An Exploration of the Coping Strategies used by Children who have a Sibling with Autism or Down's Syndrome

And Research Portfolio

PART ONE

(Part two bound separately)

Jennifer Low

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For my Gran

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Chapter 1: Small Scale Service Evaluation

The Impact of the Provision of Information Prior to First Appointment in a Primary Care Clinical Psychology Service

Small Scale Service Evaluation submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with requirements for submission to Clinical Psychology Forum (Appendix 1.1)

Address for correspondence
Jennifer Low
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Introduction

High rates of non-attendance are commonplace in many Psychology Out-Patient Clinics and result in the wasting of time as well as lowering the morale of therapists (Startup, 1994). In Great Britain, Farid and Alaport (1993), put the rate of non-attendance at between 20 – 30% and Hughes (1995), found that 7% of first appointments were not attended.

A number of strategies have been implemented in an attempt to reduce the rate of non-attendance. Gerhand and Blakely (1994), identified patients not wanting a referral to Clinical Psychology in the first place as the most important factor in attendance, suggesting therefore that 'opting in' to treatment would be an effective method in reducing rates of non-attendance. Indeed, Green and Giblin (1988), found that when they used an 'opting in' system the rate of DNA's was reduced. As well as reducing rates of non-attendance, 'opt in' systems have additional benefits such as reducing waiting times, improving cost effectiveness in terms of a reduction in wasted appointment times and enabling resources to be targeted where most needed (Yeandle, 1999).

As many patients referred to Clinical Psychology may be 'psychologically naïve', some form of preparing clients for psychological input has also been identified as effective in reducing non-attendance. The use of information has been identified as one such method of preparation. Sandler (1989), proposed that patients show greater general satisfaction when provided with information as well as increasing their knowledge of why they had been referred and were more informed about treatment. Webster (1992), found that 82% of patients who received an information leaflet attended their first appointment compared to 57% who did not. Markham and Beeney (1990), found that the use of an information sheet did not reduce 'did not attend' rates, but 90% of the sample found it useful and reassuring.

Hughes (1995), has suggested that the 'fear of therapy', that is being considered 'mentally ill', may have a crucial role to play in the rate of patients who fail to attend. The provision of appropriate knowledge of psychological services would therefore hopefully improve individuals' expectations of it. McCaskill and McCaskill (1983), report that patients who have realistic expectations and sufficient knowledge tend to remain in treatment and have better outcomes compared to those patients who have distorted expectations and deficient knowledge and who tend to drop out of treatment early or do poorly if they remain in treatment.

However it must not be ignored that individual differences can play a role in the psychological impact of information. Westbrook (1992), sent an information booklet to patients on a primary care service to test the effect on attendance rates. He found a higher rate of non-attendance in the 'booklet group' compared to a no-intervention group and identified a high attrition rate suggesting that information may, in fact, make people worse. Additionally work by Miller et al (1988), suggest that people differ in their desire for knowledge and that for some, preparatory information can be daunting and anxiety provoking.

However, the majority of the above literature suggest that giving prospective clients an information leaflet to read serves to reduce DNA rates as a result of allowing the individual to actively make the decision as to whether they wish to proceed with psychological input.

It also suggests that giving patients information about Clinical Psychology prior to attending an appointment can increase knowledge, therefore reducing individuals' anxiety, and allow for the development of realistic expectations of treatment.

The Department of Clinical Psychology was interested in individual expectations of, and attitudes towards, Clinical Psychology, and in particular, in identifying any differences between those groups who received information and those who did not. The results of the survey will hopefully highlight the impact of the information leaflet on both patients' anxiety and expectations of treatment, and illustrate the importance of providing information prior to initial appointment.

Research Questions

- Does the provision of an information leaflet serve to lessen individuals' anxiety about coming to see a psychologist?
- Are there differences in perceived knowledge levels of the psychologist's role between individuals who receive information leaflets and those who do not?
- Does the provision of an information leaflet affect how keen an individual is to attend an appointment with a psychologist?
- Do expectation levels of psychological treatment differ between those individuals who receive an information leaflet and those who do not?

Methodology

Subjects

Clinical Psychologists employed in the West sector of Glasgow were approached and asked if they would agree to the sending out of questionnaires relating to attitudes about, and expectations of, Clinical Psychology to their patients. It was envisaged that the questionnaire would be distributed with 'opt in' letters over a 3 month period. Eight of the ten psychologists asked agreed to participate. Only one psychologist employed in the West sector provided an information booklet which he had personally devised along with an 'opt in' letter.

Materials

Information Leaflet (see Appendix 1.2)

The leaflet consisted of 10 pages of A4 and contained information on the following areas:

How to get an appointment.
What is a Clinical Psychologist?
Is a Psychologist the same as a Psychiatrist?
What problems do Psychologists deal with?
How can a Psychologist help you?
What will happen at your first appointment?

An 'opt in' form was also included within the leaflet, as was a short semi-structured questionnaire focusing on the main problem that the individual was experiencing, and a copy of the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983).

Individuals were asked to complete these forms and to return them in the stamped addressed envelope provided.

Measures

Patient Survey (see Appendix 1.3)

Given that the information booklet already contained a short questionnaire, two versions of a semi-structured questionnaire examining attitudes towards and expectations of Clinical Psychology were developed – one for the 'information' group, and the other for the 'no information' group covering identical questions. This prevented repetition of items and avoided individuals answering the same questions twice. A short introduction explained the reason for the survey and assured individuals that they were under no obligation to participate, and that should they choose to complete the questionnaire any information volunteered would not have any effect on the treatment they received. Open – ended items relating to the current problem being experienced were included, and both groups were asked to rate their anxiety about visiting a psychologist both retrospectively when their GP initially told them of their referral to Clinical Psychology, and currently, on receiving their 'opt in' letter. They were also asked to rate how keen they were to come and see a Psychologist, how much they felt they knew about what a Psychologist does, and how much of a problem their current difficulty was to them. Additionally, individuals were asked to select from a list of six, different treatment approaches they felt would work best for them. Finally both groups were asked to rate their expectations of psychological input.

Procedure and Design

A postal survey was used. A total of 39 copies of the information leaflet and attitudes and expectations questionnaire was distributed to those patients under the care of the Clinical Psychologist who provided the information booklet along with 'opt in' letters, and 40 patients under the care of the remaining Clinical Psychologists who had agreed to participate in the study were sent copies of the questionnaire and Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983), along with their 'opt in' letter. That is, all patients who were sent 'opt in' letters over a three month period were asked to participate in the study.

Results

In total, 90% (35 individuals) of the 'information' group and 67.5% (27 individuals) of the 'no information' group returned their questionnaires, along with their 'opt in' forms and Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983).

Individuals' perception of problem

Subjects were asked to rate, on a ten-point scale, how much of a problem their current difficulties were for them. The mean rating for both the 'information' group and the 'no information' group was 8.2.

Initial reaction to referral

Table 1.1 shows how subjects rated their anxiety when told by their G.P. of their referral to Clinical Psychology and **before** receiving an information pack and / or opt in letter.

Respondent Group	not at all anxious	fairly anxious	very anxious
Information Leaflet	10 (29%)	10 (29%)	15 (43%)
No Information	7 (26%)	14 (52%)	6 (22%)

Table 1.1

Both groups felt similarly in their initial reaction to the referral to Clinical Psychology with 72% of the 'information' group and 74% of the 'no information' group feeling some degree of anxiety.

Current reaction to referral

Table 1.2 illustrates individuals' levels of anxiety in relation to their referral **after** having receiving their 'opt in' letter either with or without an information pack.

Respondent Group	not at all anxious	fairly anxious	very anxious
Information Leaflet	13 (37%)	16 (46%)	6 (17%)
No Information	8 (30%)	14 (52%)	5 (18%)

Table 1.2

63% of individuals who had received information packs felt fairly or very anxious compared to 70% of individuals who did not receive information packs. A slightly larger proportion of those who did not receive information reported feeling fairly anxious compared to those who did receive information.

'Keenness' to see Psychologist

Only very few individuals were not at all keen to see a Psychologist (9% of the 'information' group and 4% of the 'no information' group). In both groups the majority of patients reported that they were very keen for psychological input. It can be surmised that those individuals who were least keen to see a Psychologist would be least likely to attend. However, in this study, it is impossible to state whether the provision of information made patients keener to see a Psychologist and therefore more likely to complete their questionnaire and subsequently attend their appointment.

Knowledge about Psychology

Table 1.3 shows how subjects rated their perceived knowledge of Clinical Psychology after having received their information pack and / or 'opt in' letter.

Respondent Group	**nothing at all**	**a little**	**a lot**
Information Leaflet	2 (6%)	15 (43%)	18 (51%)
No Information	9 (33%)	15 (56%)	3 (11%)

Table 1.3

51% of the 'information' group felt that they knew a lot about what a psychologist does, compared to only 11% of the 'no information' group. 33% of the 'no information' group felt that they knew nothing at all about Psychology compared to 6% of the 'information' group. Statistical analysis using the Chi Square statistic revealed these differences in ratings to be significant at the .001 level of significance. However, such data does have a lot of demand characteristics with patients being likely to want to please the therapist and therefore making them more likely to answer in a positive manner.

Treatment Expectations

The mean ratings on a ten-point scale for individuals in the 'information' group and 'no information' group in response to the question 'How much do you think psychological input will help you?' were 7.8 and 7.6 respectively, with a score of 1 signifying 'won't help at all' and a score of 10 signifying 'will help a great deal'. However, once again patients may be actively answering in a way which they expect will please the therapist.

Treatment Approach

Overall, both the 'information' group and the 'no information' group felt that talking through their problems and receiving active advice would be the most helpful treatment approach (selected 83% and 78% respectively). Learning relaxation / stress management techniques was selected by 80% of the 'information' group and 61% of the 'no information' group as possibly being a helpful treatment approach. Only 17% of group 1 respondents and 18% of group 2 respondents felt that medication would be a helpful treatment approach.

HADS Scores

The mean anxiety score in the 'information' group was 16 (falling into the 'severe' category), range 12 – 21, and in the 'no information' group the mean anxiety score was 14 (falling into the 'moderate' category), range 4 – 20. Analysis using the Chi Square statistic revealed scores to be significantly higher in the 'information' group at the .001 level of significance.

The mean depression score in the 'information' group was 14 (falling into the 'moderate' category), range 4 – 20, and in the 'no information' group the mean depression score was 10 (falling into the 'mild' category), range 1 – 21. Again, statistical analysis using Chi Square revealed the 'information' group scores to be significantly higher at the .002 level of significance.

Discussion

The literature proposes that patients benefit from the provision of information before commencing treatment, and it has been suggested that such relevant information serves to create more realistic expectations of treatment and reduce anxiety in relation to attendance. The aim of this survey was to identify any differences that may exist between patients who receive such information and those who do not, in terms of reported anxiety, keenness to see a Psychologist, knowledge of the role of a Clinical Psychologist and expectations of treatment, illustrating that the provision of information is indeed beneficial to patients.

The result of the survey suggest that in terms of anxiety levels, both groups initially experienced some concerns in relation to their referral, and that the numbers of individuals who were not at all anxious increased in both groups from the time of initial referral to the receiving of the 'opt in' letter. However, a higher proportion of the 'no information' group reported feeling 'fairly anxious'. It should be noted that this time period would have undoubtedly varied between therapists, each having varying lengths of waiting lists. Those in the ‘information’ group were guaranteed an appointment within 2 weeks of returning their ‘opt in’ form, whereas those in the ‘no information’ group waited an average of around 22 weeks for an initial appointment. Patients were also asked to give a retrospective rating of their anxiety, which may have been subject to inaccuracy. However, the number who did report experiencing high levels of anxiety fell in both groups as time elapsed.

Both groups reported similar levels of keenness to see a Psychologist and expectation levels were also very alike. The treatment approaches selected as potentially being the most helpful followed similar patterns in both groups of subjects. However, the ‘information’ group did report significantly higher levels of knowledge.

A number of issues need to be addressed in relation to the findings of the survey. Previous psychological input was not taken into consideration and this would undoubtedly have an impact on perceived levels of knowledge. Actual attendance was not followed up and previous literature would suggest that those who had received information would be more likely to attend initial appointments. Indeed Anderson and White, (in press), found that sending patients information along with their ‘opt in’ letter reduced initial DNA rates from 25% to 3%.

As already mentioned, the answers given by individuals who completed the questionnaire may be open to some bias. It may be the case that patients are likely to want to please the therapist and therefore answer positively.

The comparability of the two samples in terms of socio-economic status must also be questioned. Although all the patients in the 'no information' group lived in Clydebank, the confidential nature of the questionnaire meant that it was impossible to ascertain exactly where in the catchment area of the Clinical Psychology Service subjects in the 'no information' group lived.

Similarly, in terms of perceived anxiety and depression levels as measured by the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983), the significant differences in scores obtained by the two groups must not be overlooked.

Conclusions

It appears that in this study, in terms of anxiety levels and expectations of treatment, no differences exist between those patients who receive information and those who do not. Reported levels of knowledge in relation to Clinical Psychology are significantly higher in the 'information' group, but this does not appear to be impacting on levels of anxiety experienced. Further work needs to be carried out in relation to subsequent attendance rates and involving a higher number of participants.

Cognitive Behavioural Therapy assumes that patients will take an active part in a collaborative treatment. If patients are provided with information which can help them move from being passive recipients to active collaborators then it undoubtedly has an important role to play in the outcome of their psychological therapy.

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Chapter 2: Literature Review

An Exploration of the Coping Strategies used by Children who have a Sibling with a Learning Disability

Literature Review submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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Address for correspondence:
Jennifer Low
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Abstract

There exists a popular belief that siblings are negatively affected by living with a learning disabled sibling. However the research base in this area continues to produce discrepant findings, with some studies reporting positive gains whereas others identify negative outcomes as a result of living with a learning disabled brother or sister. A number of factors have been identified as contributing to such outcomes, and the coping strategies that are utilised by children are now being explored as a possible explanation for the individual differences in adjustment that appear to exist. An exploration of the research in the field to date forms the main focus of this paper, with discussion around the possible role of coping strategies in the adjustment of children. Previous research has tended to focus on children with learning disabilities as a whole, and the relevance of exploring the coping strategies of children with a sibling with Autism or Down's Syndrome, two very differently presenting disorders, is discussed.

Keywords : Siblings, autism, Down's syndrome, coping strategies.

Introduction

The sibling relationship has been defined as a distinctive, passionate, painful and solacing power which shapes who we are and who we become. (Bank and Kahn, 1997). Such relationships among brothers and sisters are infinitely varied and siblings have been identified as having a place as companion, teacher, model, protector, playmate and enemy (Lobato, 1990 and McKeever, 1983). Such complex and enduring relationships provide an important source of emotional support (Dunn and Kendrick, 1982) and as a result of the high levels of interaction and imitation that take place between siblings the relationship will undoubtedly be of developmental importance through both the direct impact the siblings have on each other and through indirect effects of siblings' relationships with their parents (Dunn, 1988).

