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ENHANCE

ENHANCE: Enhancing resilience and self-efficacy in the parents of children with disabilities and complex health needs.

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As Principal Investigator on this project I feel that I cannot allow this long list of acknowledgements to be signed off without due recognition of the professionalism and dedication to the cause of my two colleagues, Avie Nash and Sheila Roberts who have undertaken much of the 'hard graft' that an undertaking such as this requires. We are, all three, the richer (and the wiser) for working together on this study.

Mark Whiting (Principal Investigator), WellChild Professor of Community Children's Nursing.

*Where the term 'Core University Research Team' is used within this report this is a reference to staff of the University of Hertfordshire, specifically Mark Whiting, Avie Nash, Sheila Roberts, Mary Donnelly and Sally Kendall.

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Executive summary

Previous research has found that families often experience physical, social and emotional stress in the context of living with and caring for their disabled child. The literature indicates that a key factor in determining how well the parents of these children cope with their situation maybe how resilient and self-efficacious they are. This study focussed upon the development of resilience and self-efficacy in parents of children with disabilities and complex health needs. Resilience is a complex phenomenon which refers to the ability of an individual to withstand and bounce back following exposure to stressful, adverse or difficult conditions or circumstances. Parenting self-efficacy is broadly defined as an individual's appraisal of his or her competence as a parent.

ENHANCE is a novel intervention that was specifically developed for use with a population of parents of children with disabilities and complex health needs. 15 parents (the child's main care giver) were engaged in a series of guided conversations delivered during six contact visits with Nurse Co-Researchers (Community Children's Nurses who had received an intensive three day preparation programme). The conversations, which were supported with additional material that was designed specifically for use in the study, were based around four key themes: emotional coping, practical coping, support networks and 'you and your child'.

The impact of the intervention was evaluated using both qualitative and quantitative measures. In qualitative interviews that were undertaken two weeks after the completing the ENHANCE programme, parents reported increased self-belief and self-confidence and indicated that they felt better supported and stronger as a result of the intervention. This was consistent with the quantitative evaluation which identified significant improvements on scores for active coping and self-blame on the brief COPE inventory scale and for empathy and understanding and self-acceptance on the TOPSE scale. Scores on the self-report Distress Thermometer demonstrated a significant reduction in self-reported distress scores at the end of the intervention period. Although ten parents reported that they felt more resilient as a result of the intervention, this was not mirrored in the scores recorded by parents on a novel 'Resilience Thermometer' which was introduced in this study. Both parents and Nurse Co-Researchers evaluated the intervention itself in strong positive terms. The Nurse Co-Researchers reported increased job satisfaction, related specifically to the amount of time that they were able to spend with the parents.

The study findings indicated that further research related to the potential to enhance resilience in this population through an intervention-based approach would be of value. It is proposed that the ENHANCE intervention might be subjected to further testing to incorporate:

- a larger sample size to support a more robust statistical analysis;
- the collection of more detailed biographical data related to the timeline for the emergence of the child's disability or complex health need in order to determine whether it is possible to correlate this with parental resilience;
- possible identification of an earlier point within that timeline for entry to the study;
- establishment of an additional data capture point, perhaps six months post intervention;
- refinement and re-testing of the 'Resilience Thermometer';
- examination of how resilience and self-efficacy might be related to health-seeking behaviours and
- detailed examination of the economic viability of the intervention in respect of the costs of delivery of the programme compared with potential savings in terms of health services expenditure arising as a result of enhanced parental resilience.

Background to the project

Introduction

ENHANCE is a study which is concerned with the development of resilience and self-efficacy in the parents of children with disabilities and complex health needs.

In 2007, a report issued jointly by Her Majesty's Treasury and the Department for Education and Skills advised:

"The 570,000 children in England, around 100,000 of whom have complex care needs, need support from a wide range of services." (Page 11)

This statement both acknowledges the extent of the population to whom this study relates and highlights the challenge that is to be addressed in order to ensure that families are fully supported by a range of services, including statutory health, education and social care services in providing the best possible care to their children.

