role models. However, in the current study, 12 of the 14 participants who reported that they did not have children, felt that in the future their stuttering would *not* influence their decision to have children.

### 3.5.5. *Perceived impact of stuttering on relationships with child/children*

The two individuals who did have children, believed that their stuttering had *not* impacted on their relationships with their children, for example, “*No, because I don’t stutter when I talk to my children*”. Similarly, [Boberg and Boberg’s \(1990\)](#) study indicated that in many cases stuttering did not impact on relationships between parents who stuttered and their children, as many of the children who they interviewed were not particularly aware of their parents’ stutter and those who were, were not unduly concerned about it. The present study demonstrated that 3 of the 14 subjects who did *not* have children, mentioned that in the future they were convinced that their stuttering would not impact on their relationships with their child/children.

## 3.6. *Identity, beliefs and emotional aspects*

### 3.6.1. *Personal definitions of stuttering*

Various themes emerged in terms of participants’ definitions of stuttering. The theme of fluency surfaced in 20.69% of the responses, for example, “*Can talk but have difficulty bringing words out and making them flow*”. Other themes were verbal expression (17.24%) “*Problem with getting out the things I want to say*”; repetition (6.9%)—“*Form of repetition of partial sounds, various sounds and it varies from person to person*”; voicing mechanism (6.9%) as one of the participants mentioned, “*Stuttering is the inability of one system (speech, vocal) to bring words out*” and related to psychological factors/confidence (6.9%)—“*From my perspective stuttering is mainly with the person’s confidence with oneself. Speaking with people may make it worse. Being positive will help you live with it*”. Getting stuck (6.9%) was another theme as one of the participants used the following analogy, “*It’s like a plug or valve inside of you that you can open and shut. It’s like a plug in the bath – when you open your mouth the words are in your mind but they are stuck. It’s very frustrating. Someone*

*inside of me carries a plug, I talk, talk and talk and in the middle of the sentence the person closes the plug and I get stuck”.*

### 3.6.2. Beliefs regarding causes of stuttering

*Unknown etiology*—The main theme that emerged in relation to causation of stuttering and mentioned by half (50%) of the participants within the sample was that the cause of their stuttering was unknown. However, the other half (50%) of the sample attributed their stuttering to educational factors, heredity, family aspects, nervousness, tension and trauma.

*Educational factors (19.44% of responses)*—For example, one participant mentioned, “*My second grade teacher was a traumatic experience for me, which I believe was one of the causes*”. Another participant explained, “*I hated nursery school, my teacher was bad, in that year it all started. This experience may have provoked it. I wish I could change back the clock*”.

*Heredity (13.89% of responses)*—“*Originally I think it may have been a genetic problem because my father also stuttered. It’s possible that it might have developed that way*”.

*Family aspects (13.89% of responses)*—This theme included parental behavior, birth of siblings, and family role models.

*Nervousness, tension and trauma (11.11% of responses)*—This theme was evident in comments such as: “*By nature I was a nervous child, I worry about everything*”. One of the participants reported, “*My stuttering may be due to traumatic experiences which may have brought about psychological manifestations*”. In line with these findings, Guitar (1998) expresses the view that there are various influences that determine whether or not an individual will stutter. Neurophysiological, psychological, social, and linguistic factors all probably contribute to its onset and persistence.

### 3.6.3. Effect of stuttering on sense of self-esteem/self-image/self-identity

Only 2 persons out of the total sample of 16 perceived that stuttering had exerted no effect on their sense of self-esteem, self-image or self-identity. One participant emphasized, “*Absolutely, stuttering has affected my sense of self-esteem, self-image, self-identity and the way I see and value myself*”. Analysis of responses revealed the following sub-themes:

*Lack of confidence, poor self image, self consciousness and insecurity (37.5% of responses)*—For example, “*Stuttering on your name gives you a low self-image*” and “*Yes. I possibly have low self-confidence, ‘I’m not good enough’ that kind of thing*”. Another participant mentioned, “*Before it went away when I was more cautious of it, it did in a way. I prefer to be quiet. Yes it did affect my self-esteem. When it went away miraculously I’m more confident because I don’t worry about it much. There are times when I think about it – but I tell it to go away. I have more confidence and I’m stronger than before*”.