Sibling interactions are therefore essential and powerful components of socialisation as they foster development of important instrumental and affective relationship skills (Cirirelli, 1985), and play a critical role in overall development.

As siblings share such an intimate and intense relationship (Sutton-Smith and Rosenberg, 1970), much research has focused on the nature of the impact, and factors that may influence that impact, that living with a child with chronic illness or with a disability has on a normally developing sibling. Successful 'adjustment' is frequently the focus of such research, and refers to the relationship that any organism establishes with respect to its environment. The implication is that the individual is involved in a rich, ongoing process of developing his or her potential, reacting to and in turn changing the environment in a healthy and effective manner (Reber, 1995). 'Adjustment' is thought to be mediated by individual differences in personal, social and coping processes and attenuated by various resistance factors such as family relationships.

A number of conceptual models have highlighted the role of 'stress' and coping in adjusting to chronic illness (e.g. Varni and Wallender, 1988) and living with a sibling with disability (e.g. Gamble and McHale, 1989). However such models are highly complex and it is not always clear how different variables contribute to the overall processes underlying 'adjustment'; in many cases they are simply identified and assumed to be relevant.

'Stress' is frequently assumed to play a role, but often the specific nature of this 'stress' is not adequately defined. Definitions of 'adjustment' also vary amongst researchers, depending on the nature of the study being undertaken. The adjustment of children who have a disabled brother or sister has been conceptualised to be, a function, in part, of a process that includes the type and quantity of stress children experience, their affective reactions to stressful events, and responses they employ to cope with those stressors (Gamble and McHale, 1989), and not the reaction to a child's disability *per se*. Poor adjustment is often defined in terms of the presence of depression, anxiety, behavioural difficulties and poor social interactions.

It is clear, them, that the concept of 'adjustment' involves the contribution of a number of factors to varying degrees, although the respective contribution of such factors is impossible to specify, with individual differences further complicating the picture.

Given the complicated nature of defining 'adjustment', it is also difficult to determine which factors play a more or less role in favourable outcomes. It is not surprising therefore that research in the area has yielded conflicting results. Additionally much of the literature in this field is plagued with limitations in that many studies do not use comparison or control groups, and have used various methods of observation from sources other than the siblings themselves. Widely different outcome measures, often inadequately defined, have been utilised with varied populations and often with very small sample sizes. It is the aim of this literature review to describe the research to date in this field, discuss the inconclusive results obtained to date and highlight where further study is merited.

Living With a Sibling with a Disability

The common assumption exists that living with a child with a disability has a harmful effect on normally developing siblings (e.g. Breslau et al, 1981; Gold, 1993), and that such siblings experience more 'adjustment' difficulties than those children who live with a normally developing sibling. However research in the area has failed to support such assumptions with any certainty.

Early studies suggest that living with a sibling with a disability can have a negative effect on psychological well-being. Gath (1974), examined the behaviour of 174 children who had a sibling with Down's Syndrome using the behavioural questionnaires for parents and teachers devised and developed by Rutter et al (Rutter, Tizard and Whitmore, 1970). Siblings were matched with control children in the same school class. From their results, they conclude that the presence of a child with Down's Syndrome in the home is associated with deviant behaviour as assessed by parents and teachers.

Gold (1993), in a comparison study found all of the siblings of autistic boys in her sample to be depressed in terms of the Children's Depression Inventory (Kovacs, 1983). However these results should be treated with some caution given that three cut-off points are offered for use with the CDI and it is unclear which cut-off point should be used in a study such as the one described. If using the most conservative cut-off point only 50% of these siblings fall into the depressed range, compared to 100% when using the most liberal cut-off score.

Lobato et al (1987), also found brothers of handicapped children to be more depressed and more aggressive and sisters more aggressive than control children. The research of Gath (1973), and Tew and Laurence (1973), also supports the position that siblings of handicapped children exhibit a significantly greater number of overall adjustment problems than do siblings of nonhandicapped children. However their results are biased by the exclusive use of maternal and/or teacher reports as a database. Mother's perspectives on the adjustment of their nonhandicapped children may be strongly coloured by their own adjustment to their handicapped child (Simeonsson and McHale, 1981).

Moreover, other studies have highlighted the absence of negative effects (Caldwell and Guze, 1960; Ferrari, 1984; Gamble and McHale, 1989; Gath 1972; Gayton, Friedman, Tavormina and Tucker, 1977). Breslau (1983), in an overall comparison of 237 siblings of disabled children with 248 control siblings revealed that the proportions of siblings classified as psychologically severely impaired were approximately the same in the two samples: 16 percent of siblings of disabled children and 13 percent of control siblings were so classified. Mates (1990), examined the 'adjustment' of siblings of autistic children in terms of self-concept, academic achievement, home adjustment, and school adjustment and concluded that overall the sibling's performance was not suggestive of needing special intervention.

Positive gains have also been documented. Grossman (1972), for example, conducted standard interviews with 83 college-aged siblings of 'retarded' children and 66 'matched' siblings of normal children and judged 45% of the subjects to have benefited from the experience of having a 'retarded' brother or sister, although 45% were described as being 'harmed'. Criteria for these two attributes was however rather unclear, although reliability reported between interviewers was adequate. Those who were judged as having benefited (about half of the sample) were rated as having a 'greater understanding of people in general and handicaps in particular, more compassion, more sensitivity of prejudice, and more appreciation of their own good health and intelligence than their peers'. In that study, as well as in subsequent research, those who have reported feeling better for the challenge of growing up with a handicapped sibling have tended to say that it has made them more altruistic, more empathic, and more open to people with various sets of difficulties. Many of the positive traits that are frequently mentioned are 'externalising'; that is, related to the ability to get on with others.

To confuse matters still further, simultaneous positive and negative consequences have also been reported (Cleveland and Miller, 1977; Grossman, 1972). Wilson, Blacher and Baker (1989), interviewed 24 children about life with their younger siblings who had severe handicaps and revealed a consistently high level of involvement, strong feelings of responsibility, and an emphasis on positive aspects of family life. Hardships were not denied, including sadness, anxiety and anger, which were for some children the most salient feelings, but the authors conclude that these children appeared to be faring better than children studied in earlier research.

It seems fair, therefore, to assume that the effects on siblings are highly variable with children responding in a variety of different ways and only certain individuals being susceptible to psychological maladjustment. A number of intertwined variables appear to be involved and impact to varying degrees on different individuals.

Mediating Factors

Research on how children cope with living with a child with a disability still yields discrepant results, even with improved experimental designs. Given this phenomenon and the reported data, it is difficult to support the view that siblings are, of necessity, negatively affected by the experience of living with a child with a disability. Instead it appears that a number of extraneous factors play an influential role, including age, age interval between siblings, gender, birth order and the educational level of normally developing siblings, although confusion exists surrounding the effects of these characteristics.

Socioeconomic status alone has been reported to be influential in some studies (Farber, 1959; Gath, 1972), with rates of 'deviancy' increasing in children with a learning disabled sibling from social class I towards social class V. Socioeconomic status has also been found to interact with sibling gender in other studies (Gath, 1974; Grossman, 1972), with male siblings being significantly more likely to develop behavioural problems than female siblings. Female siblings of poorer families, however, were more likely to be involved in caring for the child with a disability, often to the detriment of educational, peer and recreational opportunities. However yet another study (Schwiran, 1976) discerned no such interaction effects.

Disagreement also exists regarding whether older brothers or sisters are more adversely affected. Hannah and Midlarsky (1987,) and Grossman (1972), reported smaller families to have more problems and Breslau et al (1981), demonstrated that older siblings, especially females, were at greater risk for adjustment difficulties related to their sibling with a disability. A reorganisation of family roles can present a special challenge for children who are younger than their sibling with a disability. Specifically, a child may experience 'role tension' when 'regardless of his birth order in the family, the severely handicapped child essentially becomes the youngest child socially', and other siblings are expected to care for him and subordinate their needs to him (Farber & Ryckman, 1965, p4).

Siblings of a child with a disability have also been described as being assigned more responsibility and receiving less attention than siblings of normally developing children (Lobato, 1990). They may feel resentment, jealousy, hostility, guilt, grief, fear, shame, rejection, and embarrassment towards their sibling with a disability (Crnic et al, 1983; Lobato, 1990). According to Seligman (1983), children living with a sibling who have a disability may have many maladjustment problems related to their extra caretaking responsibilities, difficulty in understanding the disability, and feelings of anger and guilt directed towards their sibling. The professional working with a child who is growing up with a brother or sister with a disability must acknowledge the experience of such difficult emotions and appreciate the related difficulties that a child may be experiencing.

It is generally agreed that increased stress is involved in parenting a child with a disability (Sternisha et al, 1992), but that any stress experienced is related, in part, to the entire family situation. Increases in parental stress have been shown to have concomitant or residual effects on siblings in the family (Morgan, 1988). Time, financial and social demands have been identified as significant stressors as have the reactions of parents to accepting the diagnosis of their child's disability (Beckman, 1983). Poor family relationships, marital discord, depression or other psychiatric illness in the parents, all increase the risk of disturbance in both typically developing children and children with a disability (Howlin, 1988). Conversely, warm, harmonious family relationships have a protective effect, even when the impairment is severe (McHale et al, 1984). One of the most powerful influences on siblings' adjustment appears to be the ability of parents to convey positive attitudes about the child with the disability. A number of studies have shown that providing the 'burden of care' is not too great, if parents demonstrate their acceptance of the child with a disability, siblings tend to react in a similar fashion (Grossman, 1972). The degree to which parents communicate openly regarding their child's disability also appears to be a major factor in promoting siblings' understanding of and, therefore, adjustment to the disabling condition (Simeonsson & McHale, 1981).

Siblings of children with a learning disability often report feelings of having to excel in order to make up to their parents for the limitations of the child with a learning disability. Similarly they report feelings that their parents' expectations of them exceeded what was appropriate for their age or self-perceived capabilities. (Lobato, 1990). This may lead us to hypothesise that such children are placing high demands on themselves in an already stressful situation.

Additionally the nature of the disability has also been shown to impact on the incidence of behaviour problems exhibited by siblings. Fisman et al (1991), found the experience of living with a sibling with either autism or Down's Syndrome to be very different. This perhaps is not surprising given that the presentations of these disorders vary greatly. Whilst children with Down's Syndrome are developmentally delayed, they do not tend to be socially impaired. On the contrary the triad of impairments associated with Autism (social impairment, impairment of thought and language and of language and communication), can have a great impact on social interactions. The individual nature of each of the disabilities therefore produces differing stresses within the family environment, suggesting that siblings may be differentially affected.

Gath and Gumley (1987), found that behavioural problems in siblings of children with Down's syndrome and those with a 'retarded' brother or sister were related to the severity of the problems shown by the impaired child. Rodriguez et al (1993), found that siblings of children with pervasive developmental disorder had more internalising and externalising behaviour problems than siblings of children with Down's Syndrome and developmentally normal controls. A longitudinal study by Carr (1988), found siblings of Down's Syndrome to have fewer behavioural problems than comparison siblings when evaluated at 4, 11, and 21 years, and a greater degree of variability in response has been shown to exist in the siblings of children with autism, some being extremely positive but others reporting much more negative attitudes (Howlin, 1988). This variability in response has also been noted by McHale et al (1986), in their work examining the sibling relationships of autistic, mentally retarded, and non-handicapped children to their normal brothers and sisters. They concluded that there are siblings of autistic and retarded children who are doing extremely well, but there are also those who describe a significant amount of distress surrounding the issue of their brother or sister who is handicapped.

Other studies have also reported a higher incidence of behaviour problems in siblings when the impairment is more severe (Breslau et al 1981; Grossman 1972; Kowalski 1980; Tew and Laurence 1973).

The 'visibility' of the impairment further complicates the picture. Siblings of children with 'vague' or ill-defined problems have been shown to be more likely to suffer than when the condition is well-defined or very obvious (Howlin, 1988). Gath and Gumley (1987), posit what they term the 'Sainsbury's Syndrome' as a possible explanation. For instance, if a child with Down's Syndrome misbehaves in a supermarket, his/her family are probably likely to be treated by onlookers with sympathy, whereas if a less obviously impaired autistic child misbehaves in a similar manner, the reaction of others is likely to be less understanding.

The above research illustrates a very inconclusive picture in respect of the effect that living with a child with a disability has on a sibling. Further investigation is required to aid in the clarification of which factors may be playing an influential role to a greater or less extent. This is a daunting task, but several conceptual models have been used in an attempt to guide research with the aim of explaining the different ways in which children are affected to varying degrees by the experience of living with a sibling with a disability.

The Concept of 'Coping'

As previously discussed, many variables contribute to the overall impact of living with a child with a disability. Coping efforts have been identified as playing a role and have been suggested as a possible explanation for differences in 'adjustment'. They have been defined as 'any and all responses made by an individual who encounters a potentially harmful outcome' (Silver and Wortman, 1980).

Lazarus and Folkman's (1984), cognitive appraisal model of stress and coping has had a major theoretical influence in guiding research on the ways in which children cope with stress. Coping has been defined as constantly changing cognitive and behavioural efforts to manage internal and/or external demands that are appraised as taxing or exceeding the individual's resources (Lazarus and Folkman, 1984). According to their function (alteration of the individual-environmental transaction vs. regulation of the emotions) and modes of expression (behavioural vs. cognitive), four coping response strategies have been identified: cognition of other people or the situation (e.g. blaming someone); cognition directed at the self (e.g. telling yourself not to be angry); environment-directed behaviour (e.g. problem solving activities); self-directed behaviour (e.g. withdrawal from a stressful situation).

In their 1989 study, Gamble and McHale set out to examine the adjustment levels and coping responses of children with mentally retarded and non-handicapped siblings. They found only minor differences between the two groups on ratings of the frequency and affect intensity of stressors aroused by their siblings. There was a tendency for children with handicapped siblings and for girls in general to use more coping responses which involved thoughts about the others. Two kinds of coping strategy were consistently associated with adjustment and the sibling relationship; self-directed cognition (e.g. attempts to control emotional reactions), exhibited a positive and other-directed cognition (e.g. placing blame), a negative correlation with these factors. This study highlights that the ways in which children cope may hold a crucial influential role in explaining the variability in 'adjustment' that appears to exist.

Rivers (1999), also highlighted the role of coping in her study of sibling relationships in 50 families when a brother or sister had autism. Contrary to what was anticipated, neither the temperament of the normally developing child or the child with autism differentiated reports of more positive sibling relationships from reports of more negative sibling relationships. Although not a particularly strong predictor of the quality of the sibling relationship (as compared to stress in the marital relationship), coping was identified as a predictor for aspects (such as conflict or warmth) of the sibling relationship. It can be concluded therefore that the implementation of effective coping strategies can contribute to a more positive sibling relationship.

