

Silent Voices: Listening to Young People with Selective Mutism

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Abstract

Children with Selective Mutism, a relatively rare condition, will remain silent in some situations, but speak confidently in others.

Most research on SM relates to Pre-school or Primary School aged children. There is little on older children.

The rarity of SM means that studies of these children have usually been localised and limited in numbers. The perspectives of those with SM on their condition are almost absent from the literature.

This empirical study aimed to investigate these 'gaps' in the literature and provide a vehicle through which the 'voice of the voiceless' might be heard.

Method. A questionnaire was sent to a sample of 30 10-18 year olds and their parents, drawn from the UK membership of the Selective Mutism Information and Research Association (SMIRA).

Findings. This study confirmed existing research findings about the early onset of SM, familial patterns of shyness, co-morbid anxiety conditions and the successful use of behavioural treatments.

Uniquely, though, it also provided an insight into the feelings and experiences of the young people with SM, revealing their pain, isolation, frustration, anger, courage and determination, the limiting effect of SM upon their lives and the strategies used to communicate when they could not speak, including evidence of their use of electronic devices. Their personalities were positive, sensitive and caring, more than quiet and anxious.

Their message was that they do want to talk and are not being rude when remaining silent. Acceptance and understanding helps them to overcome SM

Introduction

Children affected by Selective Mutism (SM) will speak confidently in some situations but remain silent in others, usually outside the home. The condition was originally known as Elective Mutism (EM). Although it was once thought that these children were being stubborn and oppositional, it is now recognised that they are responding to an overwhelming anxiety (Dow, et al, 1995; Anstendig, 1999).

Selective Mutism is a relatively rare condition. Ratio figures cited in published studies vary according to the diagnostic criteria employed, the age group and location of the sample, the proportion of immigrant or bilingual children in the population and under-reporting of cases. Cline and Baldwin (2004) “adopt an estimate of 6-8 cases of selective mutism per 1000 children through childhood”, but also “remain open to the possibility that that may well be an underestimate.” (p.18).

Onset of SM is usually in the early years, when the child begins to move outside the home environment. Girls are often more affected by SM than boys and incidence rates are higher in ethnic minority and bilingual populations. There are often high levels of co-morbid conditions, especially anxiety disorders (Kratochwill, 1981; Cline and Baldwin, 2004).

Most case study and research evidence on SM relates to Pre-school or Primary School aged children. There is little about those of Secondary School age.

The relative rarity of SM also means that studies have usually been localised in area and limited in numbers. However, the UK membership of the Selective Mutism Information and Research Association provided the opportunity to undertake an investigation over a wide geographical area, with larger numbers of participants in the under-researched older age group.

Another element largely absent from the literature was evidence of the perspectives of selective mutes on their condition and their opinions on the factors that helped or hindered both their communication and their recovery (Cline and Baldwin, 2004).

This empirical study sought to address these omissions and find a means of listening to ‘silence users’.

History and Etiology

The literature on SM reveals that Kussmaul (1877) first identified the condition and named it ‘aphasia voluntaria’, as he thought there was a voluntary decision not to speak. However, Tramer (1934) coined the term ‘elective mutism’ to describe the behaviour of an eight year old boy who was silent with all but a small group of relatives and peers (Kratochwill, 1981; Cline and Baldwin, 2004). This term suggested, “that the child elected to talk to certain people, but not to others.” (Sharkey and McNicholas, 2008).

Although identified, elective mutism only became more widely recognised from the 1950s (Labbe and Williamson, 1981). In the following decades, authors wrote of the difficulties of defining a consistent behaviour profile, the length, complexity and difficulty of treatment programmes (Hayden, 1980).

Perhaps due to the term ‘elective’, it was thought that these children were being stubborn and oppositional. Reed (1963) was the first author to suggest, “elective mutism might be a learned pattern of behaviour” and described two

types, one “characterised as immature and manipulative” and the other “as tense and anxious.” (Labbe and Williamson. 1984, p. 274-275).

Kolvin and Fundudis (1981) distinguished between traumatic mutism, which had a sudden onset following some kind of shock, and elective mutism, where talking was confined to a small group. They noted that the rarity of elective mutism meant that most knowledge about the condition came from case studies or small samples without control groups. They conducted a study of 24 electively mute children (13 girls and 11 boys) in Newcastle-upon-Tyne and compared them with 84 speech retarded controls and 102 normal controls, following them up from 5 to 10 years later. In the electively mute children they found evidence of developmental immaturity, particularly in speech and speech abnormalities; a high rate of behaviour problems, enuresis and soiling; the presence of shyness from early years and high levels of psychiatric problems in families. They considered elective mutism to be complex and its etiology multifactorial. On follow-up, “elective mutism proved to be a rather intractable condition.” (p.232).

Lesser-Katz (1988), using psychodynamic theory, viewed the condition as ‘stranger reaction’, suggesting it was a regression to or fixation at an earlier infantile stage, a notion first proposed by Salfeld et al (1950). She identified two types of reaction in the child, ‘compliant’ or ‘oppositional’, noting issues in the family backgrounds of both.

Sluckin and Jehu (1969), Sluckin (1977) and Williamson et al (1977) all approached the condition from a behavioural position. Whilst acknowledging issues in the family histories and dynamics that may have contributed to the child’s mutism, they sought to help both the child and the family.

The growing recognition of the underlying role of anxiety in the condition and its situational nature led to a change in its name from ‘Elective’ to ‘Selective Mutism’ when the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders was published in America in 1994. The diagnostic criteria for Selective Mutism were set as:

- Consistent failure to speak in specific social situations (in which there is an expectation for speaking, e.g. at school) despite speaking in other situations.
- The disturbance interferes with educational or occupational achievement or with social communication.
- The duration of the disturbance is at least 1 month (not limited to the first month of school).
- The failure to speak is not due to lack of knowledge of, or comfort with, the spoken language required in the social situation.
- The disturbance is not better accounted for by a communication disorder (e.g. stuttering) and does not occur exclusively during the course of a pervasive developmental disorder, schizophrenia or other psychotic disorder. (American Psychiatric Association. 1994)

After the publication of the criteria, there was an increase in studies on SM.

Black and Uhde (1995) undertook a study of 30 children (21 females and 9 males) aged 5-12 years in America. They found that in addition to SM, most of the children also had social phobia or avoidant disorder of childhood or adolescence and 30% had other phobias. They concluded that SM could be a symptom of social anxiety rather than a distinct syndrome.

Dummit et al (1997) published a study of 50 selectively mute children (36 females and 14 males) aged 3-15 years in America. They found that all the children met the criteria for social phobia or avoidant disorder and 48% had additional anxiety disorders.

Simons and Fombonne (1997) reported a case of Elective Mutism associated with Chromosome 18 Abnormality.

In one of the largest samples in the literature, Steinhausen and Juzi (1996) used the ICD-10 criteria (WHO, 1992) to identify a total of 100 children in three groups from Switzerland and Germany. They found a male-female ratio of 1:1.6 with onset at pre-school age across all social groups. One third of the sample had pre-morbid speech or articulation problems and three-quarters had behavioural abnormalities in infancy or pre-school. The most common personality traits were shyness, anxiety and other internalising behaviour problems, although one fifth showed oppositional-defiant or aggressive behaviours. School or social situations outside the home were the most common places in which the child did not speak. They found some evidence of co-morbid disorders of eating or sleeping and 25% of cases with enuresis. They noted a relatively high proportion of immigrant families in the samples and concluded that in predisposed children the additional cultural strain of acquiring another language may precipitate the response of SM. This finding was supported by the research of Elizur and Perednick (2003),

Steinhausen and Adamek (1997), working in Switzerland, compared the family backgrounds of 38 EM children and 31 others with emotional disorder and developmental disorder of articulation or expressive language. They found evidence of mutism and psychiatric disorders in the relatives of the EM group. Speech and language disorders were common in the relatives of both samples. They suggested that, "genetic factors may play a role in the etiology of elective mutism." (p.107).

Incidence levels of SM in the population were surveyed in schools in two districts of West Central Göteborg in Sweden by Kopp and Gillberg (1997), who found a ratio of 18 to 10,000, which was higher than the rate suggested by earlier studies and led them to conclude that SM may be more prevalent than previously suspected.

Kumpulainen et al (1998) surveyed teachers of children aged 8-9 years in Finland using a questionnaire. They found 38 with SM, amounting to 2% of the population, with a higher proportion of girls than boys. The SM children "were characterized as shy, withdrawn and serious, with only some being hyperactive or aggressive." (p. 24).

Ford et al (1998) undertook a phenomenological survey in America with the largest sample in the literature, 153 cases of current or previous SM, including 18 adults. The male to female ratio was 1:2.1, higher than in other studies. They found evidence of variant talking behaviours in addition to mutism, both prior to the identification of SM in the child and as part of the SM syndrome, with the setting affecting the rate of occurrence. They also found evidence supporting the link between SM and social anxiety or social phobia, even after apparent recovery.

Kristensen (2000) followed up the earlier findings of SM in association with developmental disorder/delay (Kristensen. 1997) by comparing 54 SM children with 108 controls in Norway, concluding that SM could be associated as frequently with developmental disorder/delay as with anxiety disorders.

Kristensen and Torgersen (2001) compared self-reported personality and symptom traits in the parents of 50 SM children and matched controls in Norway. The results confirmed the familial connection with SM and social anxiety found in other studies.

Cunningham et al (2004) compared 52 children with SM to 52 community controls in Canada. They found the SM children to be more anxious and obsessive, but less oppositional and having fewer attention difficulties in school than children in the control group.

Twenty-five years after Kolvin and Fundudis (1981) concluded that SM was a complex condition with multifactorial etiology, Cohan, Price and Stein (2006) in their review of the literature, suggested:

that the disorder can result from several diverse pathways reflecting complex interactions among multiple genetic, temperamental, psychological, developmental, and social/environmental systems. The presence of risk and vulnerability factors may predispose certain children to develop SM, but these same factors could also lead to different outcomes. (p. 351).

Johnson and Wintgens (2001) listed the most common predisposing, precipitation and perpetuating factors for SM. They then made detailed recommendations for assessment and treatment.

Treatment

Methods of treatment for SM have reflected the assumptions of clinicians about its etiology and maintenance. Various types of treatments have been used including psychodynamic, behavioural, therapeutic and family systems approaches, sometimes used in combination. In recent decades, the use of drugs in psychopharmacological treatments has also been reported (Kratochwill, 1981; Spasaro and Schaefer, 1999; Cline and Baldwin, 2004).

Historically, the psychodynamic approach was the first to be tried, but with little success. Kratochwill (1981) observed of SM that, “a consistent theme running throughout the psychodynamic literature is that this childhood problem is difficult to treat.” (p. 54). Spasaro and Schaefer (1999) noted that the duration of the treatment, “places an enormous burden on the family’s resources, straining its emotions, finances, and limited time.” (p. 7).

