Calm Child Programme: Parental Programme for Anxiety in Children and Young People with Autism Spectrum Disorder and Intellectual Disabilities

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Abstract

Children with autism spectrum disorder (ASD) and intellectual disabilities (ID) are more vulnerable to experience anxiety disorders. Parental involvement in intervention is crucial for successful management of the interventions in the population of people with autism spectrum disorders. This paper describes the design and evaluation of parenting programme for anxiety disorders in children and young people with ASD and ID.

Method: Phase (1): Semi- structured interviews were conducted to explore management strategies for anxiety at home and in school settings. A total of 34 participants (14 parents, 20 teachers) participated in the interviews. A Delphi process was conducted with health professionals to develop consensus on appropriate anxiety interventions. Phase (2): The intervention programme was implemented by seven parents, who also participated in focus group to evaluate the developed programme.

Results: A parental programme, Calm Child programme was developed, implemented and evaluated. The evaluations show significant decrease in children's anxiety as a result of implementing the programme. This study contributes further evidence to parental involvement in interventions for children and young people with ASD and ID. The CCP is a useful and cost effective approach in enabling parents to provide anxiety interventions in a home setting.

Background

Parental involvement in intervention is crucial for successful management of the interventions in the population of people with autism spectrum disorders (ASD) and or intellectual disability (ID) (Reaven and Hepburn 2006; Dillenburger et al. 2002). Thus, it is important to empower parents to help their children. Parents are considered as a main source

of support for their children throughout the child's lifetime (Heiman & Berger 2008; Buckley 2002). A number of factors contribute to this: the majority of caregivers can give better care to their children than anyone else; parents usually spend more time with their children, in different and more diverse situations (Matson et al. 2009); and that involving parents in intervention may strengthen the family's capability to meet the needs of their children. In addition, parents' views on their own lives, experiences and feelings on those of their children may be able to provide a consistent picture of issues affecting their family quality of life (Wang et al. 2006). Despite this, there is a dearth of research attempting to develop parental interventions that address anxiety in children and young people who are diagnosed with both ASD and ID.

Teachers have also a crucial role not only in early recognition and evaluation of any behaviour problems with children with ASD but also in the management of these behaviour and monitoring the progress of such child. Literature regarding teacher involvement in intervention often had positive outcomes for individuals with disabilities (Alsayedhassanm et al 2016; Koegel et al 2012; Lang et al. 2010). Hence, it is important to involve teachers in meaningful ways in research-based intervention (McConkey & Bhlirgri, 2003; Robertson et al 2003).

The co-morbidity of ASD and ID makes these children and young people more susceptible to anxiety. Individuals with mild to moderate ASD and ID, have higher abilities and are proportionately more disabled by their autistic features and they are therefore more likely to develop mental health problems (Morgan et al. 2003). Prevalence studies demonstrate higher prevalence rates of anxiety for individuals with comorbidity ASD and ID (Gobrial & Raghavan 2012) compared to people with ID without ASD (Bradley et al. 2004; Hill & Furniss 2006). They are more vulnerable to experience anxiety as a result of the interplay

between ASD and ID and other factors, for example lack of social and cognitive resources and poor coping skills (Cooray & Bakala 2005; Deudney & Shah 2004).

Significant levels of anxiety can be disabling for children with ASD and ID, with negative consequences for children and their families. This may cause considerable distress and interfere with daily activities (Muris and Steernman 1998; Bellini 2004). Research has indicated that emotional and behavioural difficulties can have important effects on family wellbeing and anxiety causes family dysfunction or parental stress (Herring et al. 2006; Tehee et al. 2009). Caring for a child with ASD and ID results in parents being more likely to develop mental health problems such as stress or depression compared with other parents (Hastings et al. 2006; Heiman 2002; Grant et al. 1998) and as a result the family is more likely to reach a crisis (Weiss et al. 2014).

A substantially increased burden results from anxiety in children and young people with ASD and ID. There is a need for a validated intervention involving parents in supporting such children and young people. This paper discusses a programme to support parents in managing their child's or young person's anxiety and describes the development, implementation and evaluation of the "Calm Child Programme".

Method

A combined approach including both quantitative and qualitative methods was employed in this research. Ethical approval was sought and successfully granted from the local NHS Research Ethics Committee (REC); and University of Northumbria, School of Health, Community and Education Studies Research Ethics Sub-Committee prior to the study with due consideration given to safety, anonymity, confidentiality and expected involvement of

participants. Informed consent was obtained from each participant prior to the study. A two phase procedure was applied:

I. Phase 1: Exploration of intervention strategies with parents and teachers

The purpose of this phase was to develop a parental programme of anxiety management strategies for children with ASD and ID.

Participants:

Thirty-four participants were interviewed: fourteen were parents and twenty were teachers. All were caring for children and young people with ASD and ID with an anxiety diagnosis according to the ICD-10 diagnostic criteria. The children ranged in age from 5 to 18 years, with a mean age of 12.25 years (SD = 3.47), who had a prior diagnosis of ASD as demonstrated by a school or parents report.

Measures:

1. Semi-structured interviews aimed to explore the interventions, processes and procedures used by parents and teachers in anxiety management of children and young people with ASD and ID;
2. Delphi process (Powell, 2002) was applied to obtain a consensus between professionals regarding the appropriate and most useful strategies for those children and young people.

Procedures:

A semi-structured interview schedule was developed to explore the management strategies used by parents and teachers. Our aim of the interview was to identify parents' and teachers' experiences of managing the children's and young people's anxiety and on the effectiveness of those strategies.