Previous research has revealed that families experience physical, social and emotional stress in coping with day-to-day living with their disabled child. In addition, it has been shown that the need to provide additional care for children with disabilities or complex health needs impacts significantly on quality of life for members of the child's immediate family, with the potential to affect social engagement, employment, income and family finances, uptake and utilisation of health and social care services and the mental and physical health of family members (Contact-a-Family, 2004a, 2004b; Hewitt- Taylor, 2007a, 2007b; Whiting, 2009, 2013). Studies undertaken by Kirk and Glendinning (1999), MENCAP (2003, 2006) and Contact-a-Family (2004a) have all reported how the presence of a disabled child within a family can be a significant contributory factor in marital breakdown.

A key factor in determining how well parents of children with disabilities and complex health needs cope with their situation is how **resilient** they are. Previous research by the study's Principal Investigator (PI) revealed considerable variability in the nature of resilience as described by the parents a number of whom discussed various aspects of resilience in both positive and negative terms. For example, for some, the experience of parenting a child with disabilities or complex health needs reinforced or strengthened their resilience, but for others the situation made them less resilient. Parents identified changes in both their own resilience-related behaviours and attitudes arising as a result of their experiences (Whiting 2009, 2017).

Resilience

What then is resilience? It is important to recognise that resilience is not simply about coping on a day-to-day basis. Reference to the literature on resilience suggests that there is no single definition of resilience as a psychological construct. Resilience is variously described as the ability to cope "*adaptively with traumatic stressors*" (Schwarzer & Warner, 2013, p140), the "*ability to withstand and rebound*

from crisis and distress" (Heiman, 2002. p159), or to "*the protective factors and processes or mechanisms that contribute to a good outcome, despite experiences with stressors shown to carry significant risk for developing psychopathology*" (Hjemdal, Friborg & Stiles, 2012, p 176). However, all definitions include one common factor – exposure to stressful, adverse or difficult conditions or circumstances.

Carver (1998) describes how individuals may benefit from exposure to adversity:

- adaptation and recovery to the previous level of functioning (homeostasis) and with subsequent crises producing a lesser effect,
- adaptation and 'bouncing back' where the extent of the effect remains the same but recovery is quicker

Carver goes further to say that, for some individuals, exposure to crisis can go beyond resilience and lead to 'thriving' or moving to a higher level of functioning.

At one time resilience (or rather, resiliency) was regarded solely as a personality trait which, from a psychological perspective, would be regarded as fairly fixed and immune to change (Luthar, Cicchetti and Becker, 2000). However, there is now a wider recognition of resilience as a state or process (in addition to being a trait), and in terms of this study, this offers potential for the development of interventions or strategies designed to improve or ENHANCE it.

A 'keyworker' relationship?

For the parents of children with disabilities and complex health needs, previous research undertaken by the study's Principal Investigator (Whiting, 2009), suggests that the establishment of a relationship between parent and professional is an important factor in helping to build parental **resilience**. In that study the parents of 34 children identified how, as a consequence of their engagement with individual professional staff (predominantly health care professionals, but also staff from both education and social care), they felt that they were better able to deal with their situation. In particular, a number of factors, either attributes of the individual professional or features of the relationships, were regarded positively by parents. These included:

- The personal attributes of the professional:
 - Believing and valuing of parental 'instinct'
 - Responding positively to parental need
 - Being prepared to 'go the extra mile' or 'work beyond the job description'
 - Providing emotional/psychological support
 - Ability to provide practical problem solving
 - Being knowledgeable about the child's condition and needs.
- Features of the relationship
 - Longevity of engagement between parent and professional
 - Availability of 'out-of-hours' contact (not necessarily being available for face-to-face contact, but being 'on the end of a mobile phone')

In light of these findings, the current study has recognised the importance of the development of relationships between health professionals (community based children's nurses) and parents as a key feature of the intervention upon which the study is focussed. Such relationships may be considered as key working, which has been widely identified as a feature of relationships between professionals and the parents of children with disabilities and complex health needs (Sloper et al, 2006; Hewitt-Taylor, 2007b)

Family Nurse Partnership

In developing the initial proposal for this study, during 2013/14, consideration was given to the possible application of learning from the approach taken within the Family Nurse Partnership (FNP), a programme whose central feature is a relationship-based intervention that takes a positive approach to behaviour change. An outline of the Family Nurse Partnership is set out in Figure 1, and further consideration of how this approach was related within this study is provided later on in the report.

