

A training and support programme for caregivers of children with disabilities: an exploratory study

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Abstract

Our aim was to conduct an exploratory evaluation of an intervention designed to equip caregivers with simple massage skills that they could use with their children in the home. The sample comprised 82 parents and 82 children with disabilities. Data were collected by self-administered questionnaires at two points in time: baseline, and immediately post-programme (after 8 weeks). Qualitative data were collected through Home Record Sheets and Monitoring Forms completed by caregivers and therapists, respectively. Results revealed statistically significant improvements in caregivers' self-efficacy in their ability to conduct massage, in managing children's psychosocial wellbeing and in levels of anxious mood. Caregiver reports of children's sleeping patterns and eating showed significant improvements. Qualitative data confirmed that caregivers believed that children's sleep patterns improved and also suggested improvements in children's bowel movements, awareness of their bodies, movement, and communication; factors that could be included in future evaluation.

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1. Introduction

This paper describes an exploratory study of a training and support programme (TSP) for carers of children with disabilities. The rationale for developing the TSP arose from our experiences of working with carers of children with disabilities, the growing body of evidence showing that carers can be at risk of psychological distress, their perception that they lack sufficient skills to contribute to their child's care, and theories of stress, coping and self-efficacy.

1.1. Carers' well-being

Parents of children with disabilities assume the primary burden of care, balancing time-consuming and complex treatment regimes with other aspects of family life and work commitments. The greatest burden of care typically falls upon mothers [1,2], who are at greater risk of psychosocial distress compared with mothers of children without a disability [1]. Mothers of children with disabilities have higher levels of depression and anxiety compared with mothers of children of typical development [3]. Parents of children

with multiple disabilities have been shown to report higher levels of stress relating to their children [4] compared with parents of children without disabilities [5]. Furthermore, whilst divorce rates for couples caring for children with a disability are similar to national norms, marital conflict and dissatisfaction are more common [6].

In relation to a child's disability, parents report many sources of stress leading to anger, frustration and a sense of isolation. For example, [7] found that dealing with health professionals was a source of stress for parents of children with disabilities. Similarly, [8] report that delay in obtaining treatment, lack of information and lack of opportunity to discuss their child's condition were stressors experienced by parents of children with juvenile idiopathic arthritis (JIA). Moreover, parents felt a constant need to vigilantly monitor their child's health status for changes in symptoms or side effects of treatments. A discrepancy between health professionals' perspectives and parents' perspectives was identified, which left parents feeling confused and believing they were 'being kept in the dark'. Support for these qualitative findings was provided by a study of families attending outpatient clinics at a regional hospital [9]. Mothers of children with JIA exhibited poorer physical function, poorer general health perceptions, and greater anxious and depressed moods when compared to UK normative data.

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Given the range of health and social care professionals that can be involved in the care of children with disabilities, parents can begin to doubt their own ability to develop caring skills. Following a study of 365 mothers, [10] concluded that the distress experienced by mothers of children with disabilities could be reduced by interventions promoting skill-building and emotional validation. This finding accords with theoretical models of stress, suggesting that cognitive appraisal and coping mechanisms may play a mediating role in the stress process. Support for the importance of improving parental coping ability is provided by [11] who found that self-mastery, self-esteem, and family network size were the main predictors of mothers' psychological wellbeing and marital adaptation. Furthermore, parenting self-efficacy has been found to be a significant predictor of maternal perceptions of child adjustment, e.g. [12] and self-efficacy for managing the child's condition has been shown to mediate the impact of children's ill health on maternal wellbeing [9].

The rationale for our study was that increasing caregivers' self-efficacy regarding the care of their child, regardless of the child's disability, might improve caregiver psychological well-being. The method used to enhance self-efficacy concerned training in the use of gentle massage. We believed that positive touch in the form of gentle massage would provide an appropriate skill for carers that would not be harmful to children and may even provide benefits.

1.2. Touch

Touch is the most common of our bodily senses [13], with massage being the most popular of touch therapies [14]. Research has shown the positive benefits of massage for babies and children, e.g. [13,15]. In a review of the literature, [16] concluded that both baby and parent benefited when parents were instructed in baby massage. Babies had improved sleep patterns whilst parents felt more confident in handling their babies.