The Delphi process was used to discuss the strategies revealed by parents and teachers with an expert panel of health professionals. The aim of this Delphi process was to develop consensus about the appropriate and effective anxiety management strategies for children & young people with ASD and ID. Subsequently, the Calm Child Programme (CCP) a consensus model of practical and effective anxiety management strategies was developed. The expert panel of health professionals was selected for the Delphi process. The panel consisted of five professionals: a Child and Adolescent Psychiatrist, a Clinical Psychologist, an Educational Psychologist, a Social Worker and a Community Nurse.

Phase (2): Implementation of the parental programme (Calm Child Programme):

The purpose of this phase was to implement the CCP with a group of parents of children with ASD and ID.

Participants:

New parents were invited to participate in the second phase. Parents were recruited through advertisements and newsletters of the autism support groups at West Yorkshire and North East of England and through Special Education Schools. They were mothers aged between 25 and 49 years of age and they were parents of seven children (6 boys, and 1 girl). Children aged 5 to 14 years, with a mean age of 9.04 years (SD= 3.05) with an autism diagnosis. The inclusion criteria for those children included: mild to moderate intellectual disabilities; living at home with their parents; and not in any other treatment or appropriate intervention for anxiety or any other medication for the term of intervention as identified by parents.

Measures:

3) **Glasgow anxiety Scale** for children with intellectual disabilities: GAS-ID (Mindham and Espie 2003) was used to assess anxiety before and after implementing the

programme. The GAS-ID covers three domains (worries, specific fears and physiological symptoms) and consists of 27 items.

4) **Focus group** was conducted with the parent participants who had implemented the Calm Child Programme (CCP) to identify its usefulness and impact.

Procedures:

We conducted a pilot study to implement the CCP and to evaluate its use in everyday settings. An information pack was sent to parents by post. This information pack included: the CCP, GAS-ID scale, parents' diary, consent form and an example of visual schedule. Comprehensive information on the strategies was provided in the CCP. The researcher then contacted the families and explained the purpose and nature of the CCP and answering their questions and concerns. Parents were reassured about confidentiality issues. Parents were asked to monitor the child daily in a monitoring diary to record the strategies they used and the effect of using these strategies. Eight families agreed to take part and carried out the programme. During the implementation of the programme one of the participants dropped out after 4 weeks because the child was nonverbal and the parent was not able to communicate with him. At the final stage, this programme was carried out with seven families of children with ASD and ID. Parents were contacted by telephone every fortnight to follow up. They informed the researcher of their progress in supporting their child in managing their anxiety. At the end of implementation period of 3 months, parents completed the GAS-ID about their child and an evaluation form about the programme along with the monitoring diary for the full term of the intervention. In addition, focus group was organised with participated parents.

Results

Our aim was to design a parenting programme for anxiety disorders and evaluate its feasibility with parents who are caring for children and young people with ASD with anxiety

diagnosis. By interviewing parents of children with ASD, the first phase of this study identified the management strategies used by parents and teachers. The findings of the second phase revealed significant difference in children's and young people's anxiety between before and after implementing the CCP by parents. The secondary findings suggested an increase in parenting skills of managing anxiety following completion of the CCP.

Identifying Management Strategies

The thematic categories emerging from the data analysis of participants' descriptions provided examples of how parents and teachers supported their children and young people to manage their anxiety. The results suggested a total of sixteen different management strategies that were used. The findings revealed that the most used strategies were talking and explaining, distraction and the use of a visual schedule (Table 1 and Figure 1). The findings suggested that similar strategies were used with children and young people. However, these approaches were influenced by the individual's age as well as individual differences.

Insert Table 1 here

Insert Figure 1 here

Delphi Process: Group discussion was convened with an expert panel of health professionals for gathering data within their domain of expertise with children and young people with ASD & ID and mental health needs. This involved a discussion with the expert panel regarding the strategies identified by parents and teachers (phase1), which aimed to achieve a convergence of opinion concerning management strategies for anxiety disorders.

A consensus of anxiety management strategies was developed based on the Delphi process and parents' and teachers' experiences. This consisted of ten strategies: talking and explaining, physical activities, visual schedule, relaxation techniques, grading anxiety, distraction, have a fun, reassurance, cuddling and quiet-time. Six strategies were eliminated and these consisted of massage, flooding, removing physically from the situation,

reinforcement, stop thinking and rewarding. Those were eliminated due to its inappropriateness for children with ASD; and ethical and practical issues in its implementation in practice. As a consequence of developing the consensus of the management strategies, a parental programme "Calm Child Programme" was designed.

Developing Calm Child programme (CCP)

The CCP is designed to support parents with child /young person with ASD and ID. The child/young person should have met the diagnostic criteria for a primary diagnosis of anxiety disorders or who report high levels of anxious symptoms based on the ICD-10 diagnostic criteria. The CCP provided background information on anxiety disorders in children with ASD and ID and an outline of appropriate anxiety management strategies.

A traffic light system was designed as schematic attempt to present anxiety management strategies for parents (Figure 2). The traffic light sets out in details three sets of strategies, that influenced by the intensity of anxiety experienced, to address the range of possible strategies could be used by parents. Parent can apply each strategy according to the child's anxiety level. Those sets of strategies were intended to complement each other.