Glasberg (1999), describes the importance of the appraisal and coping process in determining one's response to stressful events. She hypothesised that a relatively immature ability to process information about autism would lead to a more negative appraisal of the disorder, and consequent difficulties with adjustment. However, no relationship was found between reasoning about autism and scores on the 'Child Behaviour Checklist' (Achenbach, 1991), or self-reported negative emotions in sixty-three children with an autistic sibling.

Different methods of coping with problems presented by adults with Down's Syndrome or autism have been described by Holmes and Carr (1991), in their study of the pattern of care in thirty-nine families. If we consider that these parents are dealing with similar problems but in different ways, then it seems logical to assume that siblings of a learning disabled brother or sister may be behaving similarly.

The importance of the association between coping and relationships in families in which there is a child with Down's Syndrome has also been discussed by Van Riper (2000), and Sloper et al (1991).

The above studies all acknowledge the importance of coping in the outcome of wellbeing in families in which there is a child with a learning disability. However, the present literature has not, as yet, considered the coping strategies utilised by children who have a sibling with autism or Down's Syndrome. Given the dissimilar nature of the presentation of these disabilities, one may expect children to be exposed to different situations. How they cope with such situations merits further exploration.

Summary

An examination of the specific coping strategies used by children and their perceived effectiveness in relation to situations connected to their learning disabled sibling has not yet been described in the literature. As noted earlier, some studies suggest that such experiences have an adverse effect on normally developing youngsters. In contrast, other children exhibit no symptoms of adjustment problems. An explanation of these differences might include the effects of children's coping abilities. In the majority of research on children's coping, however, coping strategies tend to be described in a more general sense, and do not consider the different strategies implemented across different situations. Further research is required to ascertain which strategies are used by children to the best effect across situations, in an attempt to further explain the differences that exist.

More specifically, given that the presentations of autism and Down's Syndrome vary greatly, and considering the greater variability in the responses of those children living with a sibling with autism, it is of interest to ascertain whether siblings of children in these respective groups differ in the coping strategies that they implement and whether they perceive different situations as 'difficult' in relation to their sibling. This research study aims to answer these points and gain an understanding of how effective children perceive their attempts at coping to be.

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Chapter 3 : Proposal for Major Research Paper

An Exploration of the Coping Strategies used by Children who have a Sibling with Autism or Down's Syndrome

Major Research Proposal submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines (see Appendix 2.1)

Address for Correspondence :
Jennifer Low
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Summary

There exists a popular belief that as a group, siblings are negatively affected by the presence of a learning disabled brother or sister, although very few, well-controlled empirical investigations actually exist to support this assumption. The research base to date in this area is relatively small and has yielded inconsistent and equivocal findings, with some studies supporting the hypothesis that siblings of learning disabled children are more susceptible to psychological maladjustment whereas others suggest that the presence of a handicapped child has subsequent benefits for siblings. Therefore it would appear that only certain siblings at certain times appear to be vulnerable to negative reactions. In specific relation to those children with an autistic sibling there is no expectation that they will suffer as a result of having an autistic brother or sister. However, studies have found greater variability in the siblings of autistic children, compared with, for example, the siblings of children with Down's Syndrome, although as a group they do not appear to be unduly disadvantaged. Of note, studies have shown that this latter group of children exhibit fewer behavioural difficulties and appear to be better adjusted. It has been suggested that much depends on particular family circumstances such as family size, birth order, sibling gender, socio -economic status and parental responses and individual coping behaviours adopted.

Given the range of variability reported in the impact of having an autistic sibling it is the aim of this study to identify the different strategies used by siblings in coping with a sibling with a learning disability and to establish whether such strategies differ between those children with an autistic sibling and those with a sibling with Down's Syndrome.

Subjects over the age of seven years will be recruited from special educational establishments in Forth Valley and also throughout West Central Scotland via the National Autistic Society and the Scottish Down's Syndrome Association. A screening measure will be administered to identify coping behaviour adopted and children will be asked to identify particular situations relating to their learning disabled brother or sister that they find problematic. A further standardised measure with proven reliability and validity, the Sibling Relationship Questionnaire - Brief Version (Furman and Buhrmeister, 1985), will be administered to establish the nature of the sibling relationship. In addition, general demographic information will also be requested. This will allow for the identification of the various coping strategies utilised by children and establish if these strategies differ across situations. It will allow for the identification of any variance between and groups. Finally the range of problematic situations identified by siblings will be examined and any differences noted.

Introduction

The relationship between siblings is one of great influence and importance and generally provides individuals with physical and emotional contact at critical stages throughout their lives. (Powell and Gallagher, 1993). Siblings adopt many roles within such a relationship; amongst many others Lobato (1990), and McKeever (1983), identify siblings as having a place as companion, teacher, model, protector, playmate and enemy. Sibling interactions can also provide an important source of emotional support (Dunn and Kendrick, 1982). This special relationship provides a context for social development and from these social interactions, the child develops a foundation for later learning and personality development (Powell and Gallagher, 1993).

Sibling interactions are therefore essential and powerful components of socialisation as they foster progress of important instrumental and affective relationship skills (Cirirelli, 1985), and play a critical role in overall development.

Due to the influential nature of such a relationship, much research has focused on the psychological 'adjustment' of siblings of chronically ill children or children with disabilities. In general, 'adjustment' refers to the relationship that any organism establishes with respect to its environment. When used in relation to social or psychological adjustment it carries clear positive connotations e.g. well -adjusted. The implication is that the individual is involved in a rich, ongoing process of developing his or her potential, reacting to and in turn changing the environment in a healthy, effective manner (Reber, 1995). 'Adjustment' is thought to be mediated by individual differences in personal, social and coping processes and attenuated by various resistance factors such as family relationships.

Conceptual models have highlighted the role of 'stress' and coping in adjusting to chronic illness, (i.e. Varni and Wallander, 1988), and living with a sibling with a disability (i.e. Gamble and McHale, 1989). However such models are highly complex and it is not always clear how different variables contribute to the overall processes underlying 'adjustment'; in many cases they are simply identified and assumed to be relevant. 'Stress' is frequently assumed to play a role, but often the specific nature of this 'stress' is not adequately defined. Definitions of 'adjustment' also vary amongst researchers, depending on the nature of the study being undertaken. Poor adjustment is often defined in terms of the presence of depression, anxiety, behavioural difficulties and poor social interactions.

It would appear then that the concept of 'adjustment' involves the contribution of a number of factors to varying degrees, although the respective contribution of such factors is impossible to specify, with individual differences further complicating the picture.

Past literature has failed to establish with any certainty whether siblings of children with chronic disabilities are a population at risk for 'adjustment' problems (Fisman et al, 1996). Much of the literature in this field is plagued with limitations in that many studies did not use comparison or control groups and used various methods of observation from sources other than the siblings themselves. Widely differing outcome measures, often inadequately defined, have been utilised with varied populations and often with very small sample sizes.

Some research, especially early studies, suggest that living with a sibling with a disability can have a negative impact on psychological well-being. Gold (1993), in a comparison study found all of the siblings of autistic boys in her sample to be depressed in terms of the Children's Depression Inventory (Kovacs, 1983). However these results should be treated with some caution given that three cut-off points are offered for use with the CDI and it is unclear which cut-off point should be used in a study as the one described. This leaves the researcher free to select the most appropriate option to support their conclusions.

Other studies however have found little or no impact (Gamble and McHale, 1989), or indeed, positive gains, for example, Grossman (1972), judged 45% of participants to have benefited from having a 'retarded' brother or sister, although 45% were described as having been 'harmed'. However criteria for these two attributes are rather unclear.

It is apparent that there is considerable variability in sibling adjustment with clear differences existing between different groups depending on the nature and severity of the disability. (Gath and Gumley, 1987; Howlin, 1988; Rodriguez et al, 1993). A greater degree of variability has been shown to exist in the responses of siblings with an autistic brother or sister, some children being extremely positive but others reporting much more negative attitudes (Howlin 1988), whereas a longitudinal study by Carr (1988), found siblings of children with Down's Syndrome to have fewer behavioural problems than comparison siblings when evaluated at 4, 11, and 21 years.

A number of factors has been identified as affecting the adjustment level of children who have a learning disabled sibling including age, age interval between siblings, gender, birth order and the educational level of normal siblings. Hannah and Midlarsky (1987), and Grossman (1972), reported smaller families to have more problems and according to Breslau et al (1981), older siblings, especially females, were at greater risk for adjustment difficulties related to their sibling with a disability. Increases in parental stress may also have concomitant or residual effects on siblings in the family (Morgan, 1988).

Whilst a number of studies exist examining children's overall 'adjustment', further investigation is required to increase understanding of the factors which may influence this 'adjustment'. Coping efforts have been identified as playing a role and may help to explain such differences. Coping has been defined as 'any and all responses made by an individual who encounters a potentially harmful outcome' (Silver and Wortman, 1980).

Cognitive theories of stress and coping (Lazarus and Folkman, 1984), the two- dimensional model of primary and secondary control (Rothbaum, Weisz and Snyder, 1982); Murphy and Moriarty's (1976), ego-psychological model; and the monitoring-blunting model (Miller, 1980), all provide a basis for understanding some of the ways in which siblings may be affected differentially.

In spite of the apparent diversity of these models, all of these approaches emphasise a basic distinction between two fundamental types of coping. The first type of coping refers to efforts to change or master some aspect of the person, the environment, or the relation between these two elements that is stressful and is labelled as 'problem-focused coping'. It includes strategies such as planning, seeking social support and obtaining more information. The second type of coping refers to efforts to manage or regulate the negative emotions associated with the stressful episode, such as looking for sympathy, 'shutting down' or disengaging emotionally, concentrating on the positive or turning to religious faith. This type of coping has been labelled as 'emotion-focused coping' (Lazarus and Folkman, 1984).

Coping efforts are influenced by both the characteristics of the individual and those of the situation in which he or she is coping. The coping process is responsive to the varying demands of different situations and changes in the same stressful encounter as it unfolds over time (Compas, Worsham and Ey, 1992). Studies of coping in children and adolescents suggest that problem-focused and emotion-focused coping skills emerge at different points in development, with an age related increase in the latter strategy. Nevertheless, age related differences in coping behaviours do not mean that more simplistic methods are any less effective.

In most research on children's coping, coping strategies tend to be referred to in the most general sense, or in terms of adaptive or resilient personality dispositions from which coping responses are inferred but not actually measured. An alternative approach, different from a trait oriented model, involves the identification of specific, event-related coping strategies. One important application therefore would be to identify the coping strategies that children use and to identify any differences in strategies implemented across situations.

The coping strategies used by those children with siblings with autism or Down's Syndrome are of particular interest. Given that the presentations of autism and Down's Syndrome vary greatly, it would seem fair to assume that siblings of children in these respective groups will be faced with very different situations. Whilst children with Down's Syndrome are developmentally delayed, they do not tend to be additionally socially impaired and their pattern of interaction has been found not to differ from young typically developing children (Knott, Lewis and Williams, 1995). Conversely the triad of impairments associated with autism (social impairment, impairment of thought and behaviour and of language and communication) can severely limit social interactions. It follows then that the sibling relationships within these two groups must differ and present their own individual challenges to children, with different situations to cope with. Research would also suggest that younger siblings will display more problem-solving oriented coping strategies whilst older children's coping strategies will be more emotion-focused.

It is apparent therefore that the effects on siblings are highly variable with children responding in a variety of different ways and only certain individuals being susceptible to psychological maladjustment. A number of intertwined variables appear to be involved in ‘adjustment’ and impact to varying degrees on different individuals. Given that previous research has found that Down’s Syndrome siblings appear to show relatively better ‘adjustment’ than other groups of siblings with a learning disabled brother or sister and that there appears to exist a high degree of variability in the degree of stress experienced by those children who have an autistic sibling, the factors which differentiate such individuals merit attention.

Therefore the proposed study, whilst acknowledging the existence of a number of contributory factors in successful adjustment will focus on one specific area, namely that of coping behaviours. It is hoped that a range of coping strategies utilised by children who have a sibling with a disability will be identified as well as any variability across situations and any differences between groups (autistic siblings and Down’s Syndrome siblings) detected. Results should aid in the identification of those coping strategies which are most frequently utilised by children and how each child perceives the effectiveness of each of these strategies. Findings should also aid in the planning of developmentally appropriate intervention programmes focusing on the teaching of effective coping skills.

Aims and Hypotheses

The study aims to highlight that children do differ in their individual perceptions of how well they cope with having a sibling with a disability and will identify which coping strategies are used most frequently by an individual and with the best effect. Factors such as the quality of the sibling relationship and the range of coping strategies employed will be examined. A number of specific scenarios will be presented to identify whether children respond in the same way to different situations and to identify any differences in coping strategies employed between the groups.

The study aims to address the following important research questions:

1. Is there a relationship between the quality of the sibling relationship and the nature of disability?

2. Do children differ in their perception of which situations they find most 'difficult' in relation to living with a learning disabled brother or sister?

3. What are the different coping strategies utilised by children who have a sibling with a disability?

4. Does the efficacy of coping strategies differ between groups?

5. Does the efficacy of coping strategies differ between identified 'difficult' scenarios?

Plan of Investigation

Subjects

Subjects will be recruited via 'special' schools in the Forth Valley region and through the National Autistic Society and the Scottish Down's Syndrome Association. It is envisaged that letters (See Appendix 2.4) will be distributed to parents who have either an autistic child or a child with Down's Syndrome explaining the nature of the research and requesting individuals to volunteer to take part. Consent forms will also be included (See Appendix 2.5). Given that parents often report that they feel that the non-autistic children in the family need some form of support (Evans 2000), the opportunity to participate in a sibling support group, organised by the researchers, will be offered to subjects. Children over the age of seven years who have a sibling with autism or Down's Syndrome and who both live in the family home will be included in the study. If there is more than one sibling in the family, each child will be encouraged to participate. It is hoped that at least 52 subjects in total will participate.

Siblings who themselves have a learning disability will be excluded from the study.

Measures

The following standardised measures will be employed in the study:

Kidcope (Spirito, Stark and Williams, 1988) (See Appendix 2.3)

Kidcope is the most widely adopted checklist approach to the assessment of coping in children. Available in two versions; one for younger children, aged 7-12 years, and one for adolescents, aged 13-18 years, it asks the child to identify a specific difficult situation which is then rated in terms of distress experienced by the child. The child is also asked to rate the frequency and efficacy of alternative coping strategies. It has particular value in identifying a possible profile of coping strategies being used by individual children.

For the purpose of this research children will be requested to complete the scale in relation to specific problematic scenarios, based on research by Gamble (1985), in which stressor events were identified by children with disabled or non-disabled children over a two-week period. Seven scenarios derived from these reports will be presented to participants. Children will be asked to establish which of the behaviours they experience in relation to their sibling with autism or Down's Syndrome and to rank these in order of occurrence. They will then be asked to think of and describe a specific example in each category, rate the incident in terms of distress caused, and how they coped with it.