Aim of the study

The principal aim of this study was to develop, pilot and evaluate an intervention delivered by a keyworker to support the development of resilience and self-efficacy in parents of children with disabilities or complex health needs.

Family Nurse Partnership

The Family Nurse Partnership approach was originally developed in the United States of America in the 1970s by Professor David Olds and colleagues under the title 'Nurse-Family Partnership'. This approach to care focussed on first time mothers under 19 years of age, targeting single parents in challenging social circumstances, specifically those who were identified as having low socio-economic status. The programme has developed significantly during the course of the last thirty five years and has been subject to ongoing evaluation including a number of randomised controlled trials (Olds et al 1986, 2004, 2010, 2013). The Department of Health (England) described the programme in the following terms:

"A strong and rigorous US evidence base, developed over 30 years, has shown FNP benefits the most needy young families in the short, medium and long term across a wide range of outcomes helping improve social mobility and break the cycle of inter-generational disadvantage and poverty." (Department of Health, 2012)

The Family Nurse Partnership (FNP) programme was granted a licence to be introduced in England in 2006. It is based upon a schedule of structured home visits delivered to first time mothers who are under the age of 19 years at conception and aims to recruit mothers before the 28th week of pregnancy. Each mother enrolled to the programme is linked to a small team of Family Nurses, with an identified member of the team establishing a programme of weekly, fortnightly and monthly contact visits of between one and one and a half hours duration (up to 64 visits in total for each mother up to the child's second birthday). Each visit is supported by detailed guidelines which have been designed around the challenges which parents are likely to face during pregnancy and the first two years of the child's life. Although the programme itself is highly structured, nurses are able to use their professional judgement to address with each mother those areas where they consider needs to be greatest. The development of a 'therapeutic relationship' between the nurse and client is a key element of the FNP approach, which is intended to build upon the "clients' skills, confidence and hope" (Ball et al. 2012).

Initial evaluation of the FNP programme in England was largely positive:

"Early evaluation looks promising and the Government has used the findings from the evaluation by Birkbeck to lead the expansion of FNP in England with a commitment to double the number of places to 13,000 by April 2015. We are well on our way to achieving this with 9,100 places at April 2012 and an FNP presence in 80 local authority areas across England." (Ball et al, 2012)

However, in October 2015, Robling et al published the findings of a large multi-centre Department of Health funded randomised controlled trial of Family Nurse Partnership programmes across 18 sites in England. A total of 1645 women were enrolled in the study which compared the Family Nurse Partnership model with a 'usual care' model of publically funded health and social care. The study focused upon short term outcomes including smoking during late pregnancy, mean birthweight of child, second pregnancy up to the child's second birthday, and attendance of the child at emergency department or admission to hospital before the child's second birthday. The study concluded:

"Continued provision of the Family Nurse Partnership programme cannot be supported on the basis of the trial evidence found for its effectiveness in the UK setting." (Roblings et al. 2016 – published 'on-line' October 2015).

Figure 1: Family Nurse Partnership – brief historical overview.

Development of the intervention

Understanding what needed to be included in an intervention to enhance resilience required an examination of the attributes of resilience, the nature of self-efficacy (a key attribute) and a further, more practical, exploration of how the Family Nurse Partnership programme works.

Attributes of resilience

Researchers have sought to understand what factors contribute to resilience in an individual and have identified a number of attributes. Some of these are individual characteristics or traits, for example having an optimistic outlook, other attributes include coping skills, ways of thinking, humour, physical and mental health, educational factors and intelligence (including emotional intelligence), social competence, problem solving abilities and cultural factors. Self-esteem (Condy, 2006) and self-efficacy (Rutter, 1987; Schwarzer & Warner, 2013), have also been noted as contributing to resilience. Hermann et al. (2011) argue that biological factors, such as genetics and epigenetics may have a role to play. External factors such as social support, family and friendship relationships, financial security have also been identified as contributing to individual resilience. See also the work of; Walsh, 1996; Daniel and Wassell, 2005; Kumpfer, 2009.