A number of studies conducted at the Touch Research Institute (USA) have shown the benefits to recipients of using parents as therapists in providing massage to children with various health conditions, such as diabetes, asthma and arthritis [17], although the impact of giving massage on parental well-being was not studied. In addition, studies in this area have had small sample sizes, parents were used primarily to keep the cost of delivery low, and massage was provided in timed sequences over a specified period (e.g. 15 min of massage, three times a day for 30 days). Whilst confining the massage in this way allows consistency across participants, it is not realistic to expect all parents to continue with this regime in the home environment after the study.

A study by [18] compared the effects of two maternal interactions: infant massage and reading (control group) on hospitalised premature infants and their mothers. Not only did the massaged infants gain weight, the mothers who mas-

saged their babies reported a greater sense of well-being, increased self-esteem and showed an increase in positive perception of their babies. Similarly, [19] noted that when mothers were used as the therapists, the mothers' own levels of depressive symptoms decreased. The effects of giving versus receiving massage were examined in a study by [20]. Results showed that giving massage had more positive effects than receiving massage. We hypothesized that these findings may generalize to caregivers of children with disabilities, who may benefit from massage training.

1.3. Purpose of our study

Our intervention was designed to provide training in simple massage combined with support for carers throughout the training and support programme. The purpose of this exploratory study was to determine whether the TSP was acceptable to caregivers, to document caregivers' progress through the programme, and to assess caregiver self-efficacy and psychological well-being before and after the TSP. We believe that this type of exploratory evaluation is important in order to determine whether an intervention is acceptable to target participants, and is likely to fulfil its aims (i.e. increase self-efficacy and reduce psychological distress). We acknowledge that randomised, controlled trials will be needed to confirm whether any changes are due to the intervention. The term 'caregiver' is used to refer to the main carers (e.g. mother, father, grandparent).

2. Method

2.1. Sample

Ninety-nine caregivers were recruited from a range of sources including the local media, Sense (West), Lincoln District Health Authority, South-Warwickshire Combined Care, The Dyspraxia Foundation, The Muscular Dystrophy Campaign, Blackpool Borough Council Social Services Department, Essex Social Services Department and a local Child Development Centre. Study entry criteria were:

- Child with a disability or health impairment aged up to 16-years of age.
- Parent or main carer able to attend eight sessions with the child.

The study ethos was one of inclusion rather than exclusion. Thus, children with a range of disabilities ranging from mild colic to life threatening conditions and rare syndromes were included. Support for a non-categorical approach is provided by studies showing that there are more pronounced differences within rather than between disease categories [21]. Seventeen caregivers failed to complete the 8-week follow-up. Comparisons between these non-responders and those who completed all measurements were conducted and are reported in Section 3.

Eighty-two (70 mothers, 9 fathers, 3 grandmothers) and 82 children (50 male and 32 female) completed the study.

2.2. Method

2.2.1. The training and support programme (TSP)

The TSP was designed for caregivers of children with disabilities regardless of the type of disability. The purpose of the TSP is to provide caregivers with basic massage skills that they can use in the care of their children in the home environment. Caregivers are trained by qualified, therapeutic massage therapists. The TSP comprises 8-weekly sessions, each lasting 1 h. The first session includes a consultation between caregiver and therapist to ascertain the child's case history, caregiver concerns and expectations of the TSP. An introduction to massage is provided. During sessions two to eight, one therapist works with one caregiver: child dyad, training the caregiver in massage. The precise techniques used are tailored to meet the specific needs of each child and caregiver and the same therapist works with the same caregiver: child dyad throughout the 8-week programme providing continuity of training and support. Thus, the TSP offers 8 h of contact time with a therapist during which caregivers can discuss their concerns. In addition, each caregiver receives a Training Pack that includes an introduction to the TSP, a list of contra-indications, instructions on touch therapy techniques to accompany the sessions, diagrams, and, photographs of parents using touch therapy on their children to illustrate specific movements. All therapists use the same lubricant (Sweet Almond Oil) during the TSP and caregivers are provided with a 50 ml bottle of this lubricant in the Training Pack.