However, behavioural treatments proved to be much more successful. Several paradigms influenced the development of treatments, including

- classic conditioning through systematic desensitisation;
- operant learning using stimulus fading and shaping techniques and positive or negative reinforcement;
- social learning theory using modelling techniques and cognitive behaviour therapy.

The literature on SM contains examples of the successful application of all these treatment methods, used separately or in combination (Sluckin and Jehu, 1969; Conrad, Delk and Williams, 1974; Rasbury, 1974; Colligan et al, 1977; Sluckin, 1977; Crogan and Craven, 1982; Sluckin, Foreman and Herbert, 1991; Holmbeck and Lavigne, 1992; Watson and Kramer, 1992; Rye and Ullman, 1999; Robinson and Burgess, 2001; Fung et al, 2002; Fisak, Oliveros and Ehrenreich, 2006; Vecchio and Kearney, 2009).

Various therapeutic methods have also been used to treat Selective Mutism. These include family therapy (Meyers, 1984; Sloan, 2007), group therapy (Bozigar and Hansen, 1984; Sharkey et al, 2008), play therapy (Lesser-Katz, 1988), interactive therapy (Roe, 1993), music therapy (Amir, 2005) and drama therapy (Oon, 2010).

The use of medication to treat SM was rare until the 1990s. However, following the report by Goldwyn and Weinstock (1990) of the successful use of Phenelzine in the treatment of a 7-year-old girl, despite some unpleasant side effects of the drug, interest in the use of medication increased.

Trials using Fluoxetine to treat SM were undertaken by Black and Uhde (1994) and Dummit et al (1996), whilst successful treatment of individuals with various drugs was reported by Black and Uhde (1992), Lafferty and Constantino (1998) and Lehman (2002) among others.

Cline and Baldwin (2004) in their review of the literature commented that most reports on drug treatments focused on reducing anxiety levels rather than influencing talkativeness. They noted the opposing positions of those who advocated medication as a first choice of treatment and those who considered it a method of last resort after other psychosocial interventions had failed.

Carlson, Mitchell, and Segool (2008) reviewed the literature on SM and Social Anxiety Disorder cases that were resistant to psychosocial methods and had been treated by various drugs. They contrasted the frequency with which doctors prescribed drugs to treat SM and the lack of research to support this practice. They concluded that pharmacological data appeared “promising for

the treatment of resistant cases of selective mutism.” (p. 354), but acknowledged the need for further research into the efficacy and effectiveness of methodologies.

There were a few examples of psychopharmacological treatment being combined with other approaches (Kehle, Madaus and Baratta, 1998; Maskey, 2001; Kee, Fung and Ley-Keow, 2001).

Examples of multimodal methods without the use of drugs were also present in the literature (Moldan, 2005; Jackson et al, 2005).

In order to plan any treatment, especially complex interventions, a thorough, multi-disciplinary assessment of the child and family ought to be undertaken (Klin and Volkmar, 1993; Dow et al, 1995; Standart and Le Couteur, 2003).

Cleator and Hand (2001) showed how audio-taped recordings of the child's speech at home could be used by Speech and Language Therapists as part of an assessment procedure.

Schwartz and Shipon-Blum (2005) and Vecchio and Kearney (2007) provided information and advice for General Practitioners on the identification, assessment and treatment of SM. Imich (1998) and Cleave (2009) did the same for Educational Psychologists.

Recently, multi-agency care pathways have been developed in some areas of Britain to ensure that all children with SM are identified, assessed and treated by the range of professionals who may be involved (Keen, Fonseca and Wintgens, 2008).

Rationale for this Study

The rise in interest and research into SM since the 1990s was paralleled by a similar increase in the field of 'pupil voice'. The UN 'Convention on the Rights of the Child' (UN, 1989) in Articles 12 and 13, asserted the child's right to a voice in decisions affecting them. This principle was incorporated into U.K. law in the Children Act.1989.

In the following years, evidence was emerging of the effectiveness of listening to the views of children and young people and involving them in decision-making in schools (Davie and Galloway, 1996; Charlton, 1996) and in politics (Townsend, 1996).

By the next decade, evidence from further research about the beneficial effects of listening to pupils on school improvement and practical advice on how to do it was being published (MacBeath, Demetrious, Rudduck and Myers, 2003; Flutter and Rudduck, 2004).

Alongside this general movement of listening to children was a concern that the voices of the vulnerable should be heard. A whole chapter of the revised SEN Code of Practice (DES, 2001) was devoted to 'Pupil Participation'. Articles and

whole issues of a professional journal were also focussed on the subject (Sherwin, 1996; Kiddle, 1996; Roaf, 2002; Gray and Wilson, 2004).

Yet this change to valuing the perspectives of young people did not seem to have any impact on SM research, the majority of which had taken the form of case reports, clinical record analyses, controlled studies, empirical tests and experiments, standardised checklists, structured interviews and surveys, involving clinicians, parents, teachers and children. What was singularly lacking in all these was the authentic voice of the child. Although children provided the focus and information for much of the research, their experiences and opinions were largely subsumed in a mass of data (Woodhead and Faulkner, 2000).

In reviewing over 140 articles on SM, 112 of which involved actual cases, only two could be found that related the personal opinions and experiences of the sufferer (Omdal, 2007; Omdal and Galloway, 2007).

There were other deficiencies in the literature.

- None of the 140+ articles reviewed contained reports about strategies used by the individual with SM to communicate in situations where they were unable to speak, particularly in school.
- Older children were under-represented. Only 40 articles had evidence on children aged 10-18 years; even the largest survey in the literature only had 18 subjects aged 12-18 years (Ford et al. 1998).
- Sample sizes were generally small; only 37 articles had samples greater than 10.
- Studies were often local, related to clinics, hospitals or city districts; not many covered a wide geographical area.
- Few reports had systematic follow-up of cases.

This empirical study attempted to rectify some of these deficiencies and provide a means by which the opinions and experiences of children with SM could be expressed.

Method

The best way to understand the experiences of a child with SM would seem to be simply to ask them. However, conducting interviews with selectively mute children is problematic, since they are reluctant to talk to strangers. Communication through writing, with or without a computer, was one solution (Omdal and Galloway, 2007).

A questionnaire survey had been successfully employed by Ford et al (1998) who drew their sample from the membership of the Selective Mutism Foundation Inc., a national organisation in America. The British equivalent was the Selective Mutism Information and Research Association (SMIRA). They were approached and agreed to support this research, which would also use a questionnaire.

This purposive sample may not be representative of all families with SM children, since those who had contacted SMIRA were likely to be the more motivated, articulate and computer literate parents. However, it had the advantages of providing a large sample from across the UK for a low incidence disorder, taken from a self-referred, non-clinical organization, thus reducing the referral and severity biases often found in samples from clinical settings (Ford et al, 1998).

Once the sample source and survey instrument had been selected, the content and clientele needed to be clarified. Older children were under-represented in the literature and were considered more likely to be able to articulate their experiences, thoughts and feelings than younger children. So a decision was made to restrict the age-range to 10-18 years, a group that was likely to include both present and previous 'silence-users', those in school, facing transition between Key Stages and at College.

In analysing patterns of speaking behaviour, both Ford et al (1998) and Bergman et al (2008) had used three area categories of school, home/family and public/social. It was decided to adopt these in constructing this research, as they covered the areas usually affected by the child's SM. Although much larger in scale, scope and detail than any survey undertaken by a single researcher could be, the Ford et al (1998) study covered areas that needed to be addressed, including personal background, SM history, treatment and school experience.

This research extended those to include previously un-researched areas:

- Strategies and systems used for communicating
- Use of technology to aid communication
- Factors or people that aid or hinder recovery
- Young people's opinions and feelings about living with SM.

The format devised incorporated Likert scales, closed and open questions, thus combining both quantitative and qualitative methods (Oppenheim, 1992; Dey, 1993; Gillham, 2000; Gorard, 2001; Gorard and Taylor, 2004; Best and Kahn, 2006). However, the overall aim was qualitative. "The qualitative researchers' goal is to be better understand human behaviour and experience." (Bogdan and Biklen, 1998. p. 38).

Since parents have a more detailed knowledge of their child's developmental and treatment history, a separate questionnaire was designed for them, which also explored the impact on the family of a child with SM. This additional information would serve as validation by triangulation for certain aspects of the young person's responses, where the two questionnaires overlapped in subject matter. The offer of follow-up in a few years time was added, to address another gap in the literature.

In order to ensure the questions would have the same meaning for each person and that all terms were clearly explained, the advice of others knowledgeable in the field was sought and careful piloting of the instruments was undertaken. Further revisions were made in response to suggestions.

Ethical approval for the research was obtained from the University of Leicester and BERA Guidelines were followed throughout the process. Arrangements were made to store data securely and pseudonyms were allocated to all respondents to protect identities.

Data from the responses was analysed using SPSS (Statistical Package for Social Sciences) and Excel spreadsheets (Gorard, 2006; Willis and Kim, 2006). A framework employed was "The Ladder of Analytical Abstraction" (Miles and Huberman, 1994, p. 92). Categories were created from the replies. Some categories were later combined in order to reveal trends.

The Sample

From the SMIRA database of members, 214 families were identified as potential participants. Information leaflets about the research and consent forms for parents and young people were sent out to them by post or E-mail.

Agreements were received from 39 families and 30 completed questionnaires were returned from England (27), Scotland (2) and Wales (1), by post or E-mail in equal numbers. This provided a good-sized sample in terms of SM research. Two parent-only questionnaires were also returned, but were excluded from the analysis.

All the parent questionnaires were completed by the birth parents, 93% (28 out of 30) by the mother. The young people's questionnaires were completed by 7 males and 23 females, which gave a male-female ratio of 1:3.3.

Results

Family Information

The most common family structure was 2 adults and 2 children. The SM child was first born or an only child in 56% (17 out of 30) of cases. There was a good representation of respondents across the 10-18 age range.

The majority, 84% (25 out of 30) parents and 87% (26 out of 30) young people, were White British. Other ethnicities accounted for 16% (5 out of 30) parents and 13% (4 out of 30) young people. Most respondents spoke English, but 13% (4 out of 30) were bi-lingual.

Most young people, 83% (25 out of 30), were in mainstream school, although two had been home educated in the past, one at Key Stage 2 and one at Secondary level. Despite their anxiety about speaking in the school setting, they attended school every day or most days. As Adam, aged 10, put it, "I felt I did not want to go to school because it was scary." Four respondents were at College and one was not in education or employment.