Insert Figure 2 here

Three sets of strategies were proposed, which included: proactive, communication and reactive strategies. The first set consisted of **proactive strategies.** These aimed at crisis prevention and were designed to prevent triggering the anxiety, by using visual schedules, talking and explaining, relaxation and physical activities. Second set was **a communication strategy** which aimed to develop child's/ young person's self-management, self-regulation and social interaction with parent. An anxiety scale-thermometer was developed (Figure 3). The notion behind the thermometer is to help the child identify his/er anxiety level and break it into five parts to make it easier to understand the different degrees of anxiety and,

eventually, the consequences of his behaviour. Furthermore, this helps to erase the need for parents to remind the child to check his behaviour by empowering child to self-regulate. This strategy emphasizes the importance of self-management, self-regulation and social interaction. Thus, a child will develop the ability to control their emotional responses. While the third set was reactive strategies which aimed to manage the child's anxiety, using distraction, quiet-time, have a fun and comfort strategies.

Insert Figure 3 here

Evaluation of the programme

The anxiety scores of children were compared before the start of the intervention and immediately after the intervention by applying the Glasgow Anxiety Scale (GAS-ID). Table 2 shows children's anxiety scores at the two points (T1= pre- intervention and T2 = post-intervention). The results showed substantial decrease in the anxiety score by 10.86 points at the post-intervention assessment. The children's anxiety mean scores after implementing the CCP programme were (M=16.43; SD=3.599) lower than the anxiety mean scores before the programme (M=27.29; SD = 5.282). In most cases (85%) anxiety score decreased to below the cut-off point (=20) on GAS-ID. In addition, parents presented the diary where they monitored the practice and outcome of practising the strategies and outcomes on a daily basis for the term of the intervention. There were statistically significant differences of children's anxiety between pre- and post-test using the Wilcoxon test, $Z = -2.371$, $p < .05$.

Insert table 2 here

Insert table 3 here

Insert figure 4 here

The impact of CCP parenting interventions

The findings obtained from the focus group and parents' monitoring diary show proven efficiencies of parenting programme "CCP" in managing the child's and young person's anxiety. The findings indicate the most effective strategies that parents found useful with their son/daughter were distraction (with special interest), physical activities and talking & explaining. The most frequently reported used strategies were physical activities, distraction, talking and timetable (visual or written) in sequence. The majority of parents used a combination of these different strategies to manage the child's anxiety.

Participants' perceptions were that relaxation techniques were beneficial in lowering the anxiety level. Participants reported that children and young people with ASD and ID also utilized several relaxation techniques (e.g. listening to music, deep breathing) to reduce their anxiety. The choice of relaxation method depended very much on the age of the individual and the situation at school or home. Parents indicated that young children responded to watching their favourite movies, playing with their favourite toy or a game as a relaxation, while young people and adolescents preferred to listen to calming music. Quiet time was another form of relaxation used to reduce children's anxiety symptoms.

It is important to indicate that implementing strategies were influenced by choice and individual limitation and differences. While some children enjoyed listening to music as a relaxation technique, other children preferred physical exercise.

The findings also suggest an increase in parenting skills of managing anxiety in everyday situation following completion of the CCP. Positive effects for CCP intervention have been reported by parent participants, improving parenting practices, increasing positive interactions with children; structure the family life; establishing strategies for everyday

situation; a home routine has contributed to overcome some of the obstacles that the family faced.

In addition, the CCP has contributed to the development of self-management and self-regulation. Parents described that any changes to their child's behaviour was attributed to participation in the programme. In the following excerpt, parents described how this programme impacted their child's life:

Parent (3): "Certainly, having structured what my son is doing, it is more structured in my mind now and my son's mind as well, rather than before".

Parent (2): "He is generally quiet calm on a daily basis; it is only changes to routine which cause him anxiety now, particularly holidays and visitors. However, I found the strategies useful for tackling anxiety-producing situations when they did occur".

Parent (5): "She is happier, calmer and enjoys herself".

Discussion

Our aim was to design and develop a parental intervention "Calm Child Programme" and investigate its feasibility and acceptability through a pilot study. The primary outcome of evaluating the CCP indicated a decrease in the child's/young person's anxiety level. The secondary outcome indicate that the CCP was helpful for parents in enhancing their skills in for anxiety management of their son/ daughter.

There has been a tendency within the research community to view caring in pathological terms. A strong theme as a result of CCP is that it has enabled to improve parents' confidence and better knowledge of recognising and managing anxiety. Providing parents with a programme of the most appropriate and useful strategies to help their children cope better with anxiety can increase the child's competency in coping with his anxiety as well as

improving their confidence (Plant and Sanders 2007) and the ability to manage the anxiety of their son / daughter. There is a wealth of literature about family intervention and early intervention programmes for ASD in children, such as the Son–Rise programme and Applied Behaviour Analysis (ABA). These programmes encourage many positive improvements for families, such as enhancing parents' confidence, relieving parental stress, cost effectiveness, enhancing the capacity of the family and increasing quality of life (Epley et al. 2011; Rodger et al. 2008; Grant et al. 1998).