Fifteen therapists were recruited and trained in the delivery of the TSP and study requirements.

2.2.2. Study design

The study was a pre-test, post-test design with data collected by self-administered questionnaires mailed to caregivers at two points in time: baseline (immediately before the TSP), immediately after the TSP (after 8 weeks).

2.2.3. Measures

Caregiver and child demographics (e.g. age, sex and each child's diagnosis) were collected at baseline only.

A visual analogue scale (VAS) was used to measure caregivers' perceived *Health Status* using a 10 cm horizontal line, anchored 0 (Poor) to 10 (Perfect) health.

Parents' psychological wellbeing was measured using the Hospital Anxiety and Depression Scale (HADS) developed by [22]. The HADS has 14 items (seven for anxiety and seven for depression), is quick and easy to complete and has established reliability and validity [23]. The HADS was designed to detect the presence and severity of relatively mild degrees of mood disorder in non-psychiatric, hospital outpatients. Scores range from 0 to 21, with higher scores indicating greater anxiety and greater depression.

The Psychosocial Subscale of the *Parent's Self-Efficacy Scale* (PSES) was used to assess caregiver's confidence in their ability to manage their children's psychosocial wellbeing. The PSES was adapted from the Parent's Arthritis Self-Efficacy Scale [24] designed for parents of children with JIA. The PSES consists of seven statements each rated on a scale anchored 'very uncertain' (1) to 'very certain' (7). Statements included: 'How certain are you that you can do something to help your child feel better when his/her condition makes him/her feel sad?' Item scores are summed to give a total score (range 7–49).

One item was used to assess caregivers' self-efficacy in their ability to carry out massage. Using the same format as the PSES, scores range from 1 to 7.

Based on an earlier pilot study [25], caregivers' perceptions of their child's difficulty in *Sleeping, Eating* and *Mobility* were each assessed using a VAS anchored 0 (No difficulty) to 10 (Great deal of difficulty), respectively.

Parents were asked about their aims regarding the TSP and their satisfaction with the therapist's instruction, the TSP and the accompanying Training Pack. Satisfaction with therapists was measured using a VAS anchored 0 (very dissatisfied) to 10 (very satisfied).

Caregivers completed Home Record Sheets after sessions two through to eight, recording their progress throughout the TSP and the number of times massage was conducted at home during the week following each session. From sessions two to eight, each therapist completed Monitoring Forms to record the progress of each caregiver: child dyad.

2.2.4. Analysis

Quantitative data were analysed using the Statistics Package for Social Scientists [26]. Baseline characteristics were examined to determine differences between responders and non-responders at 8-week follow-up using Fisher's exact, Pearson's chi-square and Mann–Whitney tests as appropriate. Given the exploratory nature of the study a significance level of 5% was used. Mean values on study variables were compared using paired *t*-tests. Qualitative data (i.e. open questions on the questionnaire, Home Record Sheets and Observation Forms) were analysed using standard content analysis and help to illustrate the process of the TSP.

3. Results

3.1. Caregivers' characteristics

The majority of caregivers were mothers (85%) who were married or living with a partner (87%), White European (91%), had educational qualifications (91%) and a mean age of 37 years (S.D. 7, range 23–65). Twenty-seven (33%) caregivers reported health problems including congenital heart condition, myxadaema, high blood pressure, back-problems, renal problems, epilepsy, diabetes, myotonic

Table 1
Means values (standard deviation) on study variables

	Immediately pre-programme	Immediately post-programme	<i>P</i> value for <i>t</i> -test
Carer self-efficacy (PSES) (range 7–49) ↑ = better	34.15 (8.78)	37.71 (8.65)	0.002
Carer self-efficacy for giving massage (range 1–7) ↑ = better	5.48 (1.63)	6.10 (1.37)	0.009
Anxiety (range 0–21) ↑ = worse	9.05 (4.06)	8.09 (4.32)	0.045
Depression (range 0–21) ↑ = worse	6.86 (4.25)	6.18 (4.39)	0.210
Carer's perception of children's sleeping (range 0–10) ↑ = worse	4.23 (2.97)	3.33 (2.70)	0.003
Carer's perception of children's eating (range 0–10) ↑ = worse	4.28 (3.57)	3.30 (3.00)	0.006
Carer's perception of children's mobility (range 0–10) ↑ = worse	5.76 (3.98)	5.36 (3.54)	0.133

dystrophy, eczema, asthma, psoriatic arthritis, sensory impairments and multiple sclerosis.