Onset and Triggers

Onset was at 3-5 years for 63% (19 out of 30) cases, whilst for 26% (8 out of 30) it was even earlier. There were three cases of late onset SM. In half of cases no reason was given for the onset of SM, but half did identify a trigger.

The most common trigger for SM, 30% (9 out of 30), was starting Nursery or School, or a house move necessitating a change of school. Of the three late-onset cases, one gave no reason, one was due to a house and school move, while the third was related to bullying at school.

Significantly, 77% (23 out of 30) families reported being either presently or previously affected by shyness. One mother had SM herself as a child.

Co-morbidity

Parental reports on their SM child revealed that 60% (18 out of 30) had one or more additional problem. Anxiety or phobia related conditions were reported in 40% (12 out of 30) cases. Three of the young people (females aged 10, 13 and 18) regularly gave no information in response to open questions. In one case, parents reported “extreme anxiety”, in another a phobia of “writing about herself”. In the third case no reason was deducible, but parental responses were also minimal. Other conditions co-morbid with SM included Vertigo, Dyslexia, Speech and Language Difficulties (in the past), Autistic Spectrum Traits/Disorder, Learning Difficulties and Short-sightedness.

Diagnosis and Treatment

Of the 30 cases, 28 (93%) had received a formal diagnosis of SM, but 2 cases (7%) had no official diagnosis. Psychologists were most frequently involved in diagnosis, but Speech and Language Therapists, School staff and parents were also prominent in identifying Selective Mutism. In 16 cases (53%), several different professionals were involved, but in 13 cases (43%) diagnosis was by only one person. In one case, Robert aged 13, no professionals had been involved until very recently. Many of those diagnosing SM were also involved in its treatment.

Young people and parents were asked about their experiences of the professionals involved and the outcomes of the treatments administered.

In total, Clinical, Child and Educational Psychologists, Psychiatrists and Psychotherapists had 22 positive, 10 negative and 5 mixed comments. However, CAMHS (Child and Adolescent Mental Health Service) had 4 positive, 7 negative and 2 mixed comments. The mother of Isabelle (13 years) commented, “The CAMHS team had no real strategies and seemed to be more interested in identifying the cause than helping her to speak.”

Medical professionals, including Speech and Language Therapists, GPs, Health Visitors, Paediatrician, Occupational Therapist, School Doctors and

Nurses, had 26 positive, 7 negative and 3 mixed comments. Speech and Language Therapists received the highest number of positive remarks (15).

Educational professionals, including Teachers and School staff, Teaching Assistants, SENCOs and SEN Teachers, had 33 positive, 8 negative and 5 mixed comments. Examples given included:

- allowing parents to support their child in school;
- adopting strategies suggested by parents, psychologists and SLTs;
- allocating support staff to work with the child;
- making special arrangements for break times;
- removing the pressure to speak.

Other professionals consulted by parents included Connexions Keyworker, Counsellor, Hypnotherapist, Homeopath, Healer, Play Therapist and SMIRA, who all had positive outcomes.

Various treatment strategies were used, successively and in combination. SLTs using behavioural methods were included in the behavioural category. Table 1 shows the analysis of responses.

Table 1. Methods and Outcomes of Treatment for SM

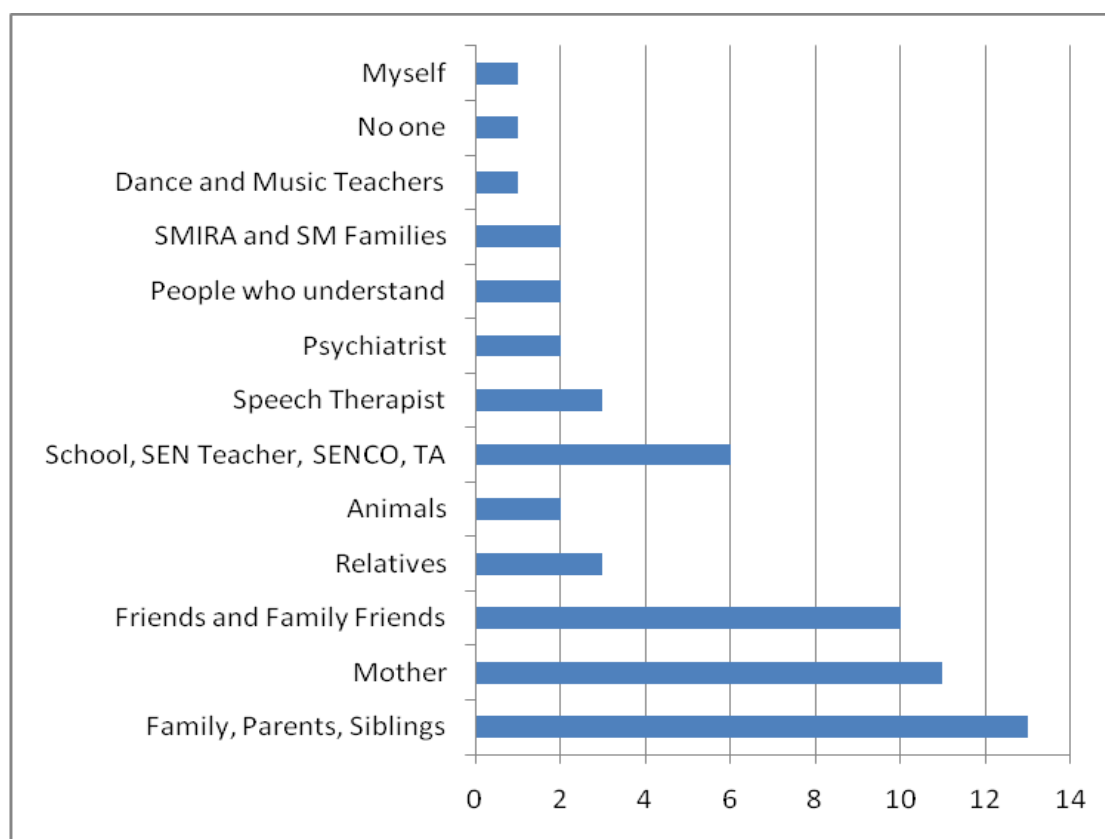
Methods and Outcomes of Treatment for SM	Positive Outcome	Negative Outcome	Mixed Outcome	Totals
Behavioural Stimulus Fading and Shaping Techniques	17	2	0	19
Speech & Language Therapy	2	0	2	4
Drugs Treatment	3	0	1	4
Cognitive Behaviour Therapy	1	1	1	3
No pressure to speak	0	0	3	3
Art Therapy	2	0	0	2
Home Education (at one KS)	2	0	0	2
Psycho-therapy	1	1	0	2
One-to-one teaching in school	1	0	1	2
Emotions Chart	1	0	0	1
Social Skills Group in School	1	0	0	1
Play Therapy	1	0	0	1
Family Therapy	1	0	0	1
Hypno-therapy	1	0	0	1
Homeopathy	1	0	0	1
Healer	1	0	0	1
Behavioural Desensitisation	0	0	1	1

Behavioural strategies were the most commonly and successfully used method in 56% (17 out of 30) cases. In eight cases the mother went into school to help the child, usually using behavioural stimulus fading and shaping techniques to enable the child to speak to a widening range of people in the school. In two cases the families deliberately planned a change of school, to a smaller and

more supportive environment, the outcome being positive, facilitating speech. Drugs were used in four cases, with mainly positive results.

The young people were asked what and/or who had helped or hindered them in dealing with their SM. Figures 1-2 below detail their replies.

Figure 1. What and/or who helps in dealing with SM?



Four respondents gave no information.

The young people considered family and friends most helpful and were keenly aware and appreciative of their efforts:

Anthea (10 years): Family treated me no different to my cousins and said I don't have to speak if I don't want to, which made me feel relaxed and enjoyed my time with them. Friends spoke for me.

Alicia (10 years): My Mum invited, one by one, ten girls in the class to play, and then she would ask the girl to sit behind the bed whilst she asked me how to say, e.g. dog in Serbian. I felt embarrassed, but after I had done it, pleased.

Adam (10 years): My Mum took me into class after school to talk in Year 2. She showed my story to the teacher. She invited friends home weekly. Having my good friend in the same class helped me a lot.

Brian (10 years): My Mum quit her job to look after me. I have a lot of play dates and met up a lot of friends after school.

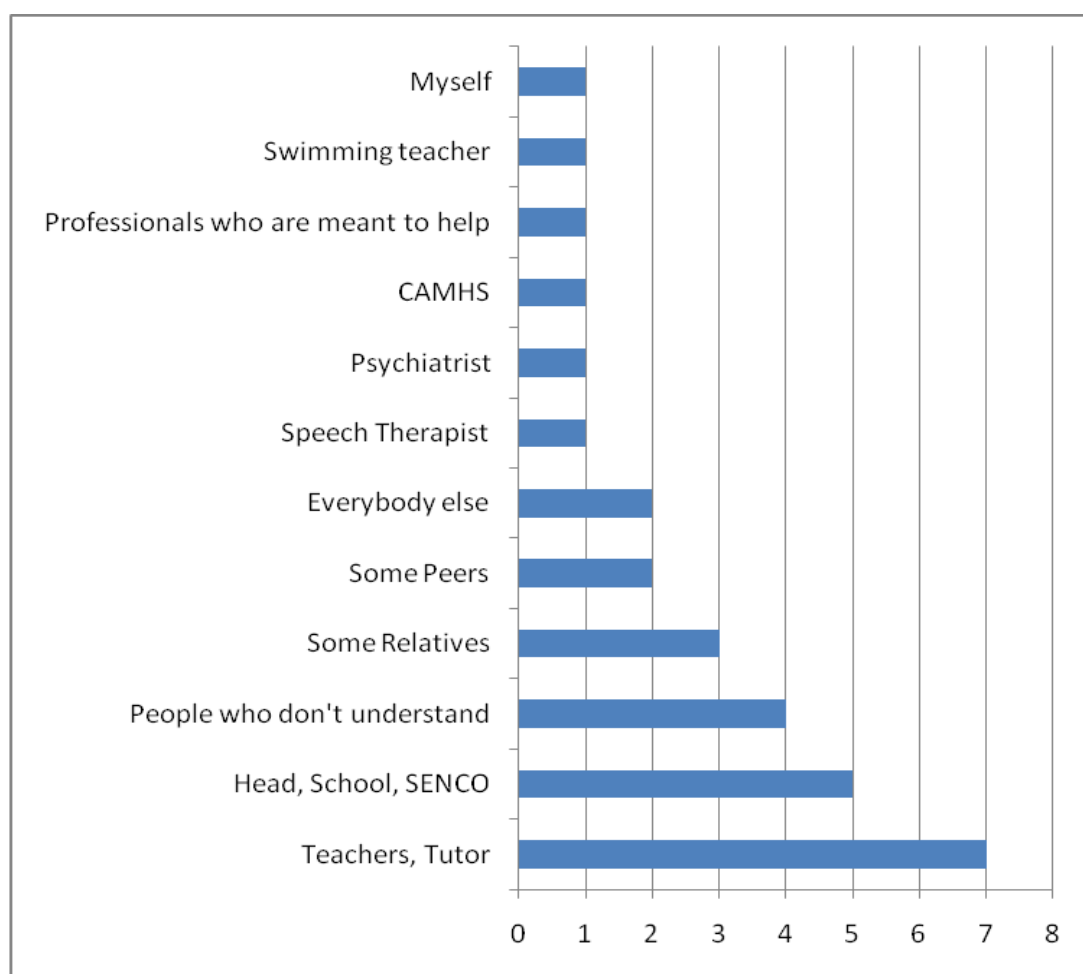
Jeremy (11 years): My family and friends talked to me and encouraged me. Having good family and good friends with the same interests made me feel happy and relaxed.