Spirito et al (1988), have demonstrated acceptable levels of reliability. The validity of *Kidcope* was established by comparing the scores with previously validated measures of coping. A strong correlation was found between predicted subscales of the *Coping Strategies Inventory* (Tobin, Holroyd and Reynolds, 1984), and the corresponding *Kidcope* items.

Sibling Relationship Questionnaire - Brief Version (Furman and Buhrmeister, 1985). (See Appendix 2.2).

The **SRQ** measures 16 dimensions of the sibling relationship, using a five-point Likert format. Scores are achieved on four factors: warmth/closeness, relative power/status, conflict, and rivalry.

The internal consistency coefficients exceed .70. Reported test-retest reliability is .71.

Design and Procedure

The research is essentially a between group design with direct comparisons being made between two groups.

A literature search did reveal a number of published studies which have utilised the measures employed in this study with similar groups. *Kidcope* has been used with siblings of children with cancer (Sloper and While, 1996) and the *SRQ* with siblings of children with pervasive developmental disorder, and children with Down's Syndrome (Fisman et al, 1996), but unfortunately neither papers quote appropriate statistics suitable for use in calculating power. Therefore reference was made to Cohen (1992), and his formula for power calculation. Based on data presented by Cohen (1992), assuming a significance level of 0.05 and a desired power level of 0.80, a figure of 26 children in each group would be required to participate in the study.

Participants will complete each of the measures described. The measures are both quick and easy to administer. Once data from each of the measures for each of the participants have been collated, it is envisaged that a range of coping behaviours will be identified. Differences between groups in coping strategies utilised across various situations will be examined.

Settings and Equipment

In order to minimise disruption to subjects it is anticipated that interviews will take place in the homes of the participants.

Data Analysis

Data from each of the measures administered will be collated and analysed using the Statistical Package for Social Sciences (SPSS for windows).

Descriptive statistics will initially be undertaken. The planned analyses can be summarised in relation to each of the specified research questions.

Question 1) - mean scores will be calculated for each of the four dimensions of sibling relationship measured by the SRQ. If the data is normally distributed within each group, then the use of t-tests (unrelated) will be appropriate. If not, Mann-Whitney U tests will be employed.

Question 2) – the total frequency of each scenario by rank order of occurrence will be calculated and Chi Square Analyses applied to ascertain whether any differences exist between groups. In addition, mean distress scores will be compared between groups and analysed similarly.

Questions 3), 4) and 5) -Coping strategies used, their efficacy overall and in identified specific 'difficult' situations common to both groups will be described. Chi Square Analyses will be employed to ascertain whether any differences exist between groups.

Practical Applications

Coping is often studied as an independent variable that is used to predict other outcomes, most frequently psychological and somatic symptoms. Therefore it is hoped that the results of the study will aid in the identification of those individuals who are most likely to be at risk from developing psychological difficulties, in that those children who appear not to have developed their own set of coping behaviours may be more likely to suffer from psychological problems. It is also possible that results could form the basis for the development of an intervention programme focusing on the teaching of effective coping strategies.

Timescales

Ethical Approval, recruitment of subjects and preparation of materials will be completed during September and October 2000. It is hoped that data collection will commence in

October 2000 and continue for a period of 6 months. Data analysis and the writing up of the research can then begin.

Ethical Approval

Ethical approval will be required. Initially submissions will be made to Greater Glasgow Primary Care NHS Trust and the Education Authority in Forth Valley. The National Autistic Society and The Scottish Down's Syndrome Association will also be approached.

Addendum

Ethical Approval was obtained from Greater Glasgow Primary Care NHS Trust in October 2000 (see Appendix 2.6). As the research progressed it became apparent that an insufficient number of participants was being recruited via the original points of contact. Therefore an additional application was submitted to Greater Glasgow Primary Care Trust outlining proposed additional organisations that were considered to be possible further contacts. Ethical Approval for continuing with the research project with the proposed amendments was granted in April 2001 (see Appendix 2.6).

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Chapter 4 : Major Research Paper

An Exploration of the Coping Strategies used by Children who have a Sibling with Autism or Down's Syndrome

Major research paper submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with requirements for submission to The Journal of Child Psychology and Psychiatry (see Appendix 3.1).

Address for correspondence
Jennifer Low
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Abstract

Research to date on the adjustment of children living with a sibling with disability has yielded inconsistent results. A number of factors have been identified as mediating this adjustment, including the nature of disability and coping strategies implemented. It was hypothesised that due to the very different presentations of autism and Down's Syndrome, siblings of children with these disorders would experience different 'stressful situations'. It was hoped that an examination of how these children coped with such situations, and the efficacy of such coping strategies, would also help explain the variation in adjustment. The nature of the sibling relationship was also explored. Interviews were conducted in the homes of 25 children who had a sibling with autism, and 24 children who had a sibling with Down's Syndrome. No significant differences were found between groups in the quality of the sibling relationship or in the frequency of 'difficult' situations reported. A number of significant differences between groups was observed in the level of distress generated by situations and the frequency of use of particular coping strategies. Possible hypotheses for the pattern of results obtained are discussed.

Keywords : Siblings, autism, Down's Syndrome, coping strategies

Introduction

The relationship between siblings is one of great influence and importance and generally provides individuals with physical and emotional contact at critical stages throughout their lives (Powell and Gallagher, 1993). Siblings adopt many roles within such a relationship; amongst many others Lobato (1990), and McKeever (1983), identify siblings as having a place as companion, teacher, model, protector, playmate and enemy. Sibling interactions can also provide an important source of emotional support (Dunn and Kendrick 1982). This special relationship provides a context for social development and from these social interactions, the child develops a foundation for later learning and personality development (Powell and Gallagher, 1993).

Sibling interactions are therefore important and powerful components of socialisation as they foster progress of important instrumental and affective relationship skills (Cirirelli, 1985), and play a critical role in overall development.

There exists a popular belief that as a group, siblings are negatively affected by the presence of a learning disabled brother or sister. However very few, well-controlled empirical investigations actually exist to support this assumption. The research base to date in this area is relatively small and has yielded inconsistent and equivocal findings. Past literature has failed to establish with any certainty whether siblings of children with chronic disabilities are a population at risk for 'adjustment' problems (Fisman et al, 1996). Some studies support the hypothesis that siblings of learning disabled children are more susceptible to psychological maladjustment (Gold 1993, Kovacs, 1983), whereas others suggest that the presence of a handicapped child has subsequent benefits for siblings (Gamble & McHale, 1989; Grossman, 1972).

It is apparent that there is considerable variability in sibling adjustment with clear differences existing between different groups depending on the nature and severity of the disability (Gath and Gumley, 1987; Howlin, 1988; Rodriguez et al, 1993). A greater degree of variability has been shown to exist in the responses of siblings with an autistic brother or sister, some children being extremely positive but others reporting much more negative attitudes (Howlin, 1988) whereas a longitudinal study by Carr (1988), found siblings of children with Down's Syndrome to have fewer behavioural problems than comparison siblings when evaluated at 4, 11, and 21 years.

Therefore it would appear that only certain siblings at certain times appear to be vulnerable to negative reactions. It has been suggested that much depends on particular family circumstances such as family size, birth order, sibling gender, socio-economic status and parental responses and individual coping behaviours adopted.

Whilst a number of studies exist examining children's overall 'adjustment', further investigation is required to increase understanding of the factors which may influence this 'adjustment'. Coping efforts have been identified as playing a role and may help to explain such differences. Coping has been defined as 'any and all responses made by an individual who encounters a potentially harmful outcome' (Silver and Wortman, 1980, p282).

Cognitive theories of stress and coping (Lazarus and Folkman, 1984), the two- dimensional model of primary and secondary control (Rothbaum, Weisz and Snyder, 1982; Murphy and Moriarty's (1976), ego-psychological model; and the monitoring-blunting model (Miller, 1980), all provide a basis for understanding some of the ways in which siblings may be affected differentially.

In spite of the apparent diversity of these models, all of these approaches emphasise a basic distinction between two fundamental types of coping. The first type of coping refers to efforts to change or master some aspect of the person, the environment, or the relation between these two elements that is stressful and is labelled as 'problem-focused coping'. It includes strategies such as planning, seeking social support and obtaining more information. The second type of coping refers to efforts to manage or regulate the negative emotions associated with the stressful episode, such as looking for sympathy, 'shutting down' or disengaging emotionally, concentrating on the positive or turning to religious faith. This type of coping has been labelled as 'emotion-focused coping' (Lazarus and Folkman, 1984).

Coping efforts are influenced by both the characteristics of the individual and those of the situation in which he or she is coping. The coping process is responsive to the varying demands of different situations and changes in the same stressful encounter as it unfolds over time (Compas, Worsham and Ey, 1992). Studies of coping in children and adolescents suggest that problem-focused and emotion-focused coping skills emerge at different points in development, with an age-related increase in the latter strategy. Nevertheless age-related differences in coping behaviours do not mean that more simplistic methods are any less effective.

In most research on children's coping, coping strategies tend to be referred to in the most general sense, or in terms of adaptive or resilient personality dispositions from which coping responses are inferred but not actually measured. An alternative approach, different from a trait-oriented model, involves the identification of specific, event-related coping strategies. One important application therefore would be to identify the coping strategies that children use and to identify any differences in strategies implemented across situations.

The coping strategies used by those children with siblings with autism or Down's Syndrome are of particular interest. Autism is a pathological syndrome, appearing in childhood, which is characterised by a withdrawn state, a lack of social responsiveness or interest in others, serious communicative and linguistic impairments, and a failure to develop normal attachments (Reber, 1995). These symptoms are often accompanied by unusual ways of responding to the environment, usually including a fascination with inanimate objects and an insistence on routine, order and sameness. The term implies that the internal state is not consistent with reality and that the individual sees things in terms of fantasies and dreams, wishes and hopes, rather than in terms of a reality shared by and with others (Howlin, 1988). A quite different presentation is seen in children who suffer from Down's Syndrome. Down's Syndrome is a congenital condition which results in learning disability and a characteristic physical appearance. The condition is due to faulty cell division and children are born with an extra 21st chromosome, making a total of 47 instead of the normal 46 (Reber, 1995). Whilst children with Down's Syndrome are developmentally delayed, they do not tend to be additionally socially impaired and their pattern of interaction has been found not to differ from young typically developing children (Knott, Lewis and Williams, 1995). Conversely the triad of impairments associated with autism (social impairment, impairment of thought and behaviour and of language and communication) can severely limit social interactions. The presentations of these disorders varies greatly and it would seem fair to assume that siblings of children in these respective groups will be faced with very different situations. Indeed Knott, Lewis and Williams (1995), found that interactions between autistic children and their siblings were more hierarchical in nature compared to the interactions between children and their sibling with Down's Syndrome. Interactions occurred less frequently in the former group with the normally developing child in the former group tended to take more control. Fisman and Wolf (1991), also identified different stresses in families with a child with autism or Down's Syndrome. It follows then that the experience of being in a family with a child with autism or Down's Syndrome is inherently different, with siblings being subjected to different stressful situations. The sibling relationships within these two groups must surely vary also and present their own individual challenges to children, with different situations to cope with.

Given the very different presentations of Autistic Spectrum Disorder and Down's Syndrome, the present research sets out to discover whether the situations that children who have a sibling with autism or Down's Syndrome find difficult differ and explores group differences in relation to such situations. It brings together the literature in the field which suggests that certain factors mediate how well a child 'adjusts' to living with a learning disabled brother and sister and hypotheses that differing coping strategies may be more frequently employed across different situations and perceived as more useful than others. Suggestions that the quality of the sibling relationship can also impact upon the distress children experience in relation to difficult situations will also be examined.

Method

Subjects

The total subject sample comprised 49 children, 25 with a sibling with an Autistic Spectrum Disorder and 24 with a sibling with Down's Syndrome. Families were recruited via the National Autistic Society, the Scottish Down's Syndrome Association and special educational schools in Central Region. Within the 'Autistic Group' 12 subjects were male and 13 were female. Eighteen were first born, six had older siblings with autism and one subject was a twin. Of the siblings in the 'Down's Group' 11 were male and 13 were female. Within this group nineteen were first born and five had older siblings with Down's Syndrome. In the 'Down's Group' three children who participated were from a four child family, and six were from three child families. The mean age of the children with an autistic sibling was 10.2 years (range 7-16 years). The mean age of the children with a sibling with Down's Syndrome was 12.5 years (range 7-18 years).

Measures

The Sibling Relationship Questionnaire (Furman and Buhrmeister, 1985).

This measure is comprised of 48 individual items which measure 16 dimensions of the sibling relationship, using a five-point Likert format. The authors have demonstrated internal consistency coefficients to exceed .70. Reported test-retest reliability is rated at .71. Children are asked to respond to questions such as 'How much do you show (insert sibling's name) how to do things he or she doesn't know how to do?' and 'How much do you and (insert sibling's name) like the same things?' Possible responses range from 'Hardly at all' through to 'Extremely much'. The structure of responses relating to the six items examining maternal and paternal partiality (i.e. 'Who usually gets treated better by your mother, you or this sibling?') are slightly different, ranging from 'My sibling almost always gets treated better', to 'I almost always get treated better'. Scores are achieved on four factors: warmth/closeness (composed of scale scores for intimacy, prosocial behaviour, companionship, similarity, admiration by sibling, admiration of sibling and affection items), relative power/status (composed of scale scores for nurturance of sibling and dominance of sibling items minus scale scores for nurturance by sibling and dominance by sibling items), conflict (composed of scale scores for quarrelling, antagonism and competition items), and rivalry (composed of scale scores for maternal partiality and paternal partiality items).

Kidcope (Spirito, Stark and Williams, 1988).

Two versions of *Kidcope* exist; one for younger children, aged 7-12 years, and one for adolescents, aged 13-18 years. It asks the child to describe a difficult situation, which is then rated in terms of distress experienced, by the child. The child is also asked to rate the frequency and efficacy of alternative coping strategies which are categorised along ten dimensions: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem-solving, emotional regulation, wishful thinking, social support, and resignation.

Spirito et al (1988), have demonstrated acceptable levels of reliability in the use of *Kidcope*. The validity of *Kidcope* was established by comparing scores with previously validated measures of coping. A strong correlation was found between predicted subscales of the Coping Strategies Inventory (Tobin, Holroyd and Reynolds, 1984), and the corresponding *Kidcope* items.

Procedure

Children were visited in their own homes, and parent and child decided whether a parent would remain throughout the interview. In 90% of cases, the child was interviewed alone. The five children who were interviewed with a parent present all had a sibling with autism. The child was asked about their understanding of the purpose of the interview, and clarification provided if necessary. The child was reminded that everything spoken about would be private, and that they were free to stop at any time, without giving any reason. Children were encouraged to answer as truthfully as possible based on their own experience.