Thirty-eight caregivers were either working full or part-time, 12 caregivers were unemployed and 12 caregivers remained at home, 2 caregivers undertook voluntary work, 13 caregivers were unable to work due to ill health, 4 caregivers were unable to work due to their children's ill-health, and 14 caregivers had reduced their working hours to care for their children at home. Mean scores of study variables are presented in Table 1.

There were no differences on study variables between responders and non-responders.

3.2. Children's characteristics

Children presented with a diverse range of disabilities. The primary medical diagnoses are presented in (Table 2). Thirty-two children had more than one diagnosis and one child's condition was undiagnosed. Children's mean age at diagnosis of the main disability was 1 year (range 0–10).

Table 2
Children's primary disability*

Disability	Number of children
Cerebral palsy	25
Autistic spectrum disorders (includes Rett syndrome)	14
Global developmental delay and learning difficulties	5
Epilepsy (includes West syndrome)	5
Muscular dystrophy	4
Dyslexia, dyspraxia	4
Chromosome abnormalities	3
Arthritis	3
Down's syndrome	5
Respiratory conditions (e.g. asthma, severe chronic lung disease, trachea-oesophageal fistula)	4
Other (e.g. Lissencephaly, Russell–Silver syndrome, hydrocephalus, Colic, achondroplasia, loose joints, strokes, visual impairment, brain damage)	9
No diagnosis	1
Total	82

* Multiple disabilities are not reflected in the table.

Children had a mean age of 6 years (range 0–16). Sixty-one (74%) children had siblings and 69 (84%) had not received any form of complementary therapy before the TSP. Complementary therapies received by the remaining children include Brainwave therapy, Conductive education, Music therapy, Cranial osteopathy, Bowen, Homeopathy, Reiki, basic meditation and Aromatherapy.

3.3. Comparisons over time

Comparisons of study variables over time showed significant improvements in parental self-efficacy for giving children massage ($P = 0.009$) and self-efficacy for managing children's psychosocial well-being ($P = 0.002$) (see Figs. 1 and 2), and in caregiver perceptions of children's sleeping ($P = 0.003$) and eating ($P = 0.006$), and in caregiver's levels of anxiety ($P = 0.04$). The percentage of caregivers at risk of clinical anxiety and depressed mood (i.e. scores > 8) were 65 and 42% immediately pre-programme, compared with 57 and 35% post-programme, respectively.

3.4. Qualitative data

The Home Record Sheets and Monitoring Forms illustrated how children and parents progressed through the TSP. Some children were clearly wary in the first few sessions, demonstrating avoidance behaviour. It is likely that many children in our sample had experience of treatments that, to them, appeared painful and threatening. However, most children quickly became accustomed to the therapists, the clinic setting and the experience of receiving massage. Children appeared to enjoy massage, with some taking the initiative and requesting massage of their parents even where speech was limited (e.g. taking the bottle of oil to their parent). In this way, children without speech or language skills communicated their desire for positive touch.

3.5. Additional findings

In contrast to the generally relaxing effects reported by most parents, two parents found that their children became hyperactive following massage. One of these children had global developmental delay and was aged 16 years, and one child had autistic spectrum disorder and was aged 5 years.