Samira (11 years): My Mum encouraged me and found lots of different people to help me and she supported me a lot.

Dennis (12 years): My family and friends asked questions with Yes/No answers so I can nod or shake my head. I felt alright.

Eleanor (17 years): My Mum and I went out shopping or somewhere every weekend. Gradually I did more and more speaking to people. I did things very slowly that I would never have done before. I feel a lot better and I'm heading in the right direction now.

Figure 2 What and/or who does not help in dealing with SM?



Five respondents gave no information.

School staff were regarded as unhelpful by 40% (12 out of 30) young people:

Jessica (11 years): Teachers of my last school.

Harriet (14 years): My Tutor. He got me to shout his name as loud as I could and said, "I am not letting you go until you actually shout." I felt humiliated and when I tried to shout, my throat tightened.

Eleanor (17 years): The SENCO at school was horrible and did not talk to me. I really hated school and felt that they never understood my problem. I was dumped in the bottom group with kids who constantly messed about and I was ignored.

Others also identified pressure and lack of understanding as issues:

Anthea (10 years): The Swimming Teacher. Although my Mum told her about my SM, she made RUDE comments about me not speaking for four weeks. When my Mum heard it, she took me out of the lessons.

Miriam (11 years): Some people in my class who try and make me talk to them.

Esther (11 years): People making a fuss.

Moira (12 years): People who said things like 'Cat got your tongue?' and 'Why don't you speak?'

Robert (13 years): People that don't understand.

Sarah (17 years): People that didn't understand and would pressure me.

The views of the young people and parents about the extent to which SM was still a problem were compared. Table 2 below analyses their response

Table 2. YP cf Parent opinion: 'Still affected by SM?'

Parent's opinions	Still SM? YP opinions			Totals
	No	Sometimes	Yes	
No	2	1	0	3
Partially	1	9	14	24
Yes	0	0	3	3
Total	3	10	17	30

Only three considered themselves to have recovered from SM. The rest were still partially or severely affected.

Communication Patterns

The confidence of the young people about speaking in the home, school and public situations was explored by asking them to indicate how often they could talk in those settings. Table 3 gives the total scores.

Table 3. Areas of confident speech analysis for whole sample

Areas of Confident Speech	Always	Sometimes	Never
At home with close family	28	2	0
At home with friends	19	6	5
At home with other relatives	13	14	3
When visiting other relatives	11	13	6
When visiting friends' homes	9	11	10
At school with friends	12	9	9
At school when in class	6	12	12
At school to the teachers	6	16	8
At school to support staff	6	15	9
Outside with close family	21	9	0
Outside with other relatives	12	13	5
Outside with friends	14	8	8
At the shops	12	11	7
At a restaurant to waiters	6	10	14
At the sport/leisure centre	8	8	14

Most could speak confidently at home and outside the home with close family, relatives and friends, although visiting the homes of relatives or friends made speech more difficult for them. In school, speaking to friends was easier than speaking to teachers or support staff. In public, more were able to speak in shops than any other setting.

The young people were asked to state where they felt most and least comfortable about speaking. The majority were comfortable speaking in the home. However, outside the home, the presence of family and friends, or others with whom the young person felt comfortable increased their confidence to speak. Those who were able to speak in most places considered themselves to have recovered from SM. School, College and places outside the home presented the greatest difficulties, as did strangers, direct questioning or pressure to speak.

Using the individual responses about areas of confident speaking, it was possible to rank the young people in order of the severity of their SM. The sample contained the full range from severely affected to fully recovered. This made it a representative sample of the SM population as a whole.

Communication Strategies

The young people were asked about the non-verbal and verbal strategies that they used to communicate with teachers, classmates, relatives or friends. Table 4 below summarises the evidence.

Table 4. Communication Strategies and Recipients

STRATEGY USED	Teacher	Classmate	Relative	Friend	Totals
Gesture/Pointing	20	16	14	10	60
Writing	20	9	4	4	37
Whispering	14	12	6	9	41
Drawing	6	5	3	4	18
Symbol Card	8	1	2	1	12
Tape Recording	8	1			9
Message Card	4		2		6
E-mail	4	1	3	6	14
Sign Language	2	1	1	1	5
Other (Speak quietly)	1	1		1	3
Other (Talk through friend)	1				1
Social Network		6	6	5	17
Computer Instant Messages		5	3	8	16
Mobile Texts		2	6	6	14
Telephone			5	4	9
Webcam				2	2

Writing and gesture/pointing were the most common non-verbal strategies, used predominantly with teachers and classmates. There was some use of drawing, message and symbol cards, mainly in communicating with teachers. Gesture/pointing was well used with relatives and friends, who were also the recipients of E-mails and mobile-phone text messages. Computer Instant Messaging and Social Networking were used to communicate with relatives, classmates and friends. The availability of electronic communication has enabled young people with SM to develop other social relationships.

Of the respondents, 80% (24 out of 30) were able to use some form of alternative verbal communication, but 20% (6 out of 30) did not, of whom five were severely affected by SM and one was recovered. Whispering was most commonly used with teachers, classmates, relatives and friends. Tape-recording was used almost exclusively with teachers, whilst the telephone was used only with relatives and friends. Webcam was used to communicate with friends by two 17 year olds, Anita, with moderate SM, and Arabella, who had severe SM.

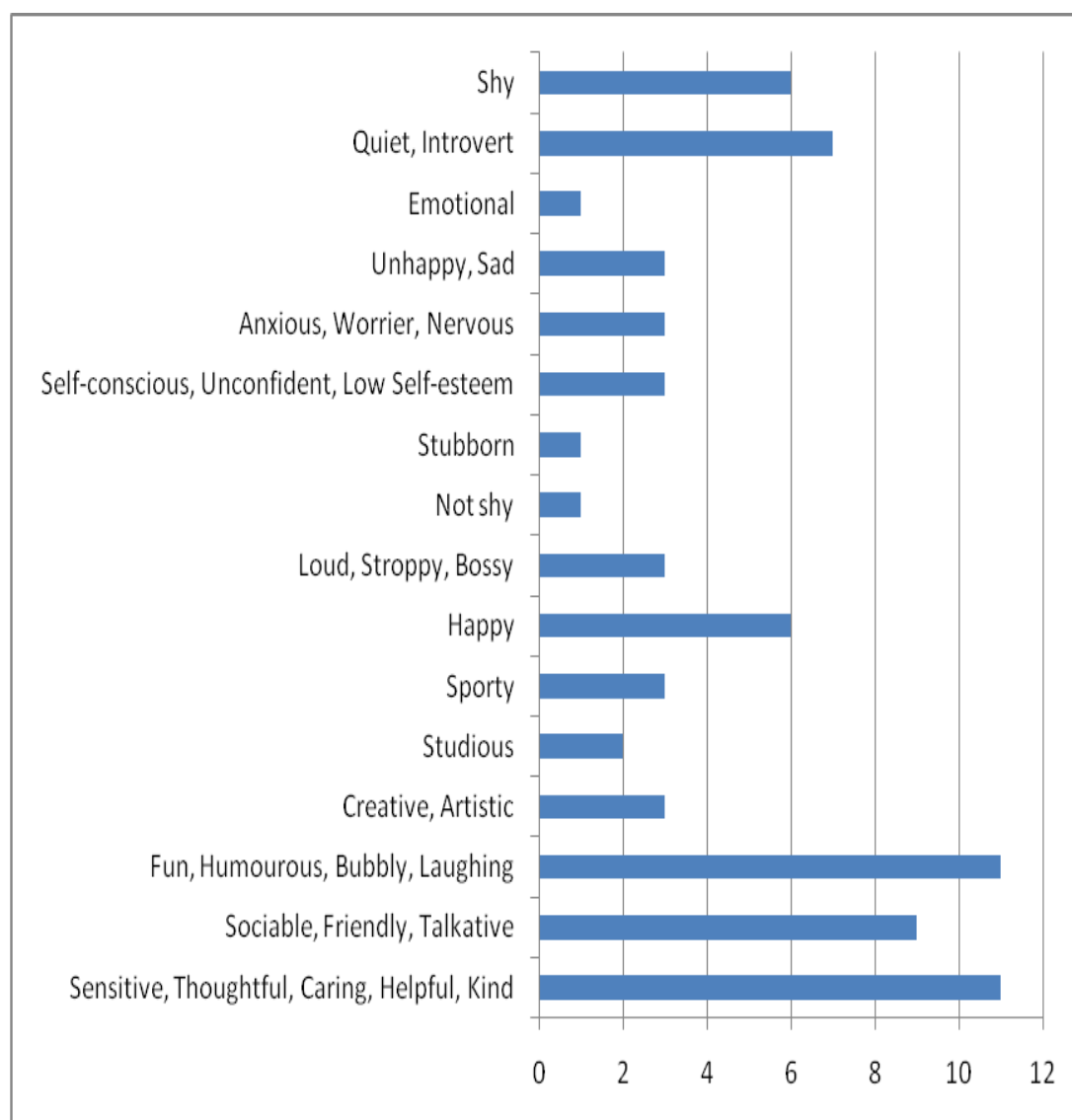
Using techniques like whispering and tape-recording can be an important stage in the recovery process. Technology that distances the speaker from the

listener may, paradoxically, facilitate communication for someone with SM by reducing the sense of pressure experienced when face-to-face.

Character

The young people's characters were explored by asking them and their parents to describe their personality in their own words. Figure 3 and 4 give their responses.