There is evidence concerning the efficacy of some of these management strategies for a range of mental health needs including anxiety for young people with ASD such as Cognitive Behaviour Therapy (CBT). It is important to highlight that the combination of different approaches in this study was similar to the content of the CBT programme which is applied in previous research concerning anxiety in children with Asperger's syndrome and ASD (Reaven and Hepburn 2006; Chalfant et al. 2007). Behavioural approaches may in fact be the 'prominent approach' for intervention in children with ID and ASD. The findings support this possibility, as the most effective strategies identified by the parents is relying on behavioural strategies more than cognitive and emotional strategies to manage the child's anxiety. The results also concur with the Stepping Stones Triple P-Standard programme (Plant and Sanders 2007), which has demonstrated its efficiency as a useful intervention for parents of children with developmental disabilities. The Triple P-Standard programme involved teaching parents twenty-five strategies to facilitate children's behaviour (e.g., talking, quiet time, discussion, distraction and engaging activities). Moreover, intervention studies indicate that relaxation strategies appear to be effective in reducing anxiety (Green et al. 2006; Morrison & Lindsay 1997; Lindsay et al. 1989). Physical activities have been used for different disorders (Pan & Frey 2006). Visual schedule is a familiar treatment strategy used by parents of children with ASD (Green et al. 2006). Anxiety Thermometer has been

suggested to be used by parents in managing anxiety with young people with ASD and typically developing children (Rapee et al. 2008).

Existing evidence of intervention studies have demonstrated the potential feasibility of cognitive behaviour therapy in reducing anxiety amongst people with ID and ASD (Dagnan and Jahoda 2006; Chalfant et al. 2007; Sofronoff et al. 2005; Joyce and Hardy 2003; Lindsay, et al. 1997). The CCP supports parents to manage their child's anxiety, thus enhancing the family protective factors and reducing risk factors associated with severe emotional difficulties in children with ASD and ID. It also helps to develop parental capacity and their expertise in planning and delivering interventions and evaluating its application and impact. The parental programme can also help reduce the distressing emotional reactions of parents including depression, anger, anxiety and high levels of stress, especially within the parenting role (Tehee et al. 2009; White and Hastings 2004). Providing parents with a practical and appropriate programme of strategies helps them to strengthen the family capacity to meet the needs of the child (Wang et al. 2006). In our study parents reported that proactive strategies proved very useful in managing child's anxiety in day to day life. The CCP is to be considered as a parental intervention in everyday life of the children with ID and ASD as it equips parents and children with strategies they can use in everyday life. The advantage of being in a familiar environment and the flexibility to apply the strategies in a family context would be helpful for the children with ASD. Findings suggest that the CCP encourages parents to interact with their children and to implement interventions. This has the added benefit of developing parental expertise in the delivery of anxiety interventions and may help to reduce the high workload of CAMHS professionals (Mudford et al. 2001; Smith et al. 2000).

Limitation and Implication

The study has some potential limitations. The CCP programme was limited to children and young people with ASD and mild / moderate ID live in the UK. The use of this programme with children and young people with severe and profound ID require further investigation. The sample size was relatively small; generalization of the findings is not feasible. Future research might investigate the impact of this intervention on a larger sample. A post intervention outcome was measured in this study; however, a long term follow-up assessment was not conducted as it was not feasible in the time frame of this research. Hence, further research is required to evaluate the outcomes of the CCP on ASD and anxiety in a large-scale study to determine the elements, length and intensity required to ensure effectiveness of the CCP programme, as well as longer-term outcomes.

There are several potentially important future directions that might further strengthen the population reach and impact of parenting interventions. The use of modelling and demonstration of core parenting skills is likely to be a core feature of any effective intervention of parenting. Future research could be enhanced on the value of observation learning and video-based modelling. Implications derived from this research will be considered for future research on parental involvement for managing other mental health problems in children and young people with ASD and ID.

Conclusion

Children and young people with ASD and ID are more vulnerable to experience anxiety disorders. This study presents a parental intervention programme 'Calm Child Programme' for anxiety disorders in children and young people with ASD and ID. Findings indicate that interventions targeting children and young people with ASD and ID were successful through

parental involvement. This study leads to the use of evidence-based information about the effects of parental intervention and would merit its further use in clinical practice. A successful programme in supporting parents will bring about improvement in parental skills and confidence and, thus, improve the quality of life for all children with ID and ASD and their parents. This study contributes further evidence to parental involvement in interventions for children with ASD and ID and add to the growing body of research on supporting parents for the anxiety management of children and young people with ASD and ID.

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Figures

Figure 1: Descriptive statistics for management strategies.