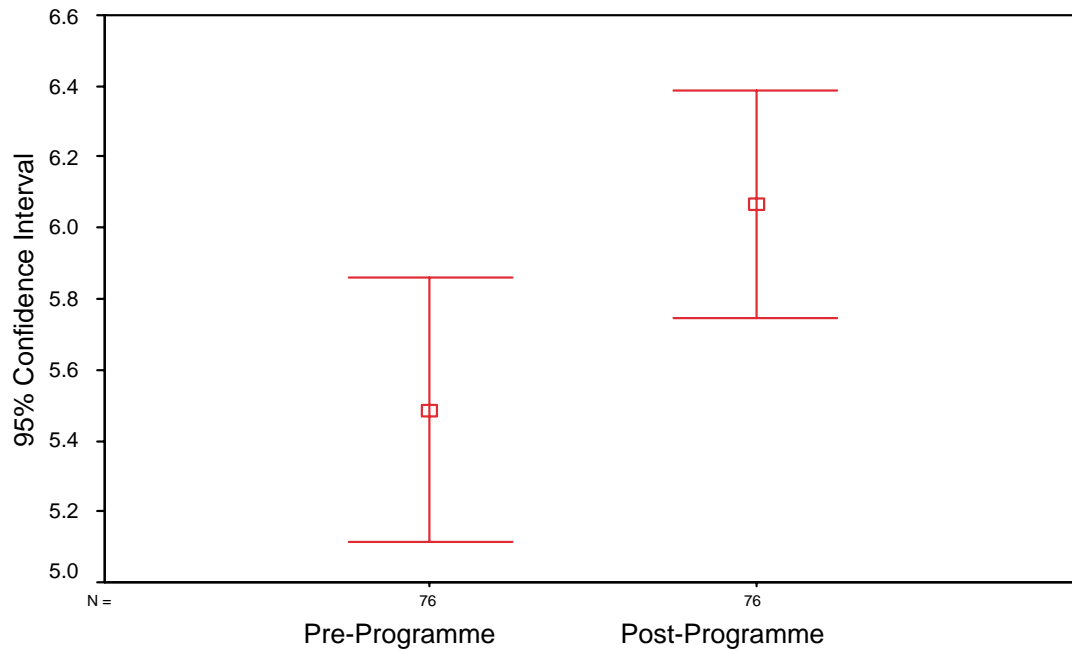


Fig. 1. Mean scores and 95% confidence intervals for parent's confidence in giving touch therapy across the programme. *Note:* Each bar represents 95% confidence interval.

Despite some initial scepticism, that the TSP was 'just another thing to try that would not do anything', the majority of participants found the TSP to be not only acceptable but also enjoyable. It provided them with 'quality time' with their children, moreover, this time was not spent in utilitarian tasks but rather in a pleasurable activity for both giver and recipient. One benefit reported by many parents concerned the relief from constipation that often resulted from the massage. Comments recorded on the Home Record Sheets include:

... what an enjoyable experience it has been for my son and me. Thank-you for giving us the opportunity to learn massage properly.

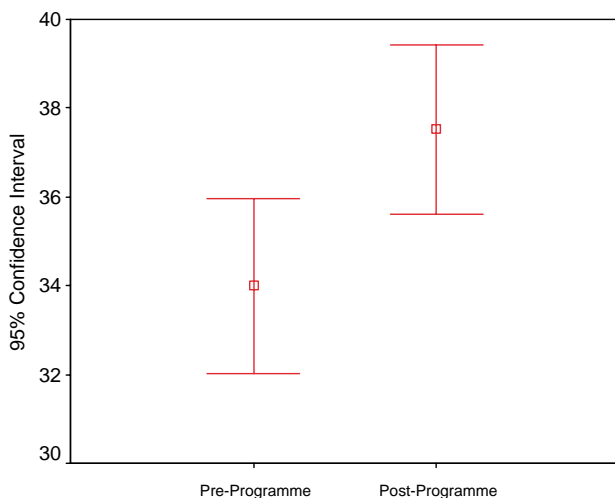


Fig. 2. Mean scores and 95% confidence intervals for parents' self-efficacy in managing children's psychosocial wellbeing, across the programme. *Note:* Each bar represents 95% confidence interval.

I found the fact that I was encouraged to take my son's twin along with us was nice, he often gets left out when his brother is receiving any form of treatment.

Caregivers were satisfied with therapists' instruction, the TSP, and the accompanying training pack. Caregivers found the diagrams a helpful reminder of the movements shown by therapists in the sessions.