Figure 3. Young People's Self-Perceptions of their Personality



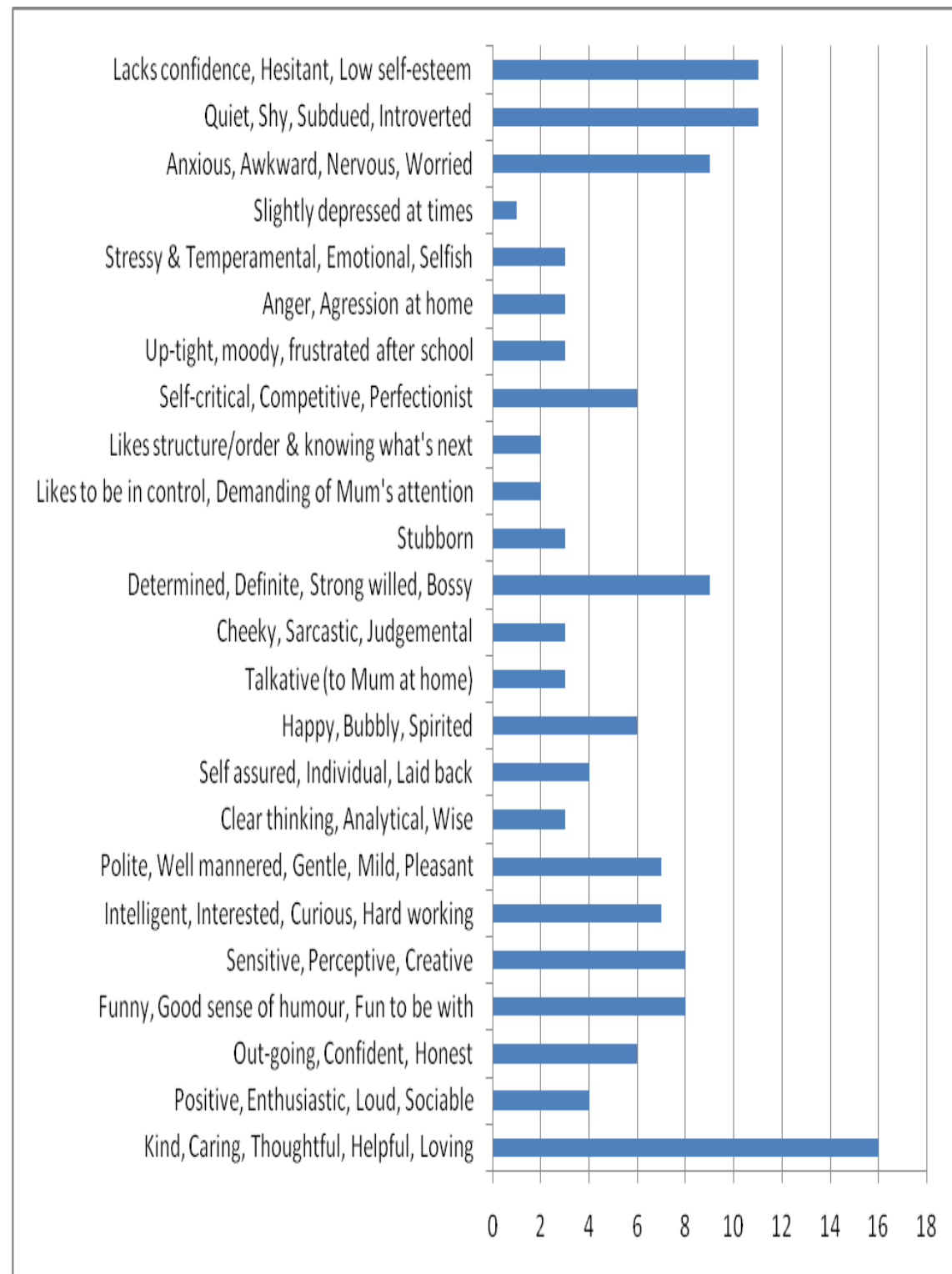
Seven respondents gave no information.

Although shy, quiet and introvert were mentioned by the young people, as would be expected, by far the greater number of descriptors related to positive attributes like sensitivity, kindness, friendliness, happiness and sense of humour. Nine respondents identified both introvert and extrovert qualities in themselves:

Harriet (14 years): At home with close family and friends I am: loud, stroppy, happy, sociable and chatty. Outside I am: quiet, anxious and self-conscious.

Eleanor, aged 17, was the only respondent to describe herself as 'stubborn'.

Figure 4. Parental Perceptions of Young People's Personality



Again, although shy, quiet, introvert and unconfident were mentioned, they were far outweighed by the incidence of more positive descriptors relating to attributes like kindness, sociability, confidence, sensitivity, politeness, happiness and humour. Other interesting characteristics identified by the parents were strength of will, a preference for structure/order and control, self-criticism and perfectionism. Emotional responses, such as anger, frustration, aggression, moodiness and even depression, displayed by the young people also featured in the parent's replies:

Mother of Samira (11 years) At school, very frustrated and she brings the frustration home. This can change into anger/aggressive behaviour, banging doors, etc., shouting, saying hurtful things. A little thing becomes a huge problem. She picks up on things, e.g. a comment about her and can dwell on it. She is over sensitive and highly emotional.

Parent responses also identified the different characters displayed by the young person within and outside the home.

The rounded picture of the characters of young people with SM provided by these responses challenge the general perception of them as merely shy.

The effects of having Selective Mutism - School

Asked if they considered SM had affected them at school, 80% (24 out of 30) young people thought it had, but 17% (5 out of 30) thought it had not. One respondent gave no information.

The young people's responses revealed that SM had limited their ability to participate fully in school, which, in turn, had affected them emotionally:

Martin (11 years): I can't be myself.

Miriam (11 years): I find it difficult to make friends, because I can't talk to them. I struggle with my learning because I can't ask for help.

Rose (11 years): I miss out on some things when I can't say what I want. I have had big problems with fiction writing because I'm afraid of what people might say.

Simon (13 years): When I know the answer but cannot speak to answer the teacher. I cannot work so well in a group, when I would like to.

Harriet (14 years): I find it hard to socialise and people think I'm a freak because I don't speak much. If I don't understand something, I'm too scared to put my hand up and ask a teacher.

Anita (17 years): Not able to stand up for yourself in certain situations. Not able to read work aloud or answer questions to show knowledge.

Arabella (17 years): I could not speak in school except for with one close friend. The inability to communicate made me feel vulnerable and fear limited my progress, as I never felt able to express myself in my work. I missed many days when I was too scared to go in.

Sarah (17 years): I got a lower grade for my English GCSE than I would have if I could do the speaking part. I couldn't ask for help when I got stuck on work, so I would do less work than I could have. I am finding it difficult to find a job.

Horatia (18 years): I couldn't do a lot of subjects, so I had to drop them and I only did 3 GCSEs. Also I didn't make any friends.

Two respondents explained why they thought SM had no effect at school:

Alicia (10 years): I don't think so, because I have a lot of friends and I am one of the cleverest

Isabelle (13 years): I work just as well as anyone else, if not better, because they are always chatting and not concentrating.

Parents confirmed the young people's responses and gave evidence that for 47% (14 out of 30) academic progress was good, despite the verbal limitations of SM, mainly due to supportive school staff. However, for 53% (16 out of 30) having SM had restricted their learning, progress and options. There was no correlation between severity of SM and academic progress.

Social

When asked if SM had affected them outside school, 70% (21 out of 30) young people thought it had, although 27% (8 out of 30) thought it had not. One respondent gave no information.

Their answers revealed the restricting effect of SM on their social lives

Alison (10 years): Not talking to certain people; not going to certain places, e.g. pictures, swimming. I am sick when worried in certain situations.

Adam (10 years): I could not get what I wanted when I needed something. I had to ask my Mum to ask it for me.

Miriam (11 years): Most of the girls in my class go shopping and to the cinema with each other. Because I can't talk to them, I don't get asked to go. I don't get invited to parties either.

- Samira (11 years) I can't ask the shopkeeper what price anything is.
- Esther (11 years) I would have liked to go to the local stage school, but I was too shy.
- Kerry (12 years): If I didn't have SM, I'd be more confident and be able to go places and do stuff and have fun.
- Robert (13 years): Unable to join in social activity with friends or buy things in shops. Fear of being spoken to when outside the house. Getting lost and unable to ask for directions.
- Anita (17 years): Not being able to order food in restaurants or talk to strangers.
- Arabella (17 years): It has left me feeling isolated and has affected so many areas it is hard to specify.

Two gave reasons why they thought SM had not affected them socially:

- Anthea (10 years): Except for not speaking to dancing teachers, but the music was on and she would just be telling the whole class what to do and would come over and show anyone who was struggling, so I didn't really need to speak. (Thank goodness)!

Isabelle (13 years): The clubs that I do don't involve talking - it's just sport.

Again the parental responses corroborated the young people's experiences. They also revealed that 73% (22 out of 30) were able to speak to friends in the home, but 27% (8 out of 30) were unable to do so, having SM severely.

Family

When asked if they thought SM had affected their family, 53% (16 out of 30) young people thought it had, but 40% (12 out of 30) thought it had not. One respondent gave no information and another did not know.

- Anthea (10 years): My Mum and Dad having to explain to people who didn't know about SM, so that I didn't look rude when they were speaking to me.

Anthea's Parents: Anthea is very confident at home, but before her breakthrough she would show signs of anger as if it was a build up over the school day being released when she got home.

- Esther (11 years) For a long time I wasn't able to speak to uncles and aunts.

- Esther's Mother: A lot of stress on us as parents, especially before we found SMIRA.
- Kerry (12 years): I can't talk to certain people in certain situations and it's embarrassing
- Kerry's Mother: Not always been easy mixing with others as I feel like I have to look out for her all the time to be her voice.
- Anita (17 years): I can't talk to some of family, even close. They may feel upset.
- Anita's Mother: Feeling uncomfortable for other people when situations arise and feeling I should apologise for what appears like rudeness.
- Emma (17 years): Mum and Dad have to do a lot for me. It puts a lot of stress on them. Also affects my brothers, auntie and grandparents.
- Emma's Mother: Limited family social life, days out, holidays, leaving the house at all are all challenging.
- Naomi (17 years): It makes my family worry about me all the time. I feel uncomfortable with some family members. My Mum and Dad are always the people who have to put up with my emotions, such as crying, anger, frustration.
- Naomi's Mother: It is very worrying for us as a family as every day is a challenge to her and me and her dad are always worried when she is faced with any new challenge, although sometimes she surprises us.
- Arabella (17 years): It has left me without a relationship with a lot of the family, as they do not understand SM and therefore feel uncomfortable around me.
- Arabella's Mother: It tends to isolate the family. If people do not see SM as a real problem, but rather due to bad parenting, there is little sympathy or desire to help. People seem angry at Arabella as though she should just pull herself together and get on with it. Only a few who really know her see how brave she is in the things she achieves.

Of those who thought SM had not affected their family, only two explained why, although their mothers gave different insights:

- Simon (13 years): Because I like to live with them and they accept I'm quiet.