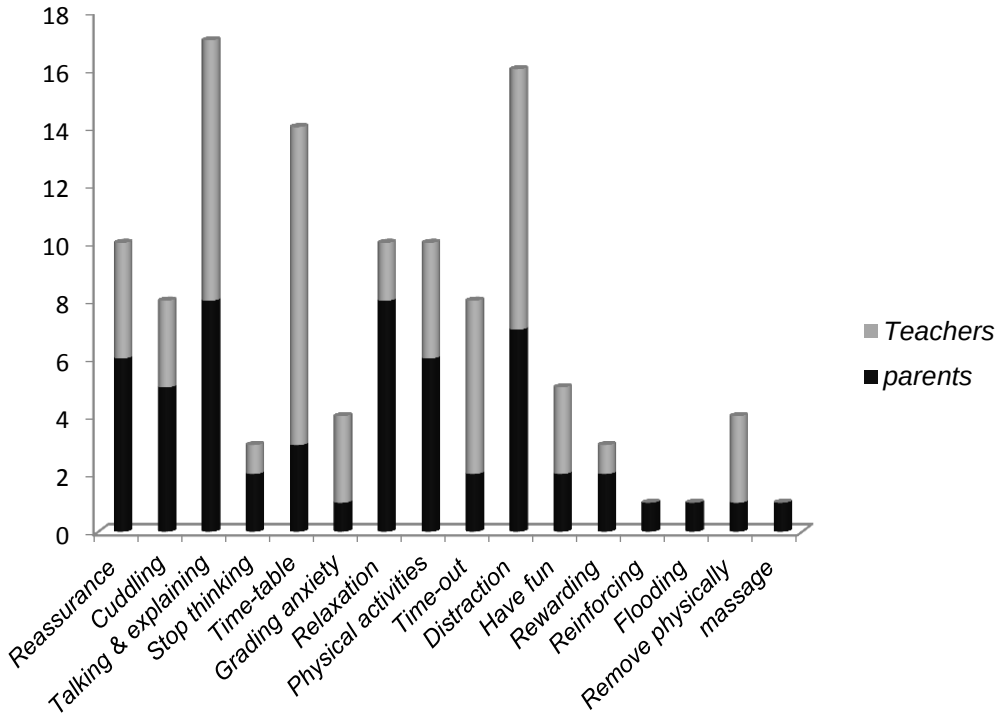


Figure 2: Traffic light system

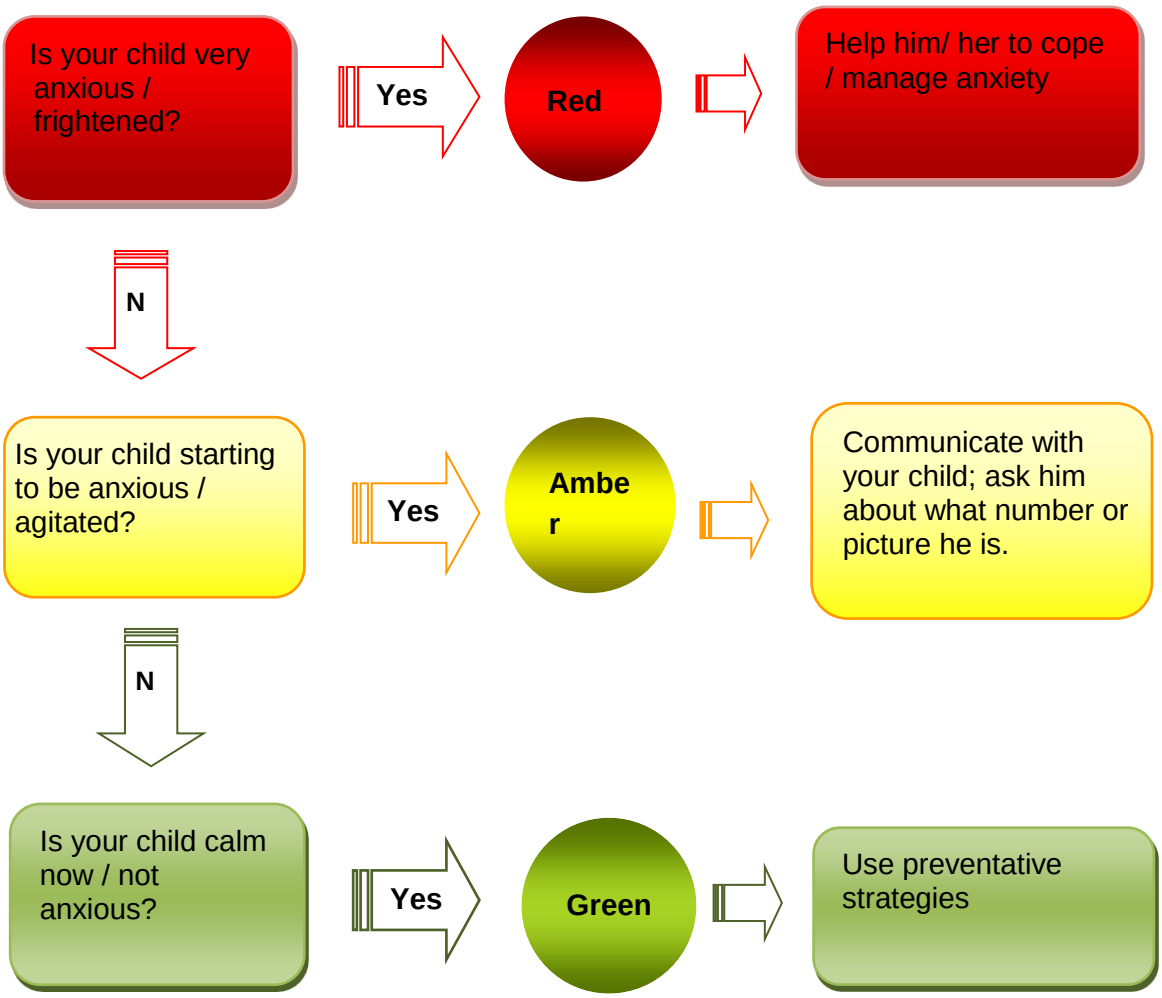


Figure 3: My Anxiety Thermometer

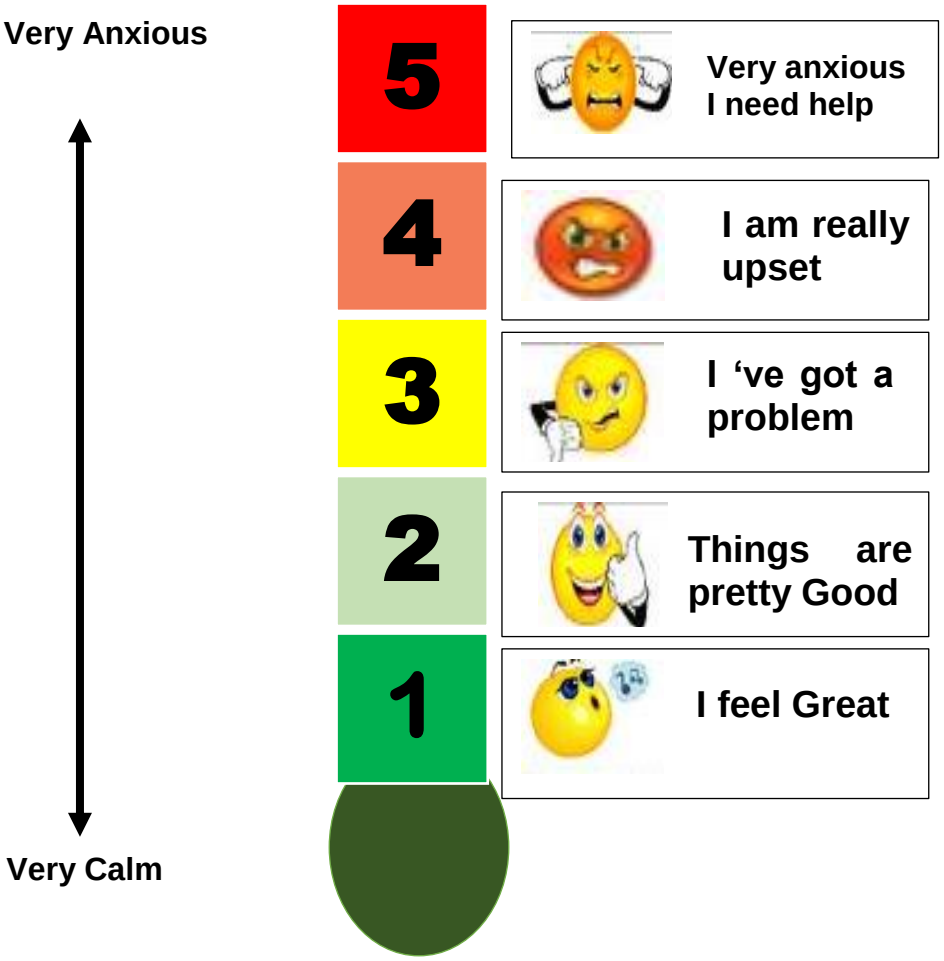
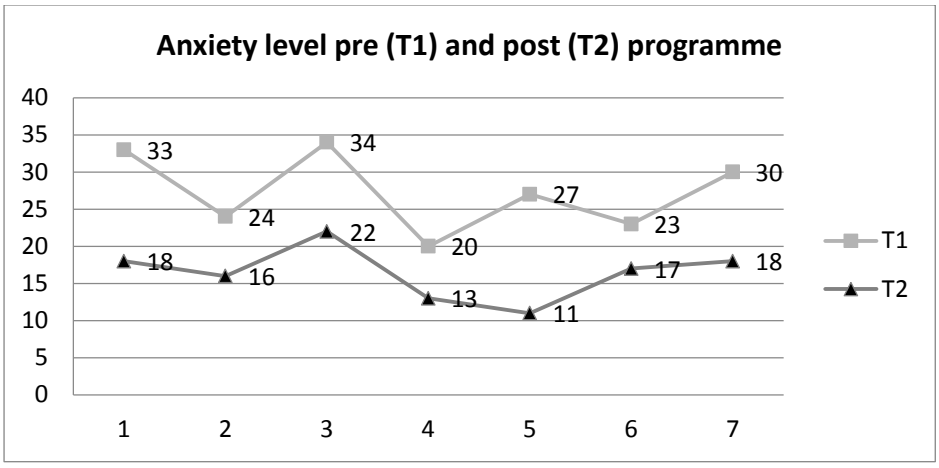


Figure 4 children's anxiety scores pre and post programme



NB:

T1= time one pre-intervention and T2 = time 2 post- t intervention

Tables

Table 1: Rank orders in terms of number / percentage of management strategies used by parents and teachers.

Management strategy	Number (N=34)	Percentage of use
1. Talking/ explaining	17	50 %
2. Distraction	16	47 %
3. Visual schedule	14	41 %
4. Reassurance	10	29.4 %
5. Physical activities	10	29.4 %
6. Relaxation techniques	10	29.4 %
7. Quiet-time	8	23.5 %
8. Cuddling	8	23.5 %
9. Have a little fun	5	14.7 %
10. Grading anxiety	4	11.7 %
11. Remove physically of the situation	4	11.7 %
12. Rewarding	3	8.8 %
13. Stop thinking	3	8.8 %
14. Reinforcing	1	2.9 %
15. Flooding	1	2.9 %
16. Massage	1	2.9 %

Table 2 Characteristics of the children and young people

Case No.	Diagnosis	Gender	Age (years)	School type	Anxiety Pre-intervention T1*	Anxiety Post - intervention T2*
1	autism & ID	M	8	Mainstream	33	18
2	autism & ID	M	14	Special	24	16
3	autism & ID	M	10	Special	34	22
4	Asperger's & ID	M	9	Mainstream	20	13
5	autism & ID	F	6	Mainstream	27	11
6	autism & ID	M	11	Special	23	17
7	autism & ID	M	5	Special	30	18

(T1= time one pre- intervention and T2 = time 2 post- intervention)

Table 3 Descriptive data for the study participants on GAS-ID scale.