The children were asked to complete three tasks. Firstly, based on the work of Gamble (1985), in which stressor events were identified by children with disabled or nondisabled siblings over a two-week period, seven scenarios, derived from these reports and described by Gamble and McHale (1989) were presented (see Appendix 3.2). Children were asked initially to divide these scenarios in two – 'yes- this happens with my brother or sister' or 'no –this does not happen with my brother or sister'. They were then asked to rank the scenarios selected in terms of the behaviour that occurs most often, down to the behaviour that happens least.

Having completed the ranking task, the first three scenarios selected were included in task two. Children were asked to give a recent example of the chosen behaviour which was recorded by the researcher. Participants then completed an individual *Kidcope* Questionnaire, in relation to each of the selected scenarios.

The quality of the sibling relationship was assessed in the final task, the completion of the Sibling Relationship Questionnaire.

Statistical Analysis

Data were analysed using the Statistical Package for Social Sciences (SPSS for windows). Descriptive statistics and frequency distributions were initially implemented to explore the data set. Exploratory data analysis and visual inspection of the boxplot generated illustrated that although the data generated by the two experimental groups as a result of the Sibling Relationship Questionnaire were normally distributed and had similar variances, they were ordinal, as opposed to interval, in nature. Mann Whitney U-Tests were therefore employed to allow for the identification of any differences between groups. A similar rationale was employed in the selection of Mann Whitney U-Tests to highlight any between-group differences in relation to the reported distress caused by each child's top three ranked behaviours. As the data relating to the use of and efficacy of coping strategies were nominal in nature, between group differences were investigated using Chi-square analyses.

Results

Sibling Relationship Questionnaire

Mann Whitney U-Tests were applied to the mean scores on each of the dimensions; warmth, conflict, rivalry and status. Scores did not differ significantly between the two groups. In addition, the standard deviation and range of scores of the two groups in each of the dimensions did not appear different. (see Table 1).

Insert Table 1 about here

Stressor Events

The frequency of the occurrence of each of the scenarios reported by children in ranks 1-3 (i.e. the top three most frequently occurring behaviours selected by each child) is depicted in Figure 1. Only 66.6% of the children in the 'Down's Group' selected three scenarios from the seven presented to them, compared to 84% of the Autistic Group, who were able to identify at least three situations which they experienced regularly. Chi-square analysis did not identify significant differences between groups.

Insert Figure 1 about here

As depicted in Table 2 the most frequently occurring event in the top three ranks, for both groups was their sibling going into their room/taking things without permission. This behaviour was reported on 16 occasions by Autistic sibs and on 15 occasions by Down's sibs. This was followed closely by their sibling having bad habits, acting strange or doing weird things (reported on 16 and 13 occasions respectively). In the 'Autistic Group' the least frequent scenarios equally reported by children, with a total of six mentions, was their sibling getting hurt or sick, and having to babysit, clean up after their sibling or help when they don't really want to. In the 'Down's Group' their sibling getting upset with other children for no reason was least commonly reported (described twice).

Distress Experienced (See Table 2)

Individual distress scores (as measured by Kidcope) for each participant's top three ranked behaviours were summed to give an overall distress score for each scenario. Mean distress scores for each scenario are illustrated in Table 2.

In the Autistic Group the most distressing reported scenario was their sibling getting upset with a child for no reason. Children with a sibling with Down's Syndrome reported their sibling being hurt or sick to be most distressing. Autistic sibs found the babysitting scenario to be significantly more distressing as compared to the Down's sibs. A trend towards the Autistic sibs being more distressed by being hit, kicked, shoved or beaten up by their brother/sister was also apparent ($p = .061$). The Autistic Group experienced more distress overall, although not significantly so.

Insert Table 2 about here

Coping Strategies

Figure 2 illustrates the number of children in each group using each of the ten coping strategies in their top three ranks.

Insert Figure 2 about here

Chi-square analyses illustrated significant differences between groups in frequency of use in two of the strategies; cognitive restructuring and wishful thinking, both strategies being utilised more frequently by the Autistic Group (see Table 3).

Insert Table 3 about here

Reported Efficacy

The reported efficacy of each of the coping strategies in children's top three ranked scenarios is depicted in Table 4. Chi-square analyses identified a significant difference between groups in the efficacy of wishful thinking; the autistic group finding this strategy more useful overall.

The efficacy of strategies in the top two ranked behaviours by each group ('sibling gets into room/takes things without permission' and 'sibling has bad habits, acts strange, or does weird things'), was also examined. (See Tables 5 and 6). Chi-square analyses were performed on the efficacy scores obtained for each coping strategy, if employed, for each of the aforementioned scenarios. No significant differences were found between groups in coping strategies used in either of the scenarios.

Insert Tables 5 and 6 about here

Discussion

The results of the research will be discussed with reference to the five main research questions in turn.

1. *Is there a relationship between the quality of the sibling relationship and the nature of disability?*

Scores in the four dimensions (warmth, rivalry, conflict and status) of the Sibling Relationship Questionnaire did not differ significantly between groups. The Autistic Group and Down's Group presented very similarly in terms of their sibling relationship profiles obtained on the measure. Scores indicated that participating children appeared to have basically very warm relationships with their siblings, with little conflict overall. There did not appear to be high levels of rivalry between siblings. Sibling relationships appeared to be generally well balanced in terms of status, with participating children being only slightly more dominating and nurturing towards their siblings than their siblings being dominant or nurturing towards them.

These results suggest that these children essentially have very similar relationships with their sibling, regardless of the nature of the disability. It would appear that the children in this study were able to foster positive relationships with their siblings despite the presence of disability.

The actual sample of participants may also be a significant factor in the result obtained. All of the participants volunteered to take part in the research and one must speculate as to the possibility that those families volunteering to take part were ones in which there were fewer relationship difficulties.

However a number of methodological problems may also explain this result. It may be that the questionnaire did not target aspects of the sibling relationship that may differ between children in which one child has a disability.

Another interpretation of the lack of any significant difference may be the structure of the questionnaire itself. All of the available responses was presented in lower case typeface, apart from one; 'EXTREMELY much'. This leads us to speculate that children may have been drawn to this choice over the others as a result of its different and more visible presentation.

The length of the questionnaire must also be considered when questioning the lack of significant results obtained. Children, especially those of a younger age, did become noticeably tired towards completing the measure, and one may speculate that their latter responses may not have been as accurate as those fuelled by initial enthusiasm.

Despite children being encouraged to respond to items in an honest manner and being reassured that answering in a less positive fashion would not be viewed in a negative light, the fact that the researcher was present throughout the completion of the SRQ may have led some children to respond in a manner in which they perceived as desirable. Unfortunately there is no method by which this hypothesis can be confirmed, but again the lack of significant between-group differences suggests that this may have been an additional explanatory factor.

2. *Do children differ in their perception of which situations they find most 'difficult' in relation to living with a learning disabled brother or sister?*

Any ranking task, is of course, limited by the behavioural examples presented to be ranked. The behavioural examples used here, derived from actual accounts (Gamble 1985), may have been insufficiently discriminating and not representative enough of the difficulties that children who have learning disabled brother or sister experience. This view is supported by the fact that children in the Down's group found it more difficult to select three behaviours from the seven presented to them, suggesting either that they did not experience so many difficulties, or that the behaviours they did experience in relation to their brother or sister with Down's Syndrome were not represented.

Children in each of the groups did show certain similarities in the ranking of 'difficult' behaviours. Both groups reported their sibling 'going into their room/taking things without permission' to be the most commonly occurring behaviour, the Autistic Group reporting their sibling' having 'bad habits, acting strange or doing weird things' to occur equally as often. This behaviour was also reported to occur second to the room scenario by the Down's group.

The overall mean level of distress experienced by each of the research groups as a result of 'difficult 'behaviours displayed by learning disabled siblings did differ, although not significantly, the Autistic Group recording slightly higher scores. It is of particular interest to note that the Autistic Group experienced the highest level of distress as a result of their sibling getting upset with another child for no reason, which was, in fact, the least common occurring behaviour described by the group. A similar trend was observed in the Down's Group, with the highest level of distress being reported by children when their sibling got hurt or sick. This behaviour was reported on only four occasions by this group. This pattern may lead us to hypothesise that children may develop effective coping strategies for behaviours that they experience more frequently and subsequently become more adept at managing the situation. Indeed this suggestion is borne out by the generally lower levels of distress experienced in behaviours that are reported to occur more often. The methods by which children develop such successful coping styles are beyond the scope of this research, but merits further exploration.

3. *What are the different coping strategies utilised by children who have a sibling with a disability?*

In considering the top three ranked behaviours, the most frequent coping strategy used by the Autistic group was wishful thinking. The Downs' group used problem solving most frequently. The strategy least favoured by both groups was self-criticism. A high degree of agreement was apparent between groups with the use of problem-focussed strategies proving most popular.

It appears then that overall the children are tending to cope with difficult situations by attempting to change or gain some form of control over the problem. They are adopting active strategies in their attempts to solve difficulties and do not appear to be blaming themselves for the difficult situations which can arise. This is encouraging, as adopting such a strategy may be expected to lead to negative self-opinions and a state of learned helplessness.

Significant differences were identified on two occasions between groups on their use of strategies in individuals' top three ranked behaviours. Cognitive restructuring and wishful thinking were utilised more often by children who had an autistic sibling. The use of these strategies suggests that perhaps these children are trying to see the difficulties they encounter in a positive light. It may be that due to the very nature of the presentation of autism, they have accepted that such difficulties are not going to disappear.

One must also consider the possibility that the siblings are modelling behaviours displayed by their parents. As previously discussed, the research sample was subject to some response bias, with many families being members of the National Autistic Society or the Scottish Down's Association. It is fair to assume that such families may be more proactive in their management of their child's disability, and may display more proactive coping strategies which reflect this.

Methodological issues may also help explain the overall lack of differences between the strategies employed by children. The *Kidcope* Questionnaire required that children respond to whether or not they used a number of coping strategies in each of their three top ranked scenarios. It was apparent during the completion of this exercise that a number of children, especially the younger ones, became very bored with this task and it appeared that they may not have been consistently discriminative between responses

4. *Does the efficacy of coping strategies differ between groups?*
5. *Does the efficacy of coping strategies differ between identified 'difficult' scenarios?*

Efficaciousness of coping strategies was examined over all three top behaviours and in the case of the two commonly ranked top scenarios – 'sibling going into your room/taking things without permission' and 'sibling has bad habits, acts strange or does weird things'. In the former scenario, distraction helped 'a little' or 'a lot' most frequently for both groups; in the latter, social support was reported to help 'a little' or ' a lot' most frequently by the Autistic group, and problem solving and social support were reported to be equally efficacious by the Down's group. Again differences were apparent in how effective children perceived their coping efforts to be, but not to a significant level. The strategies that were utilised more often were generally viewed to be more efficacious, suggesting that children develop their own repertoire of effective strategies to cope with situations.

An examination of each of the seven scenarios presented to children and the efficacy of coping strategies used in each would allow for the identification of differences in efficaciousness of strategies adopted across situations. Such analyses are unfortunately beyond the scope of this research, but merits further exploration.

Post Hoc Power Analysis

More significant results may have been achieved had a larger number of children participated in the research. Initial power calculations, assuming a significance level of 0.05 and a desired power level of 0.80, suggested that a total of 52 children would be required to participate in the project. A post hoc power analysis was conducted, based on the data obtained, and a power level of 0.782 was calculated. This suggests that the actual number of participants was not unsatisfactory, although assuming a significance level of 0.05 and a desired power level of 0.80, a figure of 29 children in each group would be recommended for participation in future investigation.

Future Research Implications

As yet no sound theoretical model exists in research on siblings of children with learning disability. Research in this area still remains a largely untapped field and a number of areas merit further examination. Whilst this study failed to identify an overall lack of significant differences between the subject groups it has raised a number of interesting points. An exploration of questions such as 'Do children use coping strategies consistently across situations?, 'Is there an association between the quality of the sibling relationship and the coping strategies used?', and 'How do children develop the coping strategies that they use?' will aid in expanding our understanding of why some children appear to cope well, and others not so well, with living with a sibling with a learning disability.

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Table 1: Mean scores on each dimension of the Sibling Relationship Questionnaire for each group

Dimension	Autistic Group N=25	Down's Group N=24	Z	p
Warmth	22.5 (SD=5.18, median=23.7, min=9.67, max=32.33)	23.5 (SD=5.49, median=25.0, min=9.33, max=33.33)	-.770	.441
Status	2.06 (SD=1.09, median= 2.33, min=.00, max=3.67)	2.52 (SD=1.82, median=2.67, min=.00, max=6.33)	-.852	.394
Rivalry	5.49 (SD=1.12, median=6.00, min=1.00, max=7.00)	5.36 (SD=1.09, median=5.84, min=2.67, max=7.00)	-.386	.699
Conflict	8.05 (SD=3.25, median=8.67, min=3.33, max=13.67)	7.06 (SD=2.42, median=6.84, min=3.33, max=13.00)	-1.002	.316

Figure 1 : Comparison of frequency of stressor events reported

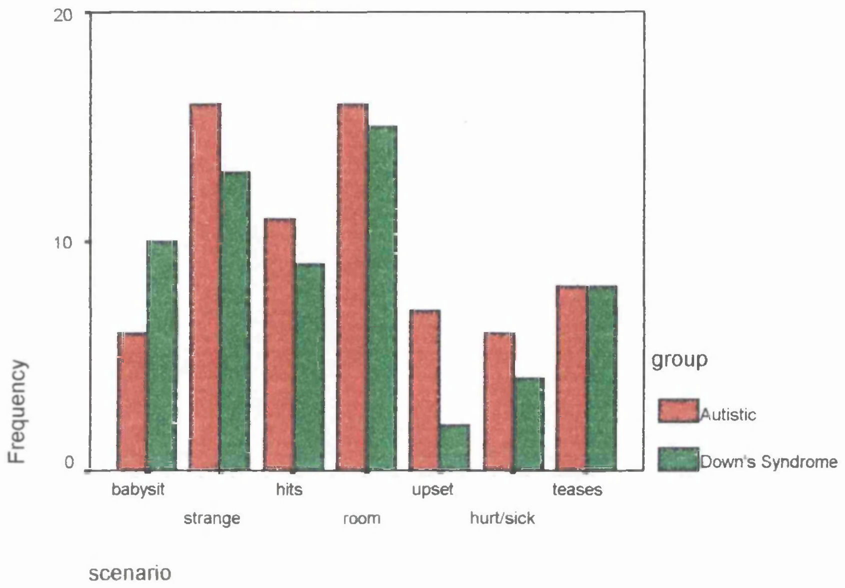

Table 2 : Number of occasions each stressor event reported by children in ranks 1-3 and mean affective response (median in parentheses)