Simon's Mother: We have to speak for him; awkward around everyone; does not really speak with brother.

Robert (13 years): Now that we all understand. My family used to get angry and upset with me when I didn't respond.

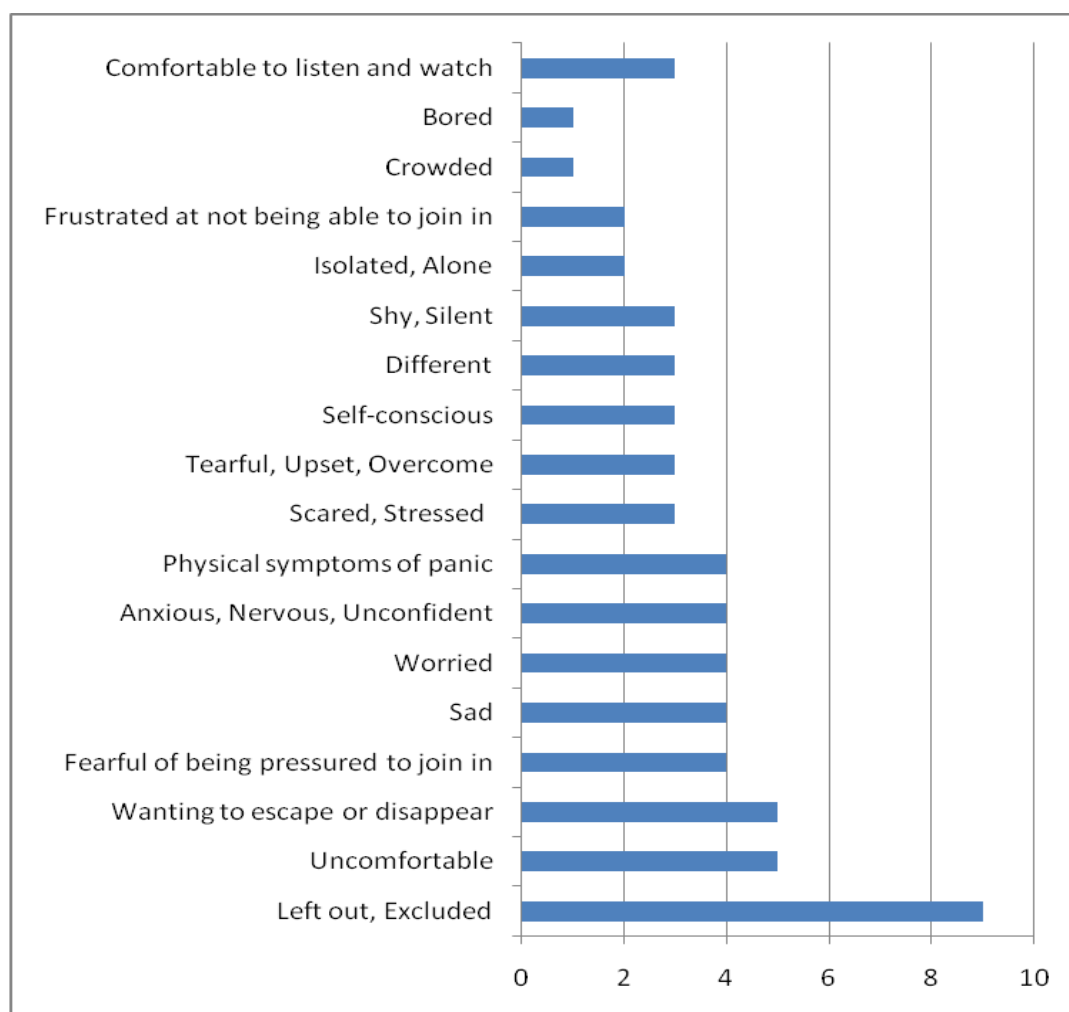
Robert's Mother: Younger sister aged 7 can get very angry with Robert. His older brothers and sisters are more understanding. His parents have felt in from an early age and have been more understanding

The answers from both respondents in the family revealed the impact of a youngster with SM on the family and the commitment of parents to their child.

Feelings

Young people were shown a social situation picture and asked how a person with SM might feel. Figure 5 details their responses.

Figure 5. Social Situation Picture Responses

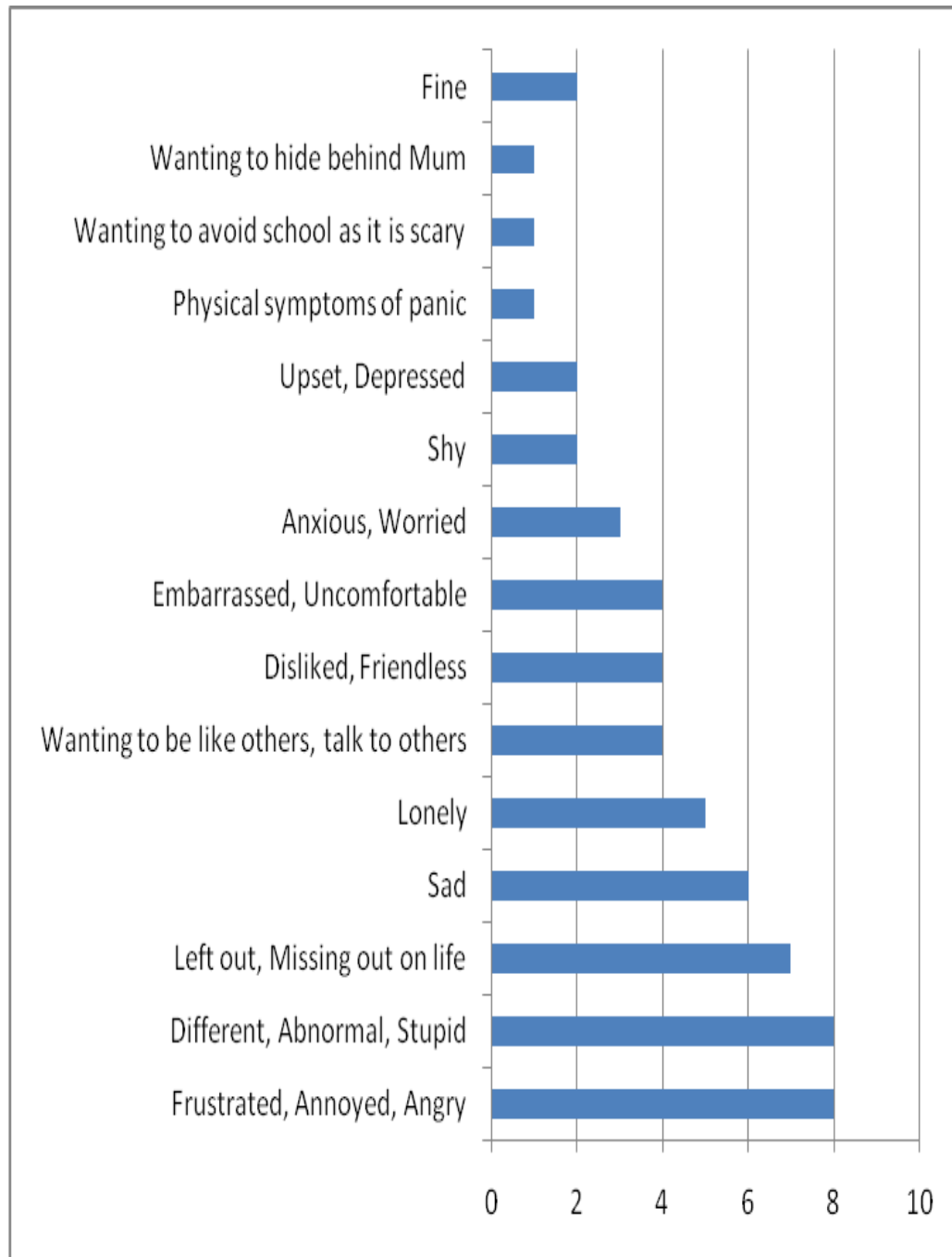


Five respondents gave no information.

Negative emotions dominated their answers, revealing their discomfort in social settings.

The young people were also asked how having SM made them feel. Figure 6 gives their replies.

Figure 6. How does having SM make you feel?



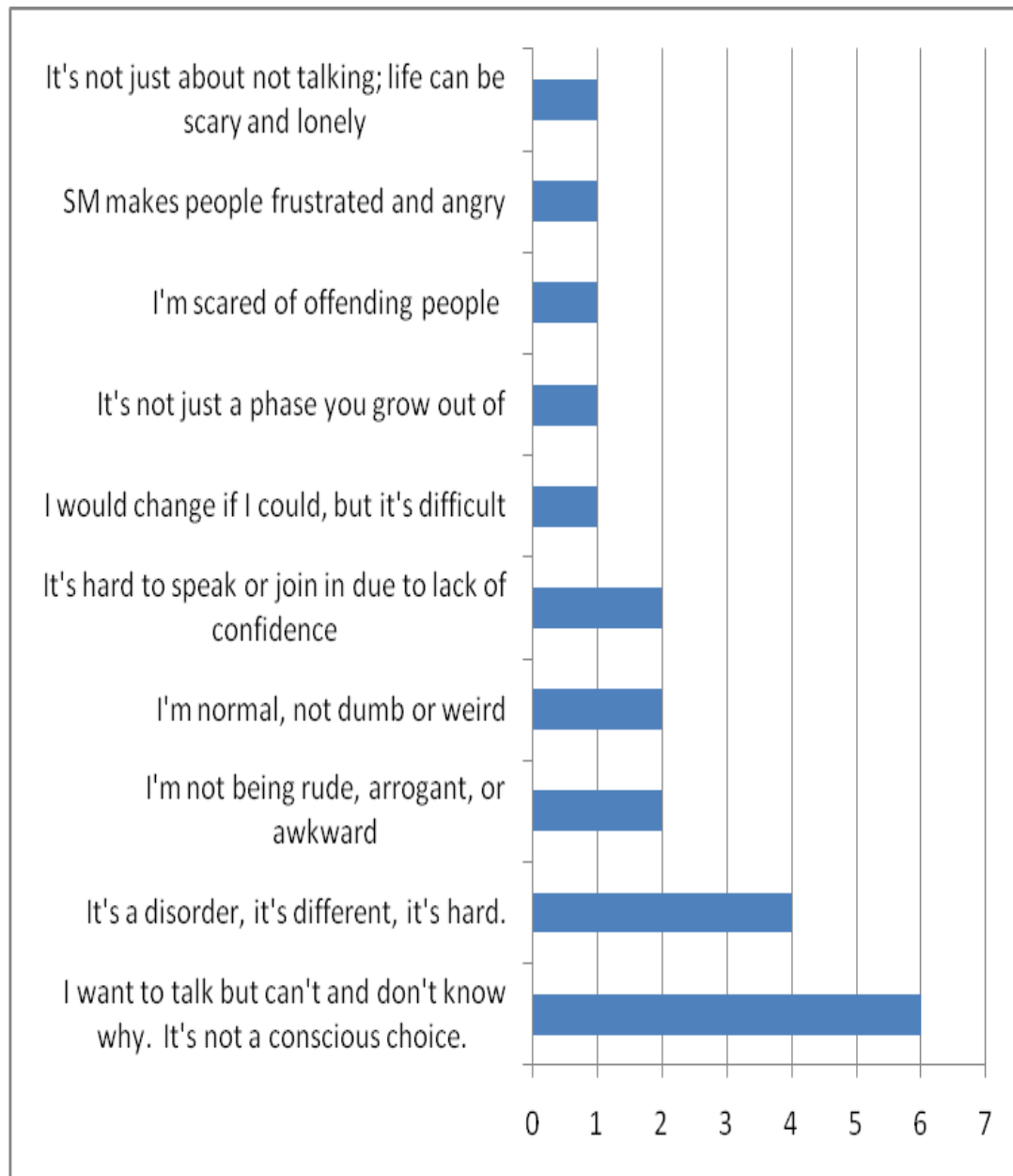
Five respondents gave no information.