*Feeling stupid (18.75 % of responses)*—This sub-theme is vividly reflected in the following statements, “*I feel stupid – You think maybe I’m a fool, you avoid answering questions*”; “*I feel I’m so stupid, I sound so stupid, get cross with myself affect self-esteem and it has gotten me where I am. I did honours not to look ‘stupid’ . A part of you is missing – have to work hard in other areas, makes you a perfectionist. Have to draw the line. Have to reach a point where ‘I have achieved enough I have made up for it’ and I can carry on with my life*

now". This finding supports the view expressed by Starkweather and Givens-Ackerman (1997) who maintain that speech is so closely related to one's self-identity that to be a "poor" speaker is like being an incompetent person.

*High self regard and pride* (18.75% of responses)—This positive sub-theme was highlighted in the following response: "*Maybe before, till I took pride in being disabled, now I don't give a damn. If you judge me on my disability I feel pride, go beyond the stereotypes, it is the content that matters*"; "*I still value and love myself, it did affect my self-esteem*".

*Effects on social life* (12.5% of responses)—This sub-theme can be illustrated by the response, "*I'm frightened men will see me as a girl who can't talk*".

*Self-hatred and feeling different* (12.5% of responses)—For example, "*... I hate myself ... If I had a bad day speaking I hate it. I hate stuttering, everything is affected by it*", and "*People look at me in a different light. I feel very different, not a normal person*".

A final point regarding this section was that positive and negative feelings often existed side by side. For example, "*I have a very high regard for myself ... But I do feel bad about my speech*" and "*Even though I'm confident, I'm insecure*".

#### 3.6.4. Participants' emotions evoked by stuttering

The findings of this study revealed that all of the 16 participants reported that stuttering had evoked positive or negative feelings or emotions in them.

*Negative emotions*—As one of the participants explained, "*Get a feeling, you are easily provoked in a sense, it gets the adrenaline pumping. Over the years I learnt to control these feelings*". The sub-theme of frustration was emphasized by half the sample, "*Nothing more frustrating than not being able to say what you want to say. It's like being permanently silenced*". Another recurring sub-theme was anger as was evident in the following response: "*Feelings of anger, because I'm a social person, often I'm angry with myself because I'm social. 'Why can't you speak?' Yes it's difficult at times. I can imagine what it would be like not to stutter*". The sub-theme of shame also emerged as one of the participants mentioned, "*After stuttering the feeling is more like shame*". Embarrassment and nervousness were other sub-themes emanating from participants' responses, "*I feel very embarrassed and highly nervous. I get very agitated*". In addition, the sub-theme of feeling stupid and foolish was apparent, as one of the participants remarked, "*Yes when I stutter I feel foolish*". The emotion of fear was starkly captured in the following verbatim comment: "*Especially in high school I was scared they would laugh at me. I was scared I would be the laughing stock of the school. I used to shake, sweat and have wobbly legs. Speaking to strangers was like a feat of Hercules*". These findings are similar to those of Corcoran and Stewart (1998) and Cream, Onslow, Packman, and Llewellyn (2003) who found that adults who stutter experience a sense of shame and helplessness associated with an intense fear of stuttering. Other sub-themes included anger, self-blame, fear, nervousness and short temper.

*Positive emotions*—In total only two positive feelings or emotions surfaced in the analysis of participants' responses, namely confidence and a positive attitude. In line with these findings, Ginsberg (2000) reports that individuals who stutter report a vast array of positive and negative psychological experiences tied to stuttering including a sense of challenge, triumph, and heartache.

### 3.6.5. Attempts at finding a cure for stuttering

Half the sample (8 of the 16 participants) reported that they had tried to find a cure for their stuttering. One of the participants mentioned, “*To find an absolute cure will be the winning prize*”. The other half stated that they did not try to find a cure as was evident in the words of one of the participants, “*No, the speech assessment that I went to is not really a cure, there is no cure at this stage. I try to minimize and control it*”; and “*No, I have just learnt to live with it*”. Various sub-themes in terms of the theme of trying to find a cure included speech therapy, wanting to attend a voice clinic, sticking pebbles under the tongue, homeopathy, quitting smoking, tai-chi, consulting literature, and singing lessons. It is of interest to note that the strategy of inserting pebbles under the tongue was tried during the time when Moses lived and experienced problems with stuttering (Van Riper, 1971). Participants who did not try to find a cure, gave as their reasons the fact that they made use of medication, there was a lack of facilities and they had given up hope of finding a cure.

### 3.6.6. Coming to terms with stuttering and acceptance of being a person who stutters

Analysis of participants’ responses, suggested that 3 out of 16 persons had *not* come to terms with their stuttering, as one of the participants mentioned, “*It would be easier if I accepted it – it’s like a pimple I want to get rid of. I don’t seem to be coming to terms with it, which is another stress. I should be coming to terms with it by now*”. Several sub-themes emerged including denial, wishing to get rid of the stutter and remaining hopeful.