In terms of this particular study, a review by Peer & Hillman (2014) identified three key contributors that mediated stress and promoted parental resilience when caring for a child with a disability or complex health needs (coping style, optimism and social support) and these are outlined below.

- Both problem-focused/problem solving and emotional **coping styles** were given consideration, with research suggesting that the problem solving coping style was more likely to be helpful in alleviating worry and stress. (Folkman et al., 1986) Nonetheless neither coping style was considered to be wrong as context is important and emotional coping may be more appropriate in some circumstances. However, avoiding thinking about the situation as an emotional coping style was, understandably, not recommended.
- The trait of **optimism** and a positive outlook are, not unsurprisingly, attributes of resilience: maintaining a positive, hopeful attitude even in difficult circumstances can protect against stress. Peer & Hillman (2014), summarising research by Kayfetz et al (2010) suggest that it may help “*parents to pay less attention to the child’s limitations and, in turn, potentially pay less attention to their limitations as parents, which offers protection against a negative sense of well-being.*” (p 95). Peer and Hillman (2014) take this further by arguing that a positive outlook helps parents to “*maintain and restore resources necessary to effectively manage the stress associated with their child*” (p95).

- Formal and informal **social support** appear to be a key features of resilience in this group of parents providing them with assistance, emotional and physical support, a link to the outside world, and some stability in difficult circumstances. This can be informally through both family and friends on the one hand and more formally through professional support on the other. (Heiman, 2002; Freedman, Litchfield and Warfield, 1995)

As mentioned earlier, one factor that appears to contribute to resilience is **self-efficacy**. This can be defined as the “belief in being able to control and shape one’s personal future and attain desired outcomes due to one’s own actions and decisions” (Bandura, 1997) or, put more simply, it is the belief in oneself to be able to cope with everyday life and achieve what is necessary or desired. In terms of parenting self-efficacy, this is broadly defined as an individual’s appraisal of his or her competence at parenting (Kendall and Bloomfield 2005), which includes the elements of self-esteem and self-confidence and has been shown to be closely correlated with parenting stress (Bloomfield and Kendall, 2012; Kendall et al., 2013).

People are motivated to attempt behaviour that they feel confident in performing. Those with high self-efficacy who believe they can perform well are more likely to view difficult tasks as something to be mastered rather than to be avoided. People with a strong sense of self-efficacy view problems as challenges to be overcome and they recover quickly from setbacks, while people with a weaker sense of self-efficacy avoid challenging tasks believing them to be beyond their capabilities. Bandura identified four major sources of self-efficacy, the most important being performance mastery. Vicarious experience, social persuasion and emotional arousal are also sources of self-efficacy expectations (Bandura, 1997).

The Family Nurse Partnership approach and this study

In order to gain insight into how the FNP approach might be applied within the study, contact was made (by the study PI) with the FNP Team based within Stevenage, Hertfordshire. The Family Nurse Partnership Supervisor was keen to support the proposed study (and, in time, became a member of the Study Steering Committee). As a result of this, members of the University research team were supported in attending two local FNP monthly meetings and accompanying the nurses, in an observational capacity, and with the verbal approval of clients, on scheduled visits. This allowed the research team to establish a more in-depth understanding of the process of FNP way of working. It is important to note that as the Family Nurse Partnership Approach is itself a licensed product no programme-specific materials were shared with the University team. This study simply sought to apply learning from the Family Nurse Partnership way of working to a different population.

Drawing upon the experience of this ‘local’ perspective as well as published material from both the US and UK Family Nurse Partnership programmes, features of the

programme which were considered to be of relevance, and potentially transferable, to the proposed study were:

- The development of a 'key-worker' approach to establish a trusting and therapeutic relationship between nurse and client
- Recognition of potential vulnerability within the intended client group
- Establishment of a pre-determined overarching structure and content to the programme of visits undertaken by the nurse with opportunity taken to focus on specific areas of the client's life (agenda-matched to client's needs)
- A clear focus on scaffolding – providing support rather than direct instruction to enable self-development and a deeper level of learning - alongside the use of non-judgmental motivational interviewing techniques to facilitate and promote adaptive behaviour change.
- The use of clearly identified activity-based engagement strategies (non-FNP) with clients