Their feelings of frustration, isolation and anxiety were strongly evidenced.

Messages

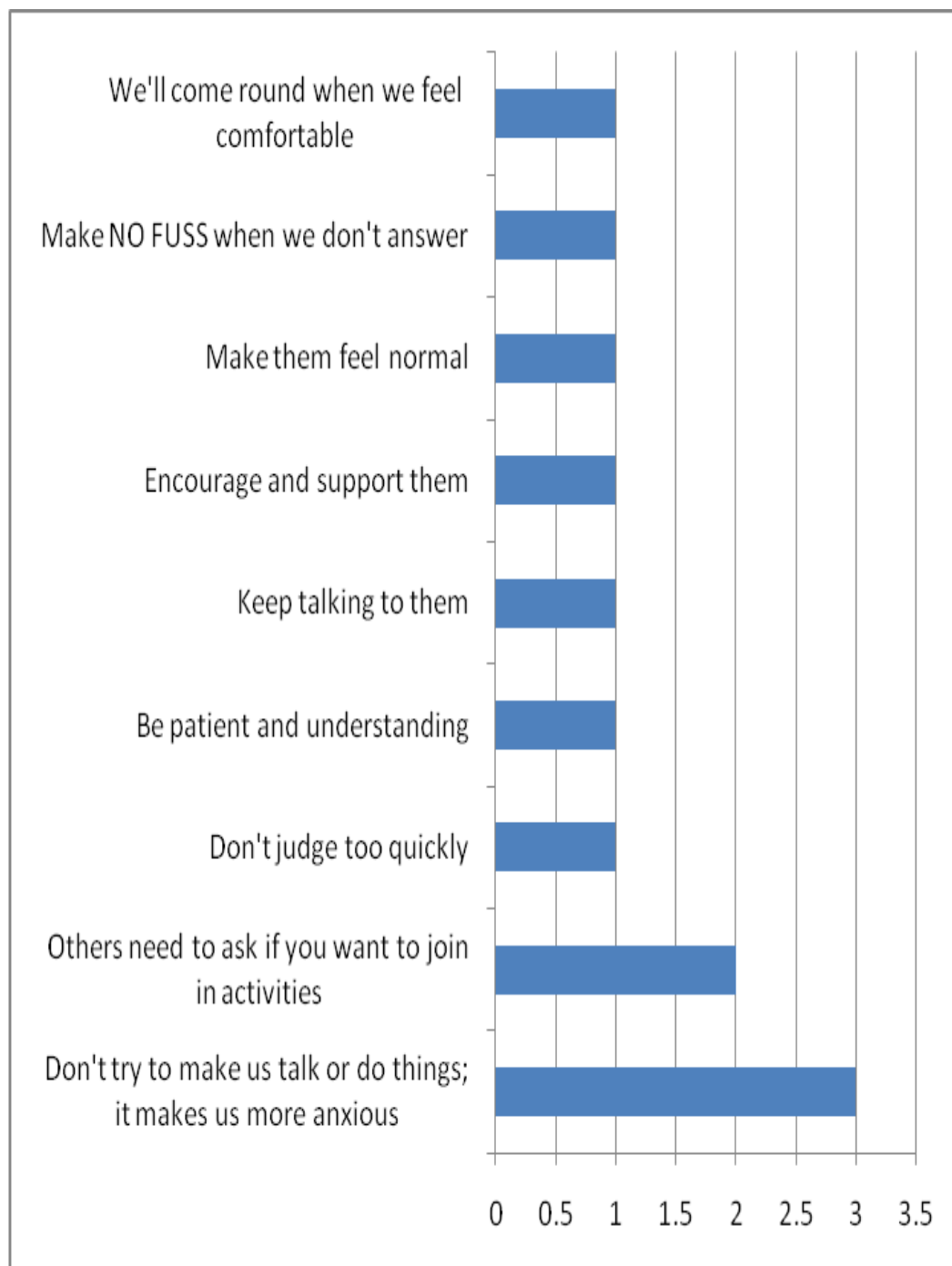
Asked what they would tell others about SM, 80% (24 out of 30) responded. Their messages fell into three categories, about having SM, advice on helping those with SM and encouragements to other SM sufferers. They are detailed in Figures 7-9.

Figure 7. Messages about having SM



Their responses evidence their desire to communicate and their difficulty in overcoming the control that SM has over them.

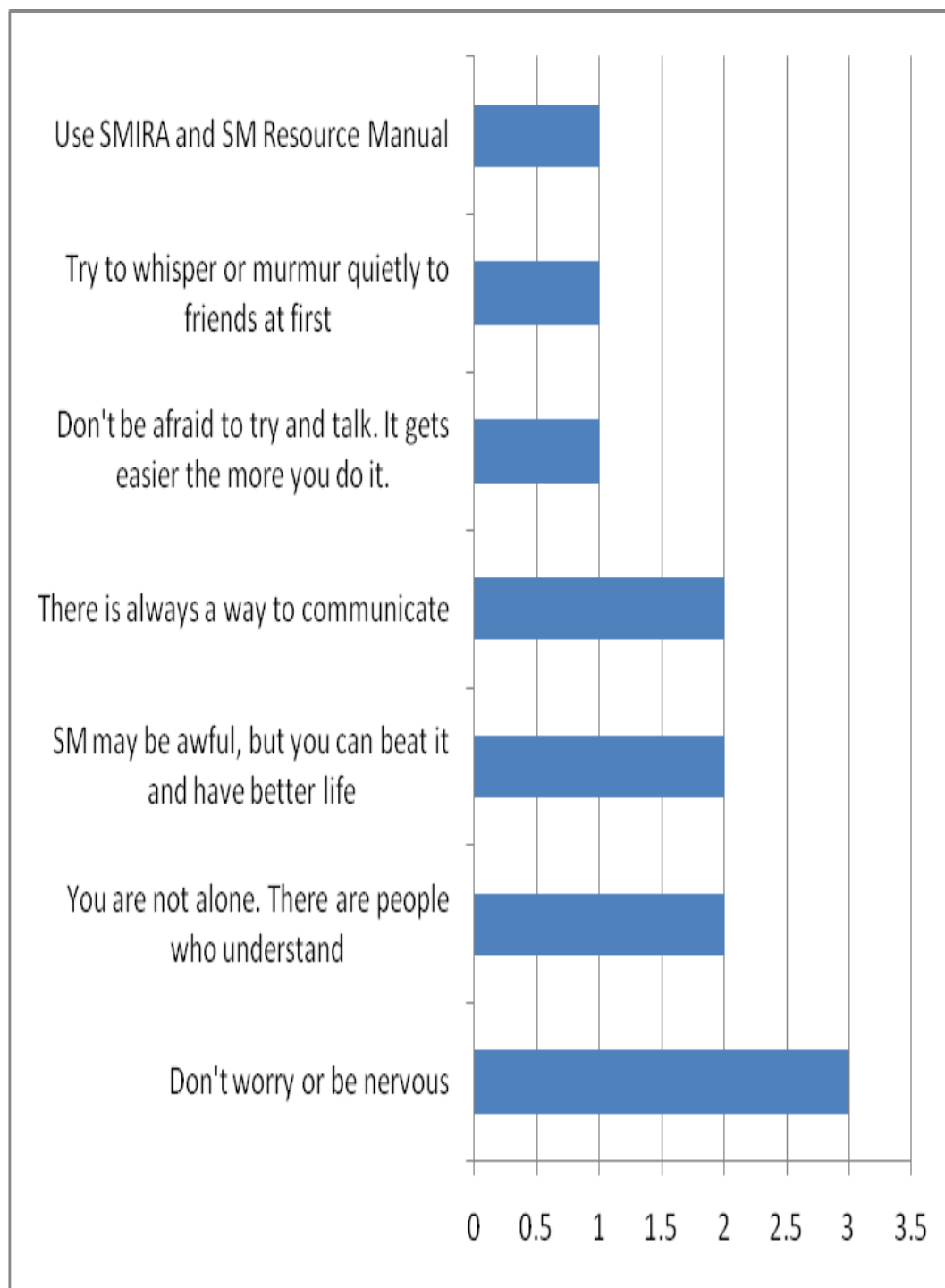
Figure 8. Advice on helping those with SM



These responses clearly show that they want to be accepted as normal young people, which they are, apart from having SM. They regard acceptance, patience, encouragement and understanding from others as most helpful to them in trying to break the barrier of silence.

Their advice for other SM sufferers was touching in its sensitivity and hope.

Figure 9. Encouragements for other SM sufferers



The responses from the young people gave a powerfully emotional impression of the impact of Selective Mutism on their lives, which has implications for all those who are dealing with them.

Discussion of Findings

The findings of this empirical study confirmed, extended and added to the existing literature on Selective Mutism.