However, 13 persons believed that they had come to terms with their stuttering to a greater or lesser extent as was evident in the following response, “*Absolutely, I have come to terms with it and have accepted the fact that I stutter*”. Speech therapy appeared as a sub-theme in more than one instance. One of the participants explained, “*Yes, that’s why I came for therapy and in the future I’ll try to come and improve my speech again. It would be strange to me to imagine talking fluently*”. Other sub-themes included seeking help, attending a speech conference and the realization that the problem would not disappear. The sub-theme of improving speech was reflected in the response, “*I know I’ll never be one hundred percent. I do accept myself to a degree but I still want to improve*”. Starkweather and Givens-Ackerman (1997) explain these results when they state that the development of stuttering in adults may be described in terms of the grief cycle, which is characterized by denial, anger, bargaining, grief or sadness, and finally acceptance. It is through these natural stages of the grief cycle that many adults who stutter find their way into the recovery process, often without any help from speech clinicians.

## 4. Conclusions and implications

The main findings that emerged from the study can be summarized in terms of the life domains that were explored. In relation to *education*, most participants perceived their stuttering to have impacted on their academic performance at school, and relationships with teachers and classmates, which they attributed to difficulties with oral presentations, lack of understanding on the part of some teachers, and teasing by some classmates. With regard to

*social life*, most of the sample reported that their stuttering did not adversely influence their ability to establish friendships. However, many participants perceived that people generally reacted negatively to their stuttering. In terms of *employment*, many felt that their stuttering did not adversely affect their choice of occupation, ability to obtain work, relationships with managers and co-workers. However, an equal number of participants felt that their stuttering did affect their performance at work as those who felt that it did not influence their work performance. Most felt that their chances for promotion were hampered by their stuttering. In respect of *speech therapy*, despite the fact that they were still dysfluent, the majority of participants stated that speech therapy had nevertheless exerted a positive effect on their quality of life in that it enhanced their self-confidence and taught them techniques for coping with stuttering. Overall, stuttering did not appear to have influenced participants' *family and marital life*. In relation to *identity, beliefs and emotional aspects*, most of the people who were interviewed felt that stuttering had exerted an impact on their self-esteem, self-image and self-identity. All participants reported that stuttering had evoked strong emotions within them—particularly feelings of frustration and anger.

These findings would appear to have important implications for the clinical practice of speech-language therapy; community awareness and education; and the advancement of theory and research.

#### 4.1. *The clinical practice of speech-language pathology*

Findings from the study showed that stuttering exerted an effect on self-esteem, self-image and self-identity, and that stuttering evoked strong emotions in all participants. It is therefore vital to incorporate into clinical practice, subjective aspects, such as feelings and the significance of stuttering in the individual's life. Furthermore, in order to enhance therapy and treatment for the person who stutters, speech-language pathologists should constantly be aware of the influences of stuttering on the individual's life in terms of social and family relationships, problems experienced in the workplace and emotional needs. Therapists should also be aware of the need for counseling when treating a person who stutters in terms of social and family relationships and dealing with the emotional needs of these clients. In fact, the need to view the person who stutters holistically and first and foremost as a person, should be the cornerstone of therapy. In the South African context speech-language pathologists encounter clients of different ethnic and cultural groups, which may impact on treatment approaches. Therefore, sensitivity and understanding of the diverse cultural beliefs such as superstitions, stereotypes around the etiology of stuttering and in terms of seeking a cure, is an essential part of therapy. An important finding was that the majority of the participants viewed their speech therapy experiences as being negative in terms of therapeutic procedures, fluency-enhancing techniques, and relationships with therapists, which demonstrates the necessity for speech-language pathologists to review and reconsider their therapeutic techniques and approaches with regard to the treatment of people who stutter.

#### 4.2. *Community awareness and education*

Findings from the study highlighted the profound impact of stuttering on all the participants in the study as well as the effect of this disorder on virtually all life domains.

For example, teasing, lack of understanding and negative responses from others (offset by support and acceptance, understanding, and the development of positive self attitudes) emerged as primary themes in school, home and work. These results suggest a need for people in educational settings, work environments and the broader community to increase their awareness and understanding of stuttering in order to improve communication channels and thereby enhance the quality of lives of people who stutter.