Following extensive discussions around the literature review on resilience and self-efficacy, the findings from the FNP shadowing experience and an understanding of the needs of the Community Children's Nursing Services, the research team decided that the intervention would:

- Be centred around four themes which incorporate and support the development of the attributes of resilience (see below)
- Take a strengths-based approach using guided conversations
- Incorporate a tool-kit consisting of a number of practical exercises/activities and other resources such as signposts to additional resources for parents.
- Focus upon building self-esteem, self-efficacy and resilience
- Be delivered by Community Children's Nurses (CCNs) drawing upon elements of the key worker approach.
- Be supported with an intensive training programme for the CCNs facilitated and coordinated by the Core University Research Team (referred to hereafter as the Research Team)
- Be delivered within 6 contact visits, each of approximately thirty minutes duration delivered over a 10-12 week period with approximately two weeks in between contact visits.

Intervention themes

As already indicated, resilience is a concept with multiple attributes, including self-efficacy. Figure 2 below provides a mind-map summarising those attributes which emerged from the literature as being particularly pertinent to this intervention. However, one item shown on the mind-map, humour, was omitted from the intervention as being inappropriate for these circumstances.

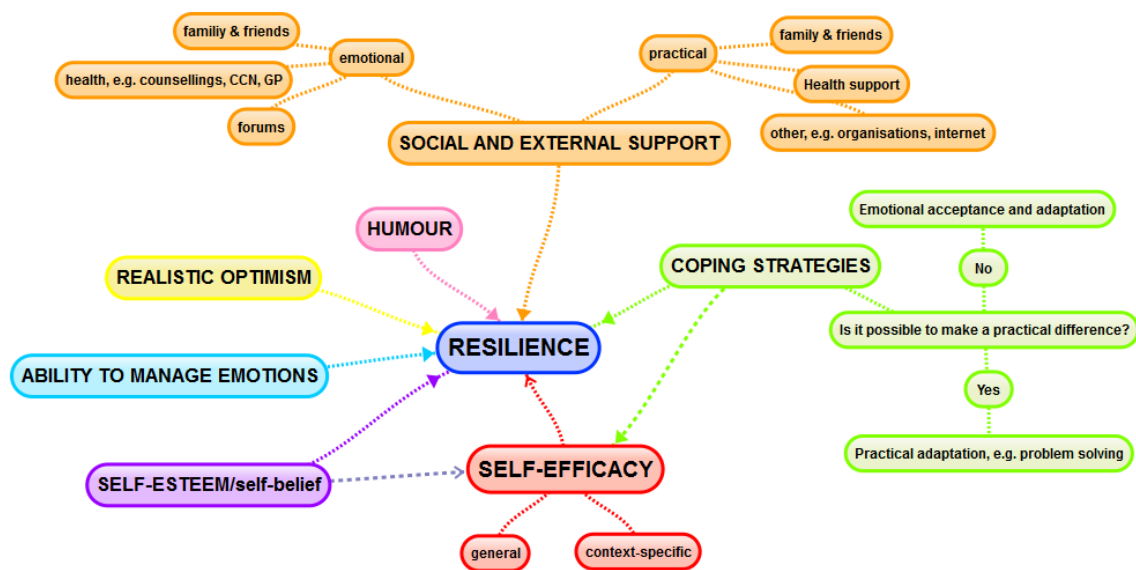


Figure 2: Resilience attributes (attributes indicated in capitals)

Based on these findings it was decided, that for the purposes of the intervention and for a coherent and simplified approach to enhancing resilience and self-efficacy, the attributes could be clustered into four main themes:

- **Emotional coping** – optimism/positive thinking, emotional coping strategies
- **Practical coping** – practical coping strategies
- **Support networks** – social support, both informal and formal, practical and emotional
- **You and your child** – self-esteem, self-efficacy, relationship with child

Mechanisms to support the development of self-efficacy and resilience

The Research Team developed a range of materials to support delivery of the intervention, the ENHANCE tool. This focused on mechanisms to support the development of self-efficacy and resilience. The mechanisms were initiated by the Nurse Co-Researchers using three to five prompt questions for each of the four themes which were then developed within the facilitated/guided conversations. For example, parents were asked to evaluate how strong they were feeling and what gave them that strength. This was intended to help them to establish ‘objectivity’ – to pause, step back and look at things differently and to think positively, and in so doing to learn and develop emotional coping skills (such as being kind to themselves). Figure 3 provides an illustrative example of the prompt questions for each of the themes. The complete set of questions can be found in Appendix 1.