Stressors	Children with		Z	sig
	Autistic Siblings (N=25)	Down's Siblings (N=24)		
Stressor 1 ; Sib 'gets into your room/ takes things without permission'				
Frequency	16 (22.9%)	15 (24.6%)		
Distress	3.88 (4.00)	4.69 (3.50)	-.420	.675
Stressor 2 : Sib 'teases you, bugs you, makes fun of you, or puts you down'				
Frequency	8 (11.4%)	8 (13.1%)		
Distress	5.00 (3.00)	5.38 (6.00)	.000	.093
Stressor 3: Sib 'has bad habits, acts strange, or does weird things'				
Frequency	16 (22.9%)	13 (21.3%)		
Distress	4.50 (2.50)	3.15 (2.00)	.553	.580
Stressor 4 : Child 'has to babysit, clean up after sib, or help when s/he doesn't really want to'				
Frequency	6 (8.6%)	10 (16.4%)		
Distress	4.83 (5.50)	2.50 (2.00)	2.043	.041**
Stressor 5 : Sib 'hits, kicks,shoves,or beats child up'				
Frequency	11 (15.7%)	9 (14.8%)		
Distress	6.55 (6.00)	3.33 (3.00)	1.871	.061
Stressor 6 : Sib 'gets hurt or sick'				
Frequency	6 (8.6%)	4 (6.6%)		
Distress	4.60 (4.00)	6.67 (6.00)	-1.375	.169
Stressor 7 : Sib 'gets upset with a child for no reason				
Frequency	7 (10%)	2 (3.3%)		
Distress	6.71 (5.00)	2.00 (4.00)	1.682	.093
Total				
Frequency	70	61		
Distress	13.8 (12.00)	10.8 (8.5)	1.242	.214

** $p < .05$.

Figure 2 : Number of children reporting using coping strategies in their top three ranked stressor events

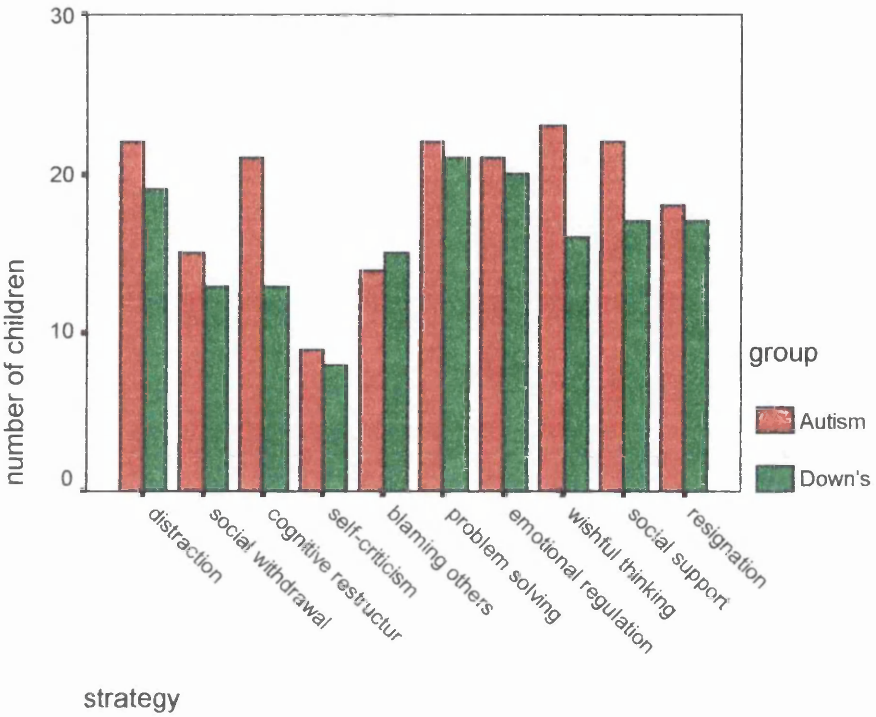

Table 3 : Reported frequency of use of coping strategies by children in their top three ranked scenarios

Strategy	Autistic Group	Down's Group	χ^2	df	sig
Distraction	22	19	.699	1	.403
Social Withdrawal	15	13	.947	1	.331
Cognitive Restructuring	21	13	5.131	1	.024*
Self Criticism	9	8	.038	1	.845
Blaming Others	14	15	.426	1	.514
Problem Solving	22	21	.003	1	.957
Emotional Regulation	21	20	.004	1	.950
Wishful Thinking	23	16	9.239	1	.002*
Social Support	22	17	2.222	1	.136
Resignation	18	17	.008	1	.928

* $P < .05$.

Table 4 : Reported efficacy of coping strategies (if utilised **) by children in their top three ranked scenarios

	Autistic Group (N=25)			Down's Group (N=24)					
Strategy	**Degree helped**			**Degree helped**			χ^2	**df**	**sig.**
	none	a little	a lot	none	a little	a lot			
Distraction	7	31	14	3	23	11	.635	2	.728
Social Withdrawal	10	15	12	8	10	6	.473	2	.789
Cognitive Restructuring	10	24	13	7	11	6	.543	2	.762
Self-Criticism	4	4	4	5	4	3	.254	2	.881
Blaming Others	4	10	11	7	12	5	3.231	2	.199
Problem Solving	0	23	26	1	24	15	3.094	2	.213
Emotional regulation	6	19	27	5	19	13	2.535	2	.282
Wishful thinking	11	27	20	11	22	12	10.171	2	.006*
Social Support	1	19	30	1	12	20	.103	2	.950
Resignation	11	13	9	7	18	6	2.235	2	.327

* $p < .05$.

** If the strategy was not utilised by an individual child, it was not rated in terms of its efficacy.

Table 5: Reported efficacy of coping strategies (if utilised*) in scenario 'your brother/sister goes into your room/takes things without permission.

	Autistic Group (N=16)			Down's Group (N=15)					
Strategy	**Degree helped**			**Degree helped**			χ^2	**df**	**sig.**
	none	a little	a lot	none	a little	a lot			
Distraction	1	12	3	0	9	6	2.399	2	.301
Social Withdrawal	2	8	2	4	2	2	3.611	2	.164
Cognitive Restructuring	5	8	1	2	5	1	.369	2	.831
Self-Criticism	0	2	1	1	0	2	3.333	2	.189
Blaming Others	1	1	1	2	4	1	.635	2	.728
Problem Solving	2	9	4	0	7	6	2.520	2	.284
Emotional regulation	2	9	2	1	6	5	2.183	2	.336
Wishful thinking	2	12	2	1	8	2	.539	2	.764
Social Support	0	5	9	1	3	5	1.633	2	.442
Resignation	3	4	1	3	7	2	.366	2	.833

*If the strategy was not utilised by an individual child, it was not rated in terms of its efficacy.

Table 6 : Reported efficacy of coping strategies (if utilised*) in scenario 'your brother/sister has bad habits, acts strange or does weird things'

	Autistic Group (N=16)			Down's Group (N=13)					
Strategy	**Degree helped**			**Degree helped**			χ^2	**df**	**sig.**
	none	a little	a lot	none	a little	a lot			
Distraction	4	8	3	1	6	3	1.131	2	.568
Social Withdrawal	4	3	2	3	4	1	.562	2	.755
Cognitive Restructuring	2	4	4	2	6	1	2.153	2	.341
Self-Criticism	1	1	0	2	3	0	.058	2	.809
Blaming Others	0	4	5	2	7	2	3.943	2	.139
Problem Solving	0	8	7	0	9	4	.738	2	.390
Emotional regulation	1	7	8	1	8	4	1.101	2	.577
Wishful thinking	2	7	7	2	6	5	.101	2	.951
Social Support	0	5	11	0	6	7	.0677	2	.411
Resignation	2	4	4	1	7	1	2.907	2	.234

*If the strategy was not utilised by an individual child, it was not rated in terms of its efficacy.

Chapter 5: Clinical Research Case Study

An Uncontrolled Case Study Exploring the Treatment of Chronic Pain

Clinical Case Research Study submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

Prepared in accordance with guidelines for contributors to Pain (See Appendix A)

Address for correspondence
Jennifer Low
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Abstract

Previous reviews of research (e.g. Flor et al 1992; Williams et al 1993; Turner 1996), have found that in the treatment of chronic pain, a multicomponent intervention is of most benefit to individuals, taking physiological, cognitive and behavioural factors into consideration. This single subject uncontrolled design attempted to ascertain the impact of each of the aforementioned factors in the treatment of a 42-year-old female suffering from chronic low back pain. The intervention consisted of a 12-session multicomponent treatment which included progressive muscle relaxation, cognitive coping strategies and a gradual increase of activity. It was hypothesised that treatment components would have an additive effect with the biggest change being seen following the introduction of the final treatment factor. The results showed a gradual decline in pain intensity experienced with a trend towards a significant change following the introduction of behavioural strategies. A significant change was apparent between baseline measurements of pain intensity and mood at end of intervention and at follow-up 3 months following the completion of treatment. As activity levels increased reported pain intensity decreased suggesting that engagement in purposeful activity plays an important role. It was therefore possible to conclude that a multicomponent treatment of chronic pain was effective in reducing level of pain experienced and had a positive impact on mood. However, alternative explanations for the described pattern of results are also acknowledged. Beliefs regarding pain remained largely organic (somatic as opposed to acknowledging the relevance of psychological contributing factors) in nature.

Chapter 6 : Appendices

Section 1 - Appendices for Small Scale Research Project

Contents page

Clinical Psychology Forum

Clinical Psychology Forum is produced by the Division of Clinical Psychology of The British Psychological Society. It is edited by Steve Baldwin, Lorraine Bell, Jonathan Calder, Lesley Cohen, Simon Gelsthorpe, Laura Golding, Helen Jones, Craig Newnes, Mark Rapley and Arlene Vetere, and circulated to all members of the Division monthly. It is designed to serve as a discussion forum for any issues of relevance to clinical psychologists. The editorial collective welcomes brief articles, reports of events, correspondence, book reviews and announcements.

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Language: contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like "the elderly" or medical jargon like "person with schizophrenia". If you find yourself using quotation marks around words of dubious meaning, please use a different word.

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Clinical Psychology in Clydebank Health Centre

Some information about the service

Dr Jim White
Consultant Clinical Psychologist

Clinical Psychology in the Health Centre

ur doctor has asked me to see you. My room is in the Black Suite (upstairs). If you prefer, I can see u at the Lansdowne Clinic (near Anniesland Cross)

How to get an appointment

There is a two month waiting list at present. Please complete the attached opt-in forms, send them back straightaway using the stamped addressed envelope and I will send on an appointment to you.

(see 'What you must do now' at the end of this handout).

help you understand the service I provide, I have answered a number of common questions that I pe you will find useful.

HAT IS A CLINICAL PSYCHOLOGIST?

Clinical Psychologist is a fully qualified professional with at least 7 years training and experience prior to alification. Clinical Psychologists are regulated by a professional charter. That means that you can be re that a psychologist meets high standards of practice.

Clinical Psychologist specialises in 'talking therapies' and will try to help you gain control over your blems by dealing more effectively with them. I will also try to help you understand why you feel the y you do.

S A PSYCHOLOGIST THE SAME AS A PSYCHIATRIST?

. A Psychiatrist is medically qualified and so may suggest that you take tablets as part of your atment. Although there is a good deal of overlap, Psychologists specialise in the treatment of anxiety d depression caused by many different problems while Psychiatrists specialise in treating mental illness ch as schizophrenia.

ychologists are not medically qualified and so do not use tablets as a way of treating you (although I ould strongly advise taking them if your GP or Psychiatrist suggests this).

HAT PROBLEMS DO PSYCHOLOGISTS DEAL WITH?

st of the problems we deal with are very common. These problems are often more intense and tressing versions of troubles such as depression and anxiety that all of us experience to some degree at tain times of our lives. These feelings could develop after a traumatic event such as a bereavement, the ak-up of a relationship or the loss of a job. Often they don't seem to have any obvious cause or to make sense at all. This does not mean you have a mental illness - you will be helped to understand the ses.

ese problems are likely to be seriously interfering with your life. Most of the people I see feel that they e lost control of the problem and need someone to help them regain control. Some of the common blems I deal with are :

Panic attacks

Anxiety

Depression

Eating disorders

Sexual problems

Problems resulting from abuse in childhood

Problems resulting from illness or chronic pain

Bereavement

Obsessions/Compulsions

Phobias (especially fear of busy places)

Posttraumatic Stress Disorder

Coping with major changes in your life

n't worry if your own problem is not on this list - there are many more problems which psychologists al with. Don't worry if you can't put your finger on what your problem is - this is common.

HOW CAN A PSYCHOLOGIST HELP YOU?

A PSYCHOLOGIST WILL:

Listen carefully and take your problems seriously

Try to understand and help you make sense of your problems

Whenever possible, give you specific advice. This might involve learning how to ***face up to problems, relax, control upsetting thought, cope with problems in your life***

A very important part of the therapy will be like homework - you will be asked to work hard at putting into practice the ideas we discuss during appointments. Appointments may revolve around talking about how well you have been able to do this 'homework'.

A PSYCHOLOGIST WILL NOT :

Prescribe medication. If necessary, your doctor will do this.

Read your mind. You choose what you want to tell me. Please try to be as open and as honest as possible with me so that I can understand your problem and help you.

Give you a magic answer or 'cure' your problems. Psychological problems are not illnesses. You will have to take responsibility for working with me in a joint effort to tackle your problems.

Betray your trust. Although I will write to your GP about your therapy, no details of what you tell me will be disclosed against your wishes except in highly exceptional cases, i.e. where your safety or the safety of others is judged to be at risk or sometimes for legal reasons. Ask me about this if you have any concerns.

HAT WILL HAPPEN AT YOUR FIRST APPOINTMENT?

u will be able to talk about your problems and the way they are affecting you. It is just the same as a t to your GP. You will not have to lie on a couch or be put into a trance - we will just sit and talk. I ask you a lot of questions about your background, family, home life and so on. Once we begin to lerstand the problem, the two of us will discuss the best ways of working together to resolve the blem. If I feel that I can't help you, I will tell you this. I will write to your doctor and, if possible, ggest what else could be tried to help.

ve both feel that we can work on your problems, we will plan how best to do this. You may be offered chance of one-to one therapy, coming to stress management classes, given self-help therapy or any mbination of these. You will usually be asked to fill out a few forms before and after treatment so that I n see what effect treatment is having. All such information is strictly confidential.

HAT CAN YOU DO TO HELP?

ou should only enter therapy if you are really determined to tackle your problems. If not, you will not prove and you should give your place to someone who is determined. You will be expected to work ry hard. You must give therapy your top priority.

you have to cancel an appointment advance, please phone the Clinical Psychology department and leave message with the secretary as soon as possible so that your appointment can be given to another person. will send another appointment as soon as possible. The number is :

211 3559

you have to cancel an appointment on the day, please phone the Health Centre on :

531 6300

you miss an appointment, you will be sent a letter inviting you to get in touch. If I do not hear from you ithin two weeks, I will assume you do not want to stay in therapy and will let your doctor know.