In terms of educational settings, it is evident from the results of the study that there is a need for teachers to increase their knowledge and understanding of stuttering and its implications for the child concerned. The role of the speech and language clinician within educational settings may take the form of an educator and facilitator in order to help teachers to deal more effectively with the person who stutters. It is also important to provide schools with information and literature about practical classroom management strategies. This recommendation lends support for the views of [Rustin, Cook, and Spence \(1995\)](#) who explain that teachers need to be aware of possible educational, psychological, emotional and behavioral impacts of stuttering upon an individual, with regard to factors such as peer socialization, teasing, bullying and associated learning difficulties. Consequently, awareness programs within the school setting should not only be directed towards teachers but also towards school-age children. Negative perceptions and stereotypes of stutterers may have an adverse effect on the assessment, instruction, and educational progress of stutterers in their classes. Pre-service coursework and continuing professional development programs for teachers should therefore address the issue of stereotypes associated with stuttering in order to make teachers aware of potential preconceptions of stutterers and the possible origins of these preconceptions.

The findings of the study also highlight the need to provide information and education regarding stuttering within the workplace in order to enhance the quality of life of people who stutter by creating work environments which are conducive to better performance at work and which afford chances for promotion. The role of the speech-language pathologist within the workplace may involve setting up workshops in order to educate employees, supervisors, managers, colleagues and co-workers and increase awareness regarding stuttering and people who stutter.

Participants in the study reported negative reactions to and lack of understanding of stuttering. Hence, the enhancement of community and public awareness may reduce stigmatization of and discrimination against individuals who stutter and thereby improve their quality of life. [Starkweather and Givens-Ackerman \(1997\)](#) emphasize the need for listeners to become more knowledgeable about the disorder of stuttering, as those who understand more about stuttering are easier to talk to. It can also be beneficial for listeners to become more familiar with the person's pattern of stuttering, for example, in terms of good days/bad days.

#### *4.3. Advancement of theory and research*

Findings from the study underline the value of personal accounts of the life experiences of people who stutter, in deepening our theoretical knowledge and understanding of stuttering and thereby enhancing the effectiveness of therapy.

However, in order to critically evaluate this study, it is necessary to consider the limitations inherent in the research design and analysis of the study. Firstly, as this research employed a qualitative, small group research design and a non-probability convenience sample, generalizations of the results to the wider population of adults who stutter may be limited. Secondly, the sample was not proportionately represented in terms of the various ethnic groups, as well as gender and marital status. Thirdly, the extensive scope of the study restricted the depth of information that was possible to gain in the given time allocated for each participant. A fourth limitation was the presence of the researcher during the face-to-face interviews, which may have influenced the information given by participants since they may have provided answers that they thought the researcher wished to hear. Furthermore, since the study considered feelings and personal accounts of participants there is the possibility that they may have furnished socially desirable responses or denied the existence of negative experiences, especially in view of the fact that the study focused on very sensitive and private domains of life. A final limitation was related to the subjective nature of content analysis—the technique used to analyze participants' responses. It is possible that the researchers' interpretations of responses may have influenced the results even though concerted efforts were made to be as objective as possible and to enhance the "trustworthiness" of the data by cross-checking the categorization of themes.

These limitations, as well as the findings from the current study, suggest important areas for future research. For example, a replication of this type of study with a more proportionate representation of ethnic groups might elicit additional data with regard to cultural differences within the South African context. Furthermore, due to the extensive scope of the current study, it was not possible to explore different life domains in greater depth. Hence, future research needs to explore such aspects as sociocultural beliefs and practices of different ethnic groups regarding the etiology and treatment of stuttering. Participants highlighted the negative attitudes of people towards stuttering, the lack of understanding of teachers, and teasing by classmates. Hence, future research needs to also focus on the attitudes of community members, teachers, learners at schools, and family members towards stuttering and people who stutter. Such information could potentially yield valuable information in the field of stuttering. In the words of Van Riper (1982, p. 1), "*Stuttering is more than a riddle. It is at least a complicated multidimensional jigsaw puzzle, with many pieces still missing*".

In conclusion, the current study investigated the life experiences of a group of adults who stutter and the impact of stuttering on their quality of life. The overall finding was that stuttering exerted a profound impact on the quality of life of those individuals who were interviewed. However, in spite of the pain and heartache experienced by many people who stutter, some participants emphasized that stuttering can also imbue the person with inner strength, courage, resilience and a sense of accomplishment, as reflected in the words of an anonymous participant in the study: "*I would choose stuttering again, all over again. It's made me who I am, the reason is I have had to work so much harder. I would take it again, gladly. It has taught me to take good and bad, and to change the bad into good. It gives you a sense of motivation, fight for yourself, it gives you that perseverance to carry on. I have succeeded and am still succeeding*".