EMOTIONAL COPING

Who or what gives you (emotional) strength?

- Are you kind to yourself?

PRACTICAL COPING

How are you coping on a practical basis – day-to-day?

- Are there any things you feel that could be better?
- And how do you think you might make them better? Is that something you feel comfortable doing?

SUPPORT NETWORKS

Who would you regard as your social support – family and friends - when you're caring for your child?

- Who can you call on for help?
- Who gives you strength, who tells you when you're doing well?
- Do you have people you can talk to?

YOU AND YOUR CHILD

How are you doing yourself – are you able to eat healthily, do you manage to make a bit of me-time? Really beneficial in counteracting stress.

- How could you do that?
- Do you manage to get any exercise?

Figure 3: Illustrative questions from each of the four resilience themes.

In addition, supplementary material to the above questions was developed. This included such things as resource sheets, or activities or exercises. These were intended to facilitate or clarify discussions, or to provide information and reference materials that the parents could draw on as a resource in the longer term.

Research approach

The development of the intervention and the pilot study was led and coordinated by a core team of research staff based at the University of Hertfordshire. The University team was supported by a Study Steering Committee and a Parent Reference Group. Three NHS Trusts in the CLAHRC East of England area were identified as potential study sites.

Study steering committee

The early stages of the research were supported by input from members of a Steering Committee whose members were appointed because of their particular expertise and knowledge. This included:

- Members of the Core University Research Team (Research Team)

- Clinical ‘experts’ working in the fields of child disability and complex needs, children’s palliative care and child bereavement
- The Supervisor of the local (Stevenage) Family Nurse Partnership
- A Parent Carer Representative
- Other ‘non-core’ members of staff from the University of Hertfordshire

During the course of the study the Steering Committee guided the progress of the research by participation in formal meetings, virtual meetings and by responding to specific requests for advice from the Research Team as the study progressed. A full list of members of the Study Steering Committee is included at Appendix 2.

Patient and Public Involvement/Parent Reference Group

In order to ensure the relevance of the proposed study to the families who were the intended subject focus for the research, it was recognised from the outset that the patient and public involvement approach within the study required a targeted approach which could draw upon the specific expertise of families with experience of caring for a child with disabilities and complex health needs. A pre-existing Parent Reference Group which had contributed to earlier work undertaken by the study PI was identified as being suitable for this purpose and members contacted to ascertain their willingness to be involved in this study. This group membership is drawn from two sources:

- Parents recruited through the PI’s previous work as an NHS Consultant Nurse in Hertfordshire including members of the Hertfordshire Parent Carer Involvement network (<http://www.hertsparentcarers.org.uk/>)
- Parents recruited through the parent network of WellChild – a national charity for children with disabilities and complex health needs (<https://www.wellchild.org.uk/supporting-you/connect-with-others/>).

Members of the Parent Reference Group were contacted by the Research Team on a number of occasions as the study progressed. They provided advice and comments by email and acted as a ‘testing ground’ particularly in relation to elements of the content of the study intervention tool-kit. They also provided comments on potential titles for the intervention.

One member of the Parent Reference Group was invited to become a Parent/Carer member the Study Steering Committee, and provided valuable advice to the Research Team both in formal and ‘virtual’ meetings and in providing commentary, guidance and robust challenge to the team as the study progressed.

The study sites

Senior Managers, with line management responsibility for Community Children’s Nursing Services, from NHS Trusts within the CLAHRC East of England area were approached to take part in the pilot study. Three potential sites were identified:

South Essex Partnership University NHS Foundation Trust, Cambridge Community Services NHS Trust, Hertfordshire Community NHS Trust.