Confirmations

Analysis of the responses confirmed many findings from existing research:

- The sample contained 7 males and 23 females, a bias found in many other studies. This gave a male-female ratio of 1:3.3, although the ratio in the 214 invited to join in the research was closer to the 1:2.1 found by Ford et al (1998).
- Although most of the sample were White British English speakers, 13% (4 out of 30) were bi-lingual. Other research has found high levels of SM in bi-lingual populations (Steinhausen and Juzi, 1996; Elizur and Perednick, 2003).
- 56% (17 out of 30) were first-born or only children, a pattern also noted by Kolvin and Fundudis (1981), Steinhausen and Juzi (1996).
- For 90% (27 out of 30), SM began by age 5, confirming existing research about early onset (Steinhausen and Juzi, 1996; Dummit et al, 1997; Ford et al, 1998; Elizur and Perednick, 2003).
- Half the sample reported a trigger event for SM. For 30% (9 out of 30) it was starting Nursery or School, something also found by Kolvin and Fundudis (1981), Steinhausen and Juzi (1996) and Ford et al (1998).
- 77% (23 out of 30) families were presently or previously affected by shyness, confirming existing research on a familial link for SM (Kolvin and Fundudis, 1981; Ford et al, 1998; Kristensen and Torgersen, 2001).
- Additional conditions co-morbid with SM were reported in 60% (18 out of 30) cases. Of these, anxiety or phobia related conditions accounted for 40% (12 out of 30) cases. This confirms the findings of Black and Uhde (1995), Steinhausen and Juzi (1996), Dummit et al, (1997); Ford et al (1998); Kristensen (2000); Kristensen and Torgersen (2001); Manassis et al (2003); Vecchio and Kearney (2005).
- Psychologists most frequently diagnosed SM, although teachers, speech therapists and parents were also involved in identifying it. This confirms the findings of Ford et al (1998).

- Of the various treatment approaches employed, behavioural strategies were successful used in 56% (17 out of 30) cases, confirming the findings of Sluckin and Jehu (1969), Colligan et al (1977), Crogan and Craven (1982), Sluckin, Foreman and Herbert (1991), Krysanski (2003).
- The young people regarded family, friends and some school staff as most helpful in overcoming SM, something found by Ford et al (1998).
- They were most confident speaking in the home situation and least confident outside the home, especially at school, also confirmed by Steinhausen and Juzi (1996), Dummit et al (1997), Ford et al (1998).

The sample also covered the whole range of SM from severely affected to fully recovered, so it may be considered representative of the SM population.

Extensions

Findings from this study extended existing SM literature in several ways.

Oppositional Behaviour

The ICD-10 definition (WHO, 1994) and several articles identified oppositional behaviour in a small proportion of children with SM, especially in the home, but offered no explanation for it (Hayden, 1980; Steinhausen and Juzi, 1996; Ford et al, 1998; Yeganeh, Beidel and Turner, 2006; Cohan et al, 2008).

Evidence from the young people and parents in this study indicated that it may be rooted in a build-up of frustration due to remaining silent during the school day, which was then released in the safe environment of the home.

Personality

The most common adjectives used by others in studies to describe youngsters with SM were shy, withdrawn, anxious and stubborn (Hayden, 1980; Steinhausen and Juzi, 1996; Dummit et al, 1997; Ford et al, 1998).

However, the descriptors self-chosen by the young people and parents in this study presented more positive personality characteristics, giving a balanced, rounded impression of the youngsters.

The different aspects of their personalities displayed within and outside the home were evidenced, as was their frustration at being unable to express themselves in situations that caused them anxiety.

Education

Several studies noted a variation in academic results amongst children with SM, with about half making good progress, but failed to comment on attendance levels (Hayden, 1980; Ford et al, 1998; Bergman et al, 2002).

This study found a similar balance in academic progress, though most young people thought SM had affected them at school. Responses revealed that those at school had good attendance, despite the anxiety engendered in them by that situation.

Treatment

Some studies compared the efficacy of the various treatments for SM (Dow et al, 1995; Stone et al, 2002; Krynski, 2003; Sharkey and McNicholas, 2008; Viana et al, 2009). Ford et al (1998) asked those with SM about factors that helped them overcome the condition, but not about hindrances.

The young people in this study provided evidence for both helps and hindrances in dealing with SM. Most considered family and friends to be of greatest help and some mentioned speech and language therapists positively. Also helpful were others who understood SM and animals.

Six regarded school staff as helpful, but twelve considered them unhelpful, some citing specific examples of ill-treatment, such as Harriet (14 years):

My Tutor. He got me to shout his name as loud as I could and said, "I am not letting you go until you actually shout." I felt humiliated and when I tried to shout, my throat tightened.

Lack of understanding from professionals, peers, relatives and others, together with being pressured to speak, were regarded by the youngsters as hindrances in dealing with SM.

New Findings

This study added new knowledge to the literature by exploring directly the personal experiences of the young people with SM.

Alternative Communication Methods

The use of non-verbal and verbal communication strategies by those with SM was mentioned in the literature (Cline and Baldwin, 2004). However, there was no structured evidence for the type of methods being used and the recipients of their use.

Responses from the young people in this study provided that evidence, since all but one used non-verbal and 80% (24 out of 30) use verbal methods.

Gesture/pointing, writing and whispering were the commonest strategies used with teachers, classmates, relatives and friends. Some strategies were used for specific groups, such as tape-recorder with teachers or telephone with relatives and friends. Mostly, though, a range of different strategies was used with each recipient, demonstrating the determination and ingenuity of the young people with SM in finding methods through which to communicate.

Electronic communication methods that do not require speech have enabled those with SM to develop their social relationships and provided a vehicle for self-expression, which their condition so often denies them. However, it may come to almost replace personal contact, as was shown in the case of Horatia (aged 18), most of whose friends were on the Internet. That is a danger, but not just for those with SM.

Effects of having SM

Although children with SM have been subjected to detailed testing and examination for decades, their subjective experiences of living with SM had almost never been explored in the literature. This study provided evidence directly from the young people about the effects of SM on their lives.

At school, 80% (24 out of 30) of the sample thought SM had affected them. It had restricted their ability to be themselves, make friends and socialise, causing them to feel isolated. It also affected their learning, as they were unable to ask for help when stuck, could not read aloud or show their knowledge by answering teacher questions, struggled to participate during group work and missed opportunities by being unable to express their preferences. For some, it limited their choice of examination subjects and resulted in lowered grades, particularly from being unable to complete oral components.

Their anxiety was revealed by their words: 'vulnerable', 'afraid', 'scared', 'fear limited my progress'. Another factor was being the recipient of anger from others over their non-response.

However, Isabelle (aged 13) who was severely affected by SM and never spoke at school thought SM had not affected her learning, because she concentrated instead of chatting.

In public settings, 70% (21 out of 30) thought SM had affected them. They were unable to speak to some people or in certain situations, e.g., to shop assistants, to waiters in restaurants, to other school pupils, to strangers. They were not invited to join social outings or attend parties, because others assumed they would not want to, so they were never given the choice. Although, perhaps, an extreme example, Horatia (aged 18) wrote, "I don't go out much."

Again, their words revealed their emotions: 'sick when worried in certain situations', 'feeling isolated', 'anxious', 'fear of being spoken to when outside, getting lost and unable to ask for directions'.

Some participated in activities like dancing or sport, which did not require speech, but allowed them to engage with others socially.

In the family, 53% (16 out of 30) thought SM had affected them. This was mainly due to their difficulty in speaking to certain family members and relatives, which affected their ability to make close relationships. They were aware that this caused those affected to feel uncomfortable or upset, especially if they did not understand SM. They were also keenly aware of the worry and stress SM caused for their parents, by having to do more for them, explain their silence to other people and put up with their occasional emotional outbursts. Being unable to speak to family members made the youngsters feel uncomfortable and embarrassed.

Feelings

Personal accounts of the emotional effects of SM on the individual were largely absent from the literature. The young people in this study provided evidence for the impact of the condition.

Their responses indicated feelings of isolation, rejection, discomfort, worry, anxiety, stress, fear, panic, frustration, anger, sadness and loneliness. Several expressed a desire to be like others and be able to join in by talking.

Messages

Nothing in the SM literature presented direct statements from those with the condition to those without it. The messages from young people in this study fell into three categories.

To those without SM, the strongest message was that those with SM do want to talk and do not know why they cannot speak. Their silence was not a conscious choice, neither was it born of rudeness or arrogance. SM was not a phase they would grow out of, but a disorder, which they found hard and difficult to overcome. They were sensitive to its impact on other people.

Their advice to those without SM about helping them was to remove the pressure to speak, as it only engendered further anxiety. Patience, understanding, encouragement, support, acceptance, continuing to talk to them and inviting them to join activities were also recommended. When faced with non-response, others were advised to make no fuss, as the person with SM needed to feel comfortable before being able to speak.

They also gave words of encouragement to other SM sufferers, not to worry or be nervous, to know they were not alone and others did understand SM. Seeking other ways to communicate, getting support from SM resources and organisations could help them overcome the condition.

Conclusions and Implications

Having listened to the voices of the young people with Selective Mutism, the implications of their experiences for those who encounter them need to be considered. Evidence from the 'pupil voice' literature revealed the positive impact on schools of consulting their pupils (Rudduck, Chaplain and Wallace, 1996; Rudduck and Flutter, 2004).

Psychologists and teachers often feel threatened and frustrated when faced with a silent child. The evidence from the young people about the profound educational, social and emotional impact of SM on them, their desire to speak but fear of doing so and their character self-assessments, may inform professionals' understanding of the motivation and personalities of these youngsters. Their messages about factors and approaches that help or hinder recovery and their willingness to use alternative communication strategies, may inform approaches to treating them in school.

Early identification and treatment may reduce or even eliminate the long-term negative effects of SM described by the young people in this study.

There is a need for all professionals, especially CAMHS psychologists, to be better educated about SM and its treatment, from the evidence of the parents and young people in this study. The professionals who were most successful usually employed behavioural strategies.

Evidence from the parent respondents revealed their commitment to their child with SM, despite the stresses engendered in their households. Their dedication in seeking to understand and help included supporting the child in school, obtaining information about SM for professionals unfamiliar with the condition, searching out other sources of professional help when one failed, devising behavioural strategies to use with their child in and outside the home, explaining SM to relatives, changing the child's school and even home educating the child. The youngsters' responses showed their appreciation of the support provided by their parents and its vital role in helping them to overcome SM.

Limitations and future research

This study set out to examine the perspectives of young people with Selective Mutism and their parents from across the UK on their experiences of living with the condition. The sample size of 30, although relatively small, was a good number within the context of this rare condition and SM research. Comparison with existing research proved the sample to be representative of the wider SM population. Although the experiences shared were personal to the respondents, "the relatability of the work is more important than its generalisability." (Opie, 2004, p. 5).

Since more than half the sample were aged 10-12, the findings could also be applicable to younger children with SM. Further research into the perspectives of those with SM over a longer period of time and at a younger age would enhance these findings. All the families in this study have agreed to follow-up.

Finally

The success of this project in attempting to give 'a voice to the voiceless' was confirmed by Hazel (aged 15) in an E-mail when returning her response:

"Thanks for giving me the chance to share my side of the story :)."

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- SMIRA families who participated in the study.

SMIRA continues its work of informing and supporting parents and professionals about SM, through a variety of methods, including leaflets, a DVD and book, national meetings, a website and online groups.

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