Anxiety scale	Pre-test		Post-test	
	M	SD	M	SD
GAS-ID	27.29	5.3	16.43	3.6

Figures

Figure 1: Descriptive statistics for management strategies.

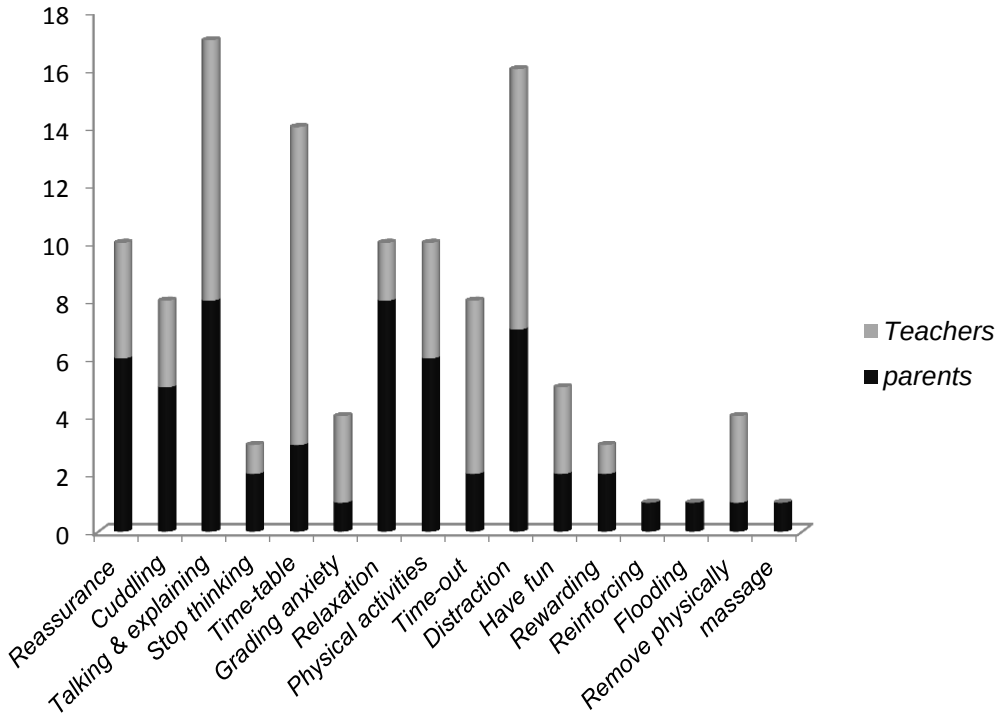


Figure 2: Traffic light system

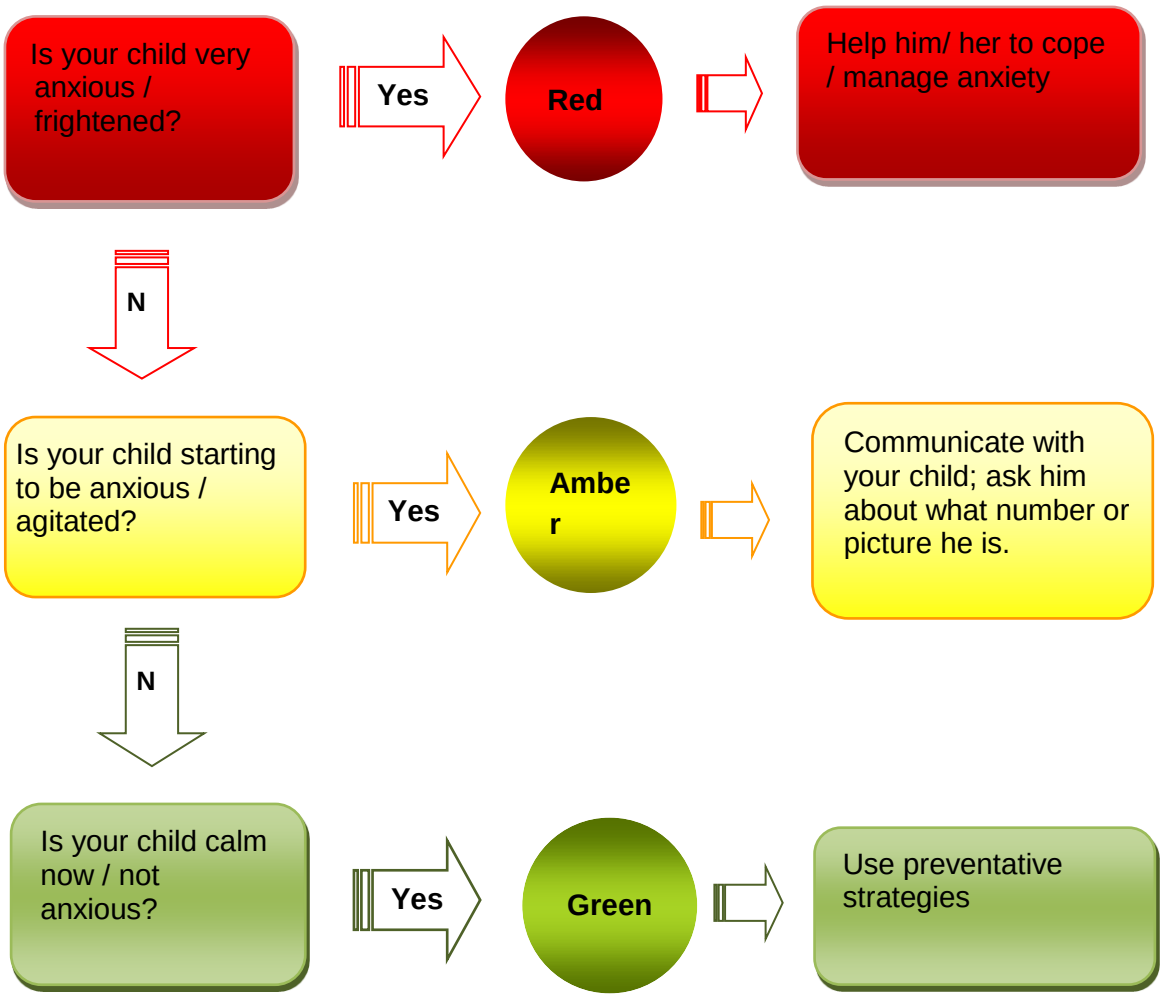