The managers were invited to attend a meeting with the Research Team. The University Team proposed to the managers the possibility that members of their own CCN Service be recruited to the study as Nurse Co-Researchers (NC-Rs) who would be involved in both delivering the study intervention and also play an active role in shaping the intervention itself as the study progressed. During the course of the meeting the Managers raised concerns about the possible resource implications arising as a result of the study, specifically the time commitment of individual CCNs who would be delivering the research intervention. The intervention programme (details are set out below) was identified by managers as at the upper limit of the time commitment of staff that they would be prepared to support in terms of releasing those staff to deliver the study intervention.

The original intention of the study was to recruit two community children's nurses from each site and managers were asked to identify staff members whom they considered to be appropriately experienced to take on this role. Ultimately five nurses (three community children's nurses, 1 family support worker and 1 special school nurse) were nominated to become the Nurse Co-Researchers for the study. However one of the CCN nominees withdrew from the study at the end of the preparation programme for personal reasons.

Research design

The ENHANCE intervention was piloted in a study which took a mixed methods approach comprising:

- Quantitative measures of parents' resilience and self-efficacy completed by the parents pre- and post-intervention:
 - The Distress Thermometer (National Comprehensive Cancer Network, 2016)(Appendix 3)
 - A 'Resilience Thermometer' – an addition and adaptation to the Distress Thermometer (Appendix 4)
 - Tool to measure Parenting Self-Efficacy- (TOPSE) (based upon a scale developed and validated by Bloomfield and Kendall (2012)) (Appendix 5).
 - 'Brief COPE Scale' as developed and validated by Carver (1997) to measure parents' ability to adapt to and cope with their situation (Appendix 6).
- Qualitative measures
 - Mid-point (telephone) semi-structured interviews with the parent participant
 - Final, face-to-face, semi-structured interviews with the parent participant

- Post-intervention, face-to-face interviews with Nurse Co-Researchers

Action research

As the study was centred around a novel intervention and in order to facilitate active re-modelling of elements of the intervention whilst the study was in progress, an action research approach was incorporated into the study design. The term was first used by Lewin in 1944 (see Lewin, 1946) in describing the inclusion of longitudinal/cyclical processes within the design of a research study in order to support the 'organic' development of different aspects of the research whilst the study is in progress (O'Leary, 2004: Figure 4).

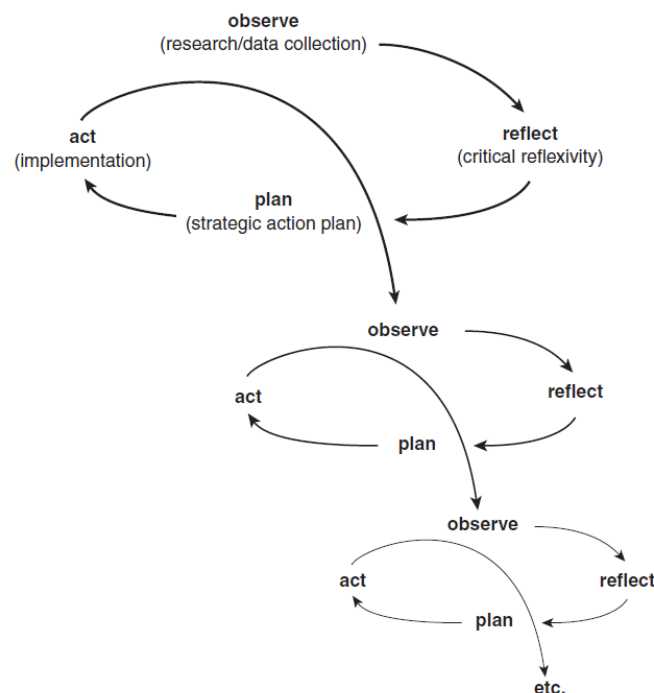


Figure 4: The Action Research Process (O'Leary, 2004)

Within this study, the action research element of the study design took the form of

- 2 x reflective focus group discussions with the NC-Rs facilitated by the Research Team
- Analysis of data derived from mid-point and final interviews with parent participants
- Analysis of data derived from the post-intervention interviews with the NC-Rs.

Nurse training programme

The Nurse Co-Researchers attended an intensive 3 day training programme at the University of