4. Discussion and conclusion

Caregivers were caring for children with a diverse range of disabilities; some being relatively minor and short-lived (e.g. colic), whilst the majority appeared to be long-term and in some cases multiple, life threatening or adversely influencing the child's quality of life (e.g. cerebral palsy, muscular dystrophy, autism). The proportions of caregivers at risk of clinically anxious and depressive mood were higher than is typically found among healthy adults [22,27], but in accord with percentages at risk in adults with chronic disease, e.g. [28].

At the end of the TSP, caregivers felt more confident in their abilities to carry out massage and in managing children's psychosocial well-being. In addition, caregivers reported a significant improvement in levels of anxiety and, although not statistically significant, there was a trend towards improvement on depressed mood, with the proportion falling in the at-risk category showing a decrease.

The statistically, significant improvements in caregivers perception of children's sleeping patterns and eating ability were reflected in the qualitative findings suggesting that

children were sleeping and eating better, and were calmer and more relaxed. Interestingly, one child requested massage at home specifically to help him relax. Children also appeared to be more aware of their bodies and movement. The hyperactivity following massage reported by two caregivers may be due to the pressure and speed of massage movements that may have stimulated rather than relaxed these children. Further, caregivers' own stress levels may have been transmitted to the child during massage. The therapists providing the caregiver training, need to be alerted to the possibility of hyperactivity following massage, so that they can closely monitor caregiver technique and adjust where necessary.

4.1. Discussion

Further studies are needed to assess changes in children in a more systematic way. For example, many caregivers mentioned improvements in constipation, suggesting that this factor would be useful to include in an evaluation. Regardless of the nature of children's disabilities, relaxation emerged as a salient outcome for both giver and recipient. However, the immense diversity of children's disabilities requires some comment. Not all children had problems with mobility, sleeping or eating. Thus, there was a floor effect in operation in the assessment of these features making it more difficult for the study to detect change. This difficulty may be overcome by adopting a carer-generated approach to assessment. Each carer could be asked to identify key areas of children's functioning that they would like to see improve. Hence, children with primarily physical conditions may aim to improve mobility whereas those with behavioural disorders may choose to focus on communication, an area that appeared to improve for a number of families (as indicated on Home Record Sheets).

A number of caveats need mentioning. The study was exploratory, thus the next stage of testing will be a randomised, controlled trial to confirm that changes noted are due to the TSP. Longer-term assessments are needed to determine whether caregivers continue to use massage in the home environment and to determine whether improvements in self-efficacy and psychological well-being are maintained. Larger scale studies are needed to clarify the effects on caregiver psychological well-being. For example, the study may have lacked sufficient power to detect improvement on depressed mood. Alternatively, improvements on depressed mood may take longer than 8-weeks to manifest. Also, a wider range of measures could be used, such as indicators of communication between caregiver and child and caregiver stress. A strength of the study was the collection of data from different sources (i.e. caregivers and therapists) and the combination of both qualitative and quantitative measures. However, it should be noted that both caregivers and therapists' reports may be biased and thus more objective observations of progress through the TSP will be needed in future studies.

4.2. Practice implications

The TSP was designed to not only provide carers with a practical skill but also with appropriate support as they progressed through the training programme. It is likely that some carers will need some additional support after the end of the programme. In addition, continued practice of massage at home may be encouraged by a booster type of session. In order to address these needs, programmes such as the TSP, may need to provide follow-up sessions, telephone support or assist past participants in the development of their own carer support network. With this in mind, we have organised follow-up sessions for families in the form of Refresher Days, which offer past participants the opportunity to have a consultation with a therapist and to have a brief update of their massage skills. In addition, we give carers the opportunity to have a massage themselves, or try other therapies such as reflexology and relaxation.

One other issue for programmes of this nature concerns the importance of keeping the approach flexible so that it meets the wide range of needs of carers and children. For example, in our study two children responded to the massage sessions with hyperactivity rather than the more typical response of relaxation. The carers involved may need extra instruction or may need to attend relaxation sessions themselves before trying to give touch therapy to their children.

In conclusion, training caregivers in simple massage in a supportive environment appears to be worthy of further investigation. The current study has provided a firm foundation for further developing this approach in order to meet the needs of greater numbers of families living with disabilities, offering a simple technique that can be used in the home environment.

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