SEFUL THINGS TO REMEMBER

ere is rarely a solution or 'cure' to a psychological problem. Problems that may have taken months or ars to develop will not go away overnight. The aim of therapy is often to learn how to cope better with a oblem rather than get rid of it altogether. For example, in the case of anxiety, if you have always been a orrier', you will probably always stay a 'worrier' but you can aim to get as much control over the worry possible.

sually appointments are given every fortnight or three weeks. It is very important that you think through ur discussions with me after each session. Although I will work as hard as possible for you, I can never ve any guarantee of success but it is worth while repeating that the harder you work, the better your ance of success.

VHAT YOU MUST DO NOW

lease fill in all the forms. These will let me know if you want an appointment, when would be the best me to attend and give me some more information about your problems. A stamped address envelope is nclosed. As soon as I get your forms back, I will send on an appointment.

hope this leaflet has helped you. I will be very happy to answer any other questions you may have when I ee you for your appointment. It might be useful to write them down so you don't forget them.

r Jim White
onsultant Clinical Psychologist

OPT-IN FORM

APPOINTMENT FOR CLINICAL PSYCHOLOGY

some people have been in touch to say that they do not want an appointment, I am writing to ask you return all these forms, using the stamped addressed envelope, and to let me know that you do want an pointment. If so, as soon as I receive this, an appointment will be sent to you.

PLEASE NOTE

I HAVE TO GET THESE FORMS BACK BEFORE I CAN SEND YOU AN APPOINTMENT

I do not hear from you within three weeks, I will assume you do not need an appointment and will let ur doctor know. Please call me at 211 3559 if you want to talk over whether you would benefit from eing me.

ours Sincerely

r Jim White
onsultant Clinical Psychologist

……………………………………………………………………………………………………

ame……………………………………………………
ddress…………………………………………………

lease tick appropriate box

☐ I would like an appointment to be sent to me

☐ I do not need an appointment

Main problem

You will probably have more than one problem you hope to control but is there one main problem you can identify? If so, can you write down what that problem is (in the first box) and then rate how much of a problem it is using the 1 -10 scale (in the second box). You can choose any number. A score of 3 would mean it is not all that bad, a score of 8 would mean it was badly affecting you. You should do the same in the third box.

Here are some examples of the kind of problems people have given me in the past :

Anxiety Depression

Anger Relationship

Drinking Smoking

Coping with the children

Problems with the neighbours

You should write down your own problem here :

Main problem..

Can you now rate how much of a problem it is to you by putting a cross at the number you feel fits best

1====2====3====4====5====6====7====8====9====10

no problem moderate problem severe problem

How well do you expect coming to the clinic will work for you ?

1====2====3====4====5====6====7====8====9====10

Won't help at all Will help a great deal

Name...

ONTACT PHONE NUMBERS

ome

ork

lease note if you do not want me to contact you at either or both numbers)

OCTOR

RIEF DESCRIPTION OF YOUR PROBLEM(S)

AVE YOU BEEN TREATED IN THE PAST FOR THESE OR OTHER PROBLEMS ?
.G. by a psychologist, psychiatrist, counsellor etc.

RE YOU TAKING TABLETS JUST NOW? WHAT ARE THEY?

LINICS IN CLYDEBANK HEALTH CENTRE ARE ON MONDAY MORNINGS AND ALL AY FRIDAY.

HAT TIMES WOULD SUIT YOU BEST:

RE THERE TIMES WHEN YOU WILL NOT BE ABLE TO ATTEND:

hank you for your help. If you have any special needs, please phone the Clinical Psychology epartment at the Lansdowne Clinic on 211 3559.

HAD Scale

Name: Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

- Most of the time ☐
- A lot of the time ☐
- Time to time, Occasionally ☐
- Not at all ☐

[redacted]

I still enjoy the things I used to enjoy:

- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

[redacted]

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

[redacted]

I can laugh and see the funny side of things:

- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

[redacted]

Worrying thoughts go through my mind:

- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

[redacted]

I feel cheerful:

- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

[redacted]

I can sit at ease and feel relaxed:

- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

[redacted]

I feel as if I am slowed down:

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

[redacted]

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

[redacted]

I have lost interest in my appearance:

- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

[redacted]

I feel restless as if I have to be on the move:

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

[redacted]

I look forward with enjoyment to things:

- As much as ever I did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

[redacted]

I get sudden feelings of panic:

- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

[redacted]

I can enjoy a good book or radio or TV programme:

- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

[redacted]

Do not write below this line

INFORMATION GROUP

Attitudes and Expectations Questionnaire

You have already answered a question on how well you expect coming to the clinic will work for you.

The next short section will focus on your attitudes and expectations about your visit to the clinic.

Please try to answer as honestly as you can.

1. How did you feel when your G.P told you of your referral to Clinical Psychology?

   not at all anxious ☐ fairly anxious ☐ very anxious ☐

2. How do you feel **now** about coming to see a Psychologist?

   not at all anxious ☐ fairly anxious ☐ very anxious ☐

3. How keen are you to come and see a Psychologist?

   Not at all keen ☐ fairly keen ☐ very keen ☐

4. How much do you feel you know about what a Psychologist does?

   nothing at all ☐ a little ☐ a lot ☐

5. Which of the following treatment approaches do you feel would prove to be most helpful to you?

   Medication (tablets or injections) ☐
   Learning relaxation/ stress management techniques ☐
   Talking through your problems whilst someone listens sympathetically ☐
   Talking through your problems and receiving active advice ☐
   Trying to uncover the causes of your current difficulties, possibly looking back into your childhood ☐
   Practical advice (i.e. in relation to housing, financial matters) ☐

   (from Torrens & Harris, 1996)

Thank you for your time.

'NO INFORMATION' GROUP

Attitudes and Expectations Questionnaire

As part of an evaluation of our service I am currently carrying out a short survey on individual's feelings and knowledge about Clinical Psychology.

It would be most helpful if you could answer the following questions as honestly as possible as it will help us to improve the service we deliver. All information will be treated in confidence and will not affect the treatment you receive.

Should you wish to complete the questionnaire please return it along with your opt-in form and HAD Scale in the stamped addressed envelope provided.

Thank you for your help.

Jenny Low

Jenny Low
Trainee Clinical Psychologist

1. What is the main problem you are experiencing?

2. How much of a problem is this to you? (please mark with a cross)

1====2====3====4====5====6====7====8====9====10

no problem	moderate problem	severe problem

3. Please give a brief description of your symptoms.

4. Have you been treated in the past for these or other problems? (e.g. by a psychologist, psychiatrist, counsellor etc?)

5. How did you feel when your G.P told you of your referral to Clinical Psychology?

not at all anxious ☐ fairly anxious ☐ very anxious ☐

Please turn over

6. How do you feel **now** about coming to see a Psychologist?

   not at all anxious ☐ fairly anxious ☐ very anxious ☐

7. How keen are you to come and see a Psychologist?

   Not at all keen ☐ fairly keen ☐ very keen ☐

8. How much do you feel you know about what a Psychologist does?

   nothing at all ☐ a little ☐ a lot ☐

9. Which of the following treatment approaches do you feel would prove to be most helpful to you?
   (you may tick more than one box)

   Medication (tablets or injections) ☐
   Learning relaxation/ stress management techniques ☐
   Talking through your problems whilst someone listens sympathetically ☐
   Talking through your problems and receiving active advice ☐
   Trying to uncover the causes of your current difficulties, possibly looking back into your childhood ☐
   Practical advice (i.e. in relation to housing, financial matters) ☐

   (from Torrens & Harris, 1996)

10. How much do you think psychological input will help you?
    (please mark with a cross)

    1====2====3====4====5====6====7====8====9====10
    won't help at all — will help a great deal

Thank you for your help.

Section 2 - Appendices for Major Research Proposal

Contents page

Guidelines for Major Research Project Proposal

Department of Psychological Medicine Course Handbook

The Research Proposal should be laid out according to the format described below. This format is based upon the application for a mini-project grant in Health Services Research (SOHHD- Chief Scientist Office). Trainees may find that forms provided by ethical committees are substantially similar and this may be an acceptable alternative format.

1.1 Applicants - names and addresses, including the names of co-workers and supervisor(s) if known

1.2 Title - no more than 15 words

1.3 Summary - No more than 300 words, including a reference to where the study will be carried out.

1.4 Introduction - of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.

1.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.

1.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.

1.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants

1.62 Measures – a brief explanation of interviews/observations/rating scales etc. to be employed, including references where appropriate

1.6.3 Design and procedure- a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements etc. A summary chart may be helpful to explain the research process.

1.6.4 Settings and equipment – a statement on the location(s) to be used and resources or equipment which will be employed (if any).

1.6.5 Data analysis – a brief explanation of how data will be collated, stored and analysed.

1.7 Practical applications – the applicants should state the practical use to which the research findings could be put.

1.8 Timescales – the proposed starting date and duration of the project.

1.9 Ethical approval – stating whether this is necessary and, if so, whether it has been obtained.

ID # ______________________________ GROUP_________

Sibling Relationship Questionnaire - Revised (Child) 3/90

My name is ___________________________________(completed by)

The phrase "this sibling" refers to ______________________(completed about)

1. Some siblings do nice things for each other a lot, while other siblings do nice things for each other a little. How much do both you and this sibling do nice things for each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
2. Who usually gets treated better by your mother, you or this sibling?	[ ]My sibling almost always gets treated better [ ]My sibling often gets treated better [ ]We get treated about the same [ ]I often get treated better [ ]I almost always get treated better
3. How much do you show this sibling how to do things he or she doesn't know how to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
4. How much does this sibling show you how to do things you don't know how to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
5. How much do you tell this sibling what to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

6. How much does this sibling tell you what to do?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
7. Who usually gets treated better by your father, you or this sibling?	[ ]My sibling almost always gets treated better [ ]My sibling often gets treated better [ ]We get treated about the same [ ]I often get treated better [ ]I almost always get treated better
8. Some siblings care about each other a lot while other siblings don't care about each other that much. How much do you and this sibling care about each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
9. How much do you and this sibling go places and do things together?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
10. How much do you and this sibling insult and call each other names?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
11. How much do you and this sibling like the same things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
12. How much do you and this sibling tell each other everything?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

13. Some siblings try to out-do or beat each other at things a lot, while other siblings try to out-do each other a little. How much do you and this sibling try to out-do each other at things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
14. How much do you admire and respect this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
15. How much does this sibling admire and respect you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
16. How much do you and this sibling disagree and quarrel with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
17. Some siblings cooperate a lot, while other siblings cooperate a little. How much do you and this sibling cooperate with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
18. Who gets more attention from your mother, you or this sibling?	[ ]My sibling almost always gets more attention [ ]My sibling often gets more attention [ ]We get about the same amount of attention [ ]I often get more attention [ ]I almost always get more attention
19. How much do you help this sibling with things he or she can't do by him or herself?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

20. How much does this sibling help you with things you can't do by yourself?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
21. How much do you make this sibling do things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
22. How much does this sibling make you do things?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
23. Who gets more attention from your father, you or this sibling?	[ ]My sibling almost always gets more attention [ ]My sibling often gets more attention [ ]We get about the same amount of attention [ ]I often get more attention [ ]I almost always get more attention
24. How much do you and this sibling love each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
25. Some siblings play around and have fun with each other a lot, while other siblings play around and have fun with each other a little. How much do you and this sibling play around and have fun with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
26. How much are you and this sibling mean to each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

27. How much do you and this sibling have in common?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
28. How much do you and this sibling share secrets and private feelings?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
29. How much do you and this sibling compete with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
30. How much do you look up to and feel proud of this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
31. How much does this sibling look up to and feel proud of you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
32. How much do you and this sibling get mad at and get in arguments with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
33. How much do both you and your sibling share with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
34. Who does your mother usually favor, you or this sibling?	[ ]My sibling almost always is favored [ ]My sibling is often favored [ ]Neither of us is favored [ ]I am often favored [ ]I am almost always favored

35. How much do you teach this sibling things that he or she doesn't know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
36. How much does this sibling teach you things that you don't know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
37. How much do you order this sibling around?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
38. How much does this sibling order you around?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
39. Who does your father usually favor, you or this sibling?	[ ]My sibling almost always is favored [ ]My sibling is often favored [ ]Neither of us is favored [ ]I am often favored [ ]I am almost always favored
40. How much is there a strong feeling of affection (love) between you and this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
41. Some kids spend lots of time with their siblings, while others don't spend so much. How much free time do you and this sibling spend together?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
42. How much do you and this sibling bug and pick on each other in mean ways?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

43. How much are you and this sibling alike?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
44. How much do you and this sibling tell each other things you don't want other people to know?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
45. How much do you and this sibling try to do things better than each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
46. How much do you think highly of this sibling?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
47. How much does this sibling think highly of you?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much
48. How much do you and this sibling argue with each other?	[ ]Hardly at all [ ]Not too much [ ]Somewhat [ ]Very much [ ]EXTREMELY much

KIDCOPE – YOUNGER CHILDREN

NFER-NELSON
INFORMING YOUR DECISIONS

st name: Date:

te of birth: Age:

x (please ring): M / F

uctions: I am trying to find out how children deal with different problems. Think of a time when you had a em that bothered you. Can you describe this problem to me?

tress items

	Not at all	A little	Somewhat	A lot	Very much
)id that time (related to the above described problem) make you eel **nervous** or **anxious**?	0	1	2	3	4
)id it make you feel **sad** or **unhappy**?	0	1	2	3	4
)id it make you feel **cross** or **angry**?	0	1	2	3	4

KIDCOPE – YOUNGER CHILDREN

NFER-NELSON
INFORMING YOUR DECISIONS

s name: ____________________

u:

	Did you . . . ?		How much did it help?		
	Yes	No	Not a lot	A little	A lot
to forget it	☐	☐	0	1	2
something like watch telly or play a game to get it	☐	☐	0	1	2
y on your own	☐	☐	0	1	2
ep quiet about the problem	☐	☐	0	1	2
to see the good side of things	☐	☐	0	1	2
ame yourself for causing the problem	☐	☐	0	1	2
ame someone else for causing the problem	☐	☐	0	1	2
y to sort out the problem	☐	☐	0	1	2
y to sort out the problem by doing something or lking to someone about it	☐	☐	0	1	2
hout, scream or get angry	☐	☐	0	1	2
ry to calm yourself down	☐	☐	0	1	2
Wish the problem had never happened	☐	☐	0	1	2
Wish you could make things different	☐	☐	0	1	2
Try to feel better by spending time with others like family, grown-ups or friends	☐	☐	0	1	2
Do nothing because the problem couldn't be solved	☐	☐	0	1	2

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KIDCOPE – OLDER CHILDREN

NFER-NELSON
INFORMING YOUR DECISIONS

irst name: Date:

ate of birth: Age:

ex (please ring): M /· F

uctions: I am trying to find out how children deal with different problems and stresses. Think of a time when had a problem that bothered you. Can you describe this problem to me?

tress items

	Not at all	A little	Somewhat	A lot	Very much
id that time (related to the above described problem) make you el **nervous** or **anxious**?	0	1	2	3	4
id it make you feel **sad** or **unhappy**?	0	1	2	3	4
id it make you feel **cross** or **angry**?	0	1	2	3	4

s there something you could change or do about it?	Yes	No
s this situation one that must be accepted or you must get used to?	Yes	No
s this situation one that you needed to know more about before you could act?	Yes	No
s this situation one in which you had to hold yourself back from doing what you wanted o do?	Yes	No

KIDCOPE – OLDER CHILDREN

NFER-NELSON
INFORMING YOUR DECISIONS

ame:

uctions: Please read each item and a phrase that *applies* (if any). Next, er both questions to the right of each ted item and circle the *best* answer.