## **Appendix A. Interview schedule regarding the experience of stuttering and its impact on quality of life**

### *A.1. Demographic information*

1. Age:
2. Gender:
3. Ethnic group:
4. Marital status:
5. Educational level:
6. Age at onset of stuttering:
7. Age at formal diagnosis of stuttering by a speech-language pathologist:
8. How would you rate the severity of your stuttering (i.e. mild, moderate or severe):

### *A.2. Education*

1. Do you think that your stuttering had any effect on your academic performance at school? If yes, please elaborate.
2. Did your stuttering have any effect on your relationships with teachers? If yes, please explain.
3. Did your stuttering in any way affect your relationship with your classmates? If yes, please explain.

### *A.3. Social life*

1. Do you think that your stuttering had any impact on your social life in terms of establishing friendships? If yes, please explain.
2. How do people generally react to your speech/stuttering?
3. Do people within your community or culture (i.e. your religion or ethnic group) hold any particular views or beliefs regarding people who stutter? If yes, please elaborate.

### *A.4. Employment*

1. Are you currently employed?
2. What is your occupation?
3. Did your stuttering influence your choice of occupation?
4. Do you feel that your stuttering has in any way affected your ability to obtain work?
5. Do you feel that your stuttering has affected your performance at work? If yes, please explain.
6. Has your stuttering affected your relationship with supervisors or managers at work? If yes, please explain.
7. Do you think that your stuttering has influenced your relationship with colleagues or co-workers? If yes, please explain.

8. Do you feel that your stuttering has had any impact on your chances for promotion? If yes, please explain.

#### *A.5. Speech therapy*

1. Have you had speech therapy for stuttering at any time in your life? If yes, please elaborate.
2. Are you currently participating in any type of speech therapy? Please give details.
3. If you have had any form of speech therapy, please comment on the impact of therapy on your quality of life in terms of the areas that we have already discussed.
4. Do you use any particular techniques or strategies to help you cope with your stuttering? If yes, please explain.

#### *A.6. Family and marital life*

1. Do you think your stuttering in any way influenced your relationship with your parents? Please explain.
2. Did your stuttering affect your relationships with your siblings? If yes, how?
3. (If married or in a relationship) Do you think that your stuttering has exerted any impact on your relationship with your spouse or partner? If yes, please elaborate.
4. Do you have any children?
5. Did your stuttering have any influence on your decision to have children?
6. Do you think that your stuttering has had any impact on your relationships with your child/children? If yes, please explain.

#### *A.7. Identity, beliefs and emotional aspects*

1. How do you define stuttering?
2. What do you believe caused your stuttering?
3. Has stuttering affected your sense of self-esteem/self-image/self-identity/i.e. the way you see and value yourself? If so, how?
4. Does your stuttering evoke any particular feelings or emotions in you? If yes, please elaborate.
5. Have you ever tried to find a cure for your stuttering? If yes, please explain.
6. Have you come to terms with your stuttering? In other words, have you accepted that you are a person who stutters?

Thank you very much for your participation.

## **CONTINUING EDUCATION**

**Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: personal accounts of South African individuals**

## QUESTIONS

1. The main aim of the present study was:
  - a. to consider the impact of stuttering on caregivers
  - b. to explore the family relationships of people who stutter
  - c. to investigate the life experiences of a group of adults who stutter and the perceived impact on their quality of life
  - d. to obtain information regarding the experience of speech therapy
  - e. none of these
2. The majority of the participants in the study felt that their stuttering severity fluctuated depending on:
  - a. the context and audience to whom they were speaking
  - b. stress levels and emotional state
  - c. health status
  - d. fatigue
  - e. all of the above
3. In terms of the perceived effect of stuttering on relationships with classmates, the main theme that emerged was:
  - a. embarrassment
  - b. teasing
  - c. lack of understanding
  - d. all of these
  - e. none of these
4. Participants mentioned that speech therapy:
  - a. enhanced their self-confidence and self esteem
  - b. helped them to obtain employment
  - c. taught them techniques to fall back on
  - d. made them dependant on the speech therapist
  - e. a and c
5. Strategies that were perceived to be helpful in coping with stuttering included:
  - a. Easy Relaxed Approach Smooth Movement (ERASM)
  - b. shortening sentences and changing words/phrases
  - c. light contacts and deep breathing
  - d. advertising
  - e. all of the above

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