Figure 3: My Anxiety Thermometer

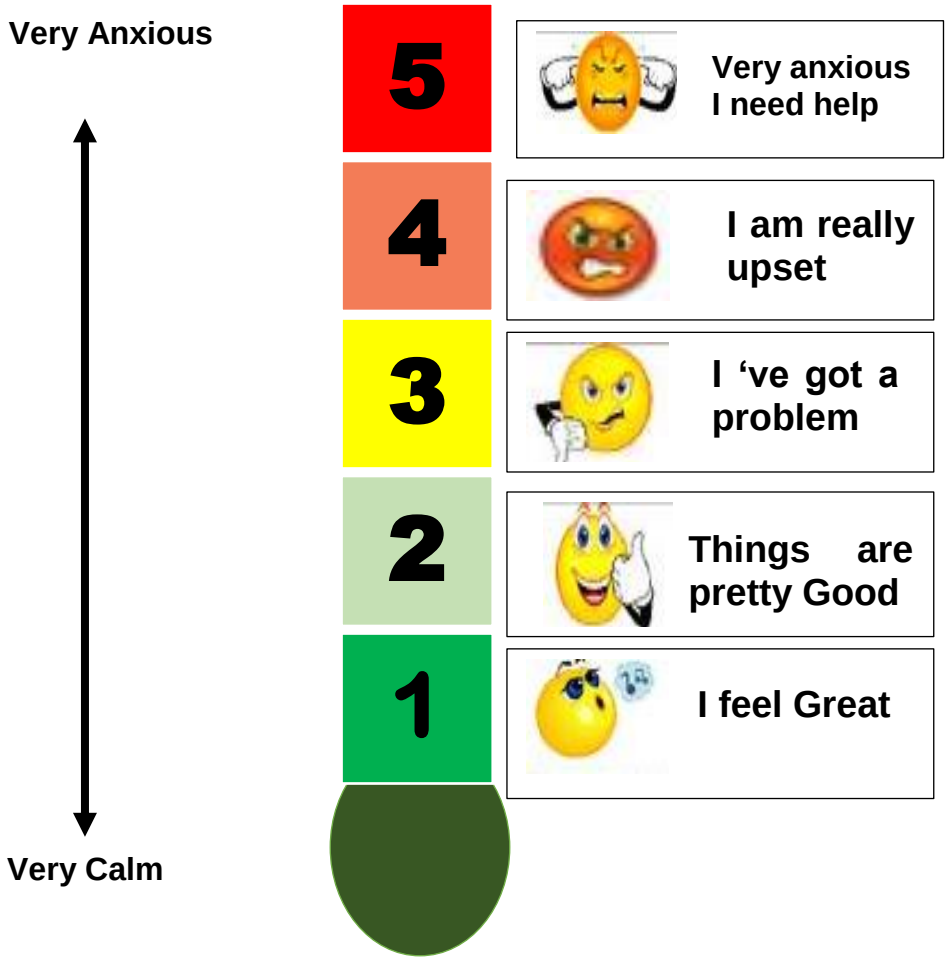
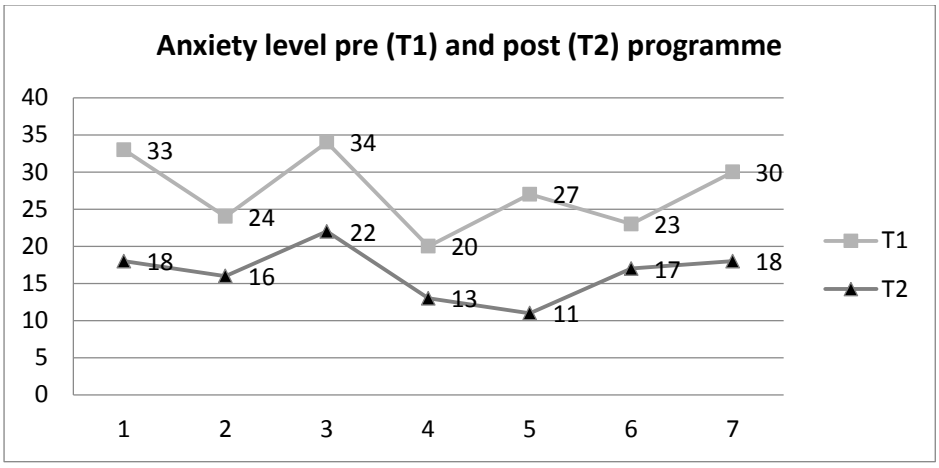


Figure 4 children's anxiety scores pre and post programme



NB:

T1= time one pre-intervention and T2 = time 2 post- t intervention