	How often did you do this?				How much did it help?				
	Not at all	Sometimes	A lot of the time	Almost all the time	Not at all	A little	Somewhat	Pretty much	Very much
hought about something else; tried to rget it; and/or went and did some-ing like watch the telly or play games get it out of my mind	0	1	2	3	0	1	2	3	4
stayed away from people; kept my elings to myself; and handled that ne on my own	0	1	2	3	0	1	2	3	4
tried to see the good side of things nd/or concentrated on something ood that could come out of it	0	1	2	3	0	1	2	3	4
realized I brought the problem on my-elf and blamed myself for causing it	0	1	2	3	0	1	2	3	4
realized that someone else caused e problem and blamed them for aking me go through this	0	1	2	3	0	1	2	3	4
thought of ways to solve the problem; lked to others to get more facts and formation about the problem and/or ed to solve the problem	0	1	2	3	0	1	2	3	4
talked about how I was feeling; outed, screamed or hit something	0	1	2	3	0	1	2	3	4
tried to calm down by talking to yself, going for a walk and/or I just laxed	0	1	2	3	0	1	2	3	4
kept thinking and wishing that this had ever happened; and/or that I could ange what had happened	0	1	2	3	0	1	2	3	4
turned to my family, other adults or iends to help me feel better	0	1	2	3	0	1	2	3	4
just accepted the problem because I new I couldn't do anything about it.	0	1	2	3	0	1	2	3	4

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GREATER GLASGOW
PRIMARY CARE
NHS TRUST

Division of Clinical Psychology
Tel : 0141 211 3920

UNIVERSITY
of
GLASGOW

(Information for Child Participants)

Study of coping strategies used by children who have a brother or sister with Autism or Down's Syndrome.

Thank you for taking the time to read this information sheet. I am a Psychologist at the University of Glasgow who is doing a project on looking at the different ways that children cope with having a brother or sister with Autism or Down's Syndrome. I am interested in the different situations to do with their brother or sister that children find difficult and what they do to help them cope with these situations. This information can help us plan ways to help children who are not coping well.

Who am I looking for?

If you are between the ages of seven and eighteen and have a brother or sister who has Autism or Down's Syndrome, then I would like to hear from you. Everything you tell me will be private and you can 'drop out' from the project at any time, without explaining why.

What do you have to do?

I will come and visit you either at home, or if you prefer, somewhere of your choice, such as your local health centre. You will be asked about different times that you found difficult to do with your brother or sister, and how you coped with these times.

You will also be asked to complete a short questionnaire which looks at how well you and your brother of sister get on.

This should take about 45 minutes altogether. You can choose if you would like your mum or dad to stay with you, or to leave the room.

I hope you will agree to take part in the project.

Thank you for your time.

Jenny Low
Trainee Clinical Psychologist

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Division of Clinical Psychology
Tel : 0141 211 3920

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Study of coping strategies used by children who have a brother or sister with Autism or Down's Syndrome

Thank you for taking time to read this information sheet. I am a post-graduate student of Glasgow University training to become a Doctor of Clinical Psychology and am conducting a study examining how children cope with having a brother or sister with Autism or Down's Syndrome.

There is a popular belief that having a learning disabled brother or sister can have a negative effect on children, but in fact previous research in this area does not completely support this view. Some studies have shown that living with a child with Autism or Down's Syndrome can have benefits for siblings, such as increased maturity and tolerance. Others, however, have shown that some children have more difficulty in this situation and may become stressed or depressed due to the pressures of living with a disabled sibling. There seems to be great variation in the way children cope with living with a disabled brother or sister and it seems that siblings of autistic children have a much more mixed experience than siblings of children with other disabilities such as Down's Syndrome. I am interested in why this is so, and plan to compare siblings in these two groups to try and identify what makes some children cope well, and others not so well.

This kind of research can therefore show us the different ways that children cope, and which ways work best for different children. This information can be used to help us plan ways in which we can help children who are having difficulties in living with their brother or sister.

Who am I looking for?

I would like to hear from children aged between seven and eighteen years, who have a brother or sister who has Autism or Down's Syndrome All information collected will be confidential and you and/or your child are also completely free to withdraw from the study at any time, without explaining why.

What do you have to do?

Your child will be asked to describe situations related to their brother or sister which he/she found difficult, and how they dealt with such situations. This task will take around 25 minutes.

There will also be a short assessment of the relationship between your child and his brother or sister with Autism or Down's Syndrome. This involves the child completing a questionnaire asking for his/her opinion about the relationship. This should only take a further 15-20 minutes. You will be free to stay throughout the assessment or to leave the room, according to what ever you and your child prefer.

Where?

I can visit you at your home, or if you prefer, somewhere of your choice, such as your local health centre.

Your child's participation in this research would be very much appreciated. If you have any queries or would like to participate please do not hesitate to contact me on one of the following numbers : **01786 480251** or **0411 580 929.**

Thank you once again for your time.

Jenny Low Trainee Clinical Psychologist

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Division of Clinical Psychology
Tel : 0141 211 3920

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Child Participant's Consent Form

Title of Study : An exploration of the coping strategies used by children who have a sibling with Autism or Down's Syndrome.

Researchers : Jenny Low B.A. (Hons)
Doctoral Student in Clinical Psychology
Trainee Clinical Psychologist
University of Glasgow
&
Greater Glasgow Primary Care NHS Trust

Name: ....

Please read the sentences below and tick 'yes' or 'no' for each.

	YES	NO
• I have read the attached information letter.	☐	☐
• I understand that I do not have to take part in the study.	☐	☐
• I understand that I am free to 'drop out' from the project at any time, without explaining why.	☐	☐
• I understand that everything I talk about will be private.	☐	☐
• I would like to receive a copy of the results of the project.	☐	☐
• I agree to take part in the project	☐	☐

Signed :..

Date : ....

REATER GLASGOW
PRIMARY CARE
NHSTRUST

Division of Clinical Psychology
Tel : 0141 211 3920

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Child Participant's Consent Form - Next of Kin

Title of Study : An exploration of the coping strategies used by children who have a sibling with Autism or Down's Syndrome.

Researchers : Jenny Low B.A. (Hons)
Doctoral Student in Clinical Psychology
Trainee Clinical Psychologist
University of Glasgow
&
Greater Glasgow Primary Care NHS Trust

Name of Participant : ....

Name of Participant's Parent/Carer :...

(delete as appropriate)

• I have read the attached information letter.	YES/NO
• I agree to my child taking part in the study.	YES/NO
• I understand that I can decline to include my child from this study without giving any reason why, and their care will not be affected in any way.	YES/NO
• I understand that I am free to withdraw my child from this study without giving any reason for withdrawal, and their care will not be affected in any way.	YES/NO
• I understand that upon withdrawal all information regarding my child will be destroyed.	YES/NO
• I wish to receive a summary of the study results	YES/NO

Parent/Carer's signature :..

Date :..............................

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PRIMARY CARE
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Ref: AmcM/0045

17 October, 2000

Ms Jenny Low
Academic Centre
Gartnavel Royal Hospital
1055 Gt Western Road
Glasgow
G12 0XH

Dear Ms Low

***PROJECT:* An exploration of the coping strategies used by children who have a sibling with autism or Down's Syndrome**

Many thanks for coming along to the meeting on Thursday, 12 October 2000 to discuss the above named submission. I am pleased to be able to tell you that the Committee now has no objections from an ethical point of view, to this project proceeding and ethical approval is formally granted.

Before your project commences you will also require to obtain management approval via the Research & Development Directorate, Gartnavel Royal Hospital.

I would also like to take this opportunity to remind you that you should notify the Committee if there are any changes, or untoward developments, connected with the study – the Committee would then require to further reconsider your application for approval. The Committee expect to receive a brief regular update every 6 months, and then a brief final report on your project when the study reaches its conclusion. (Failure to keep the Committee abreast of the status of the project can eventually lead to ethical approval being withdrawn)

May I wish you every success with your study.

Yours sincerely

A W McMAHON
Administrator – Research Ethics Committee

cc B Rae

Trust Headquarters Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH Tel: 0141 211 3600

GREATER GLASGOW
PRIMARY CARE
NHS TRUST

Ref: AmcM/0045

1 May, 2001

Ms Jenny Low
Trainee Clinical Psychologist
Academic Department
Gartnavel Royal Hospital
1055 Gt Western Road
Glasgow
G12 0XH

Dear Ms Low

PROJECT: ***An exploration of the coping strategies used by children who have a sibling with Autism or Down's Syndrome***

Many thanks for sending the proposed amendments to the above named submission to the Research Ethics Committee - it was discussed at our meeting on Thursday, 12 April 2001. I am pleased to be able to tell you that ethical approval has been granted for the amendments proposed in your letter of 24 March 2001 subject to the following –

- The study must start within two years of the date of this letter. After that time approval will be deemed to have lapsed and the project will require to be resubmitted.
- You should notify the Committee if there are any changes, or untoward developments, connected with the study – the Committee would then require to further reconsider your application for approval. Changes to the protocol must not be initiated until written Committee approval is given, except when necessary to eliminate immediate hazards to subjects.
- The Committee expect to receive a brief regular update every 6 months, and then a brief final report on your project when the study reaches its conclusion. (Failure to keep the Committee abreast of the status of the project can eventually lead to ethical approval being withdrawn).

Before your project commences you will also require to obtain management approval via the Research & Development Directorate, Gartnavel Royal Hospital.

May I wish you every success with your study.

Yours sincerely

A W McMAHON
Administrator – Research Ethics Committee

Trust Headquarters Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH Tel: 0141 211 3600

Section 3 – Appendices for Major Research

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Notes for Contributors

General

1 Submission of a paper to the Journal will be held to imply that it represents an original contribution not previously published (except in the form of an abstract or preliminary report); that it is not being considered for publication elsewhere; and that, if accepted by the Journal, it will not be published elsewhere in the same form, in any language, without the consent of the Editors. When submitting a manuscript, authors should state in a covering letter whether they have currently in press, submitted or in preparation any other papers that are based on the same data set, and, if so, provide details for the Editors.

Ethics

2. Authors are reminded that the Journal adheres to the ethics of scientific publication as detailed in the *Ethical principles of psychologists and code of conduct* (American Psychological Association, 1992). These principles also imply that the piecemeal, or fragmented publication of small amounts of data from the same study is not acceptable.

3. Papers should be submitted to the Joint Editors, care of:

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Alternatively, papers may be submitted directly to any of the Corresponding Editors whose addresses are shown on the first page. Upon acceptance of a paper, the author will be asked to transfer copyright to the ACPP.

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1. Manuscripts should be typewritten, **double spaced throughout including references and tables**, with wide margins, on good quality A4 paper, using one side of the page only. Sheets should be numbered consecutively. **Four** copies should be sent. The author should retain a copy of the manuscript for personal use. Fax and electronic mail should **not** be used for initial submission of manuscripts.
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4. Authors whose papers have been given **final acceptance** are encouraged to submit a copy of the final version on computer disk, together with two hard copies produced using the same file. Instructions for disk submission will be sent to authors along with the acceptance letter. Do **not** send a disk with initial submission of paper.

Layout

1. *Title*: The first page of the manuscript should give the title, name(s) and address(es) of author(s), and an abbreviated title (running head) of up to 80 characters. Specify the author to whom reprint requests should be directed. The covering letter should clearly state the name and address of the person with whom the Editors should correspond, giving also if possible a fax and email address. Authors requesting **masked review** should provide a first page with the title only and adapt the manuscript accordingly.
2. *Abstract*: The abstract should not exceed 300 words.
3. *Acronyms*: In order to aid readers, we encourage authors who are using acronyms for tests or abbreviations not in common usage to provide a list to be printed after the abstract.
4. *Headings*: Original articles and research reports should be set out in the conventional form: Introduction, Materials and Methods, Results, Discussion, and Conclusion. To save space in the Journal, the Method will be printed in smaller typeface. Descriptions of techniques and methods should be given in detail only when they are unfamiliar.
5. *Acknowledgements*: These should appear on a separate sheet at the end of the text of the paper, before the References.

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(a) *References in text.*

References in running text should be quoted as follows: Smith and Brown (1990), or (Smith, 1990), or (Smith, 1980, 1981a, b), or (Smith & Brown, 1982), or (Brown & Green, 1983; Smith, 1982).

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Full references should be given at the end of the article in alphabetical order, and not in footnotes. **Double spacing** must be used.

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References to articles, chapters and symposia contributions should be cited as per the examples below:

Kiernan, C. (1981). Sign language in autistic children. *Journal of Child Psychology and Psychiatry, 22*, 215–220.

Jacob, G. (1983a). Development of coordination in children. *Developmental Studies, 6*, 219–230.

Jacob, G. (1983b). Disorders of communication. *Journal of Clinical Studies, 20*, 60–65.

Thompson, A. (1981). *Early experience: The new evidence.* Oxford: Pergamon Press.

Jones, C. C., & Brown, A. (1981). Disorders of perception. In K. Thompson (Ed.), *Problems in early childhood* (pp. 23–84). Oxford: Pergamon Press.

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The Journal has a policy of anonymous peer review and the initial refereeing process seldom requires more than three months. Authors may request that their identity be withheld from referees and should follow the procedure for masked review, as above. Most manuscripts require some revision by the authors before final acceptance. Manuscripts, whether accepted or rejected, will not be returned to authors. The Editor's decision on the suitability of a manuscript for publication is final.

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Scenarios presented to children in ranking task.

Your brother/sister gets into your room/takes things without your permission

Your brother/sister teases you, bugs you, makes fun of you or puts you down.

Your brother/sister has bad habits, acts strange, or does weird things.

Your brother/sister hits, kicks, shoves, or beats you up.

Your brother/sister gets hurt or sick.

Your brother/sister gets upset with a child for no reason.

You have to babysit, clean up after your brother/sister when you don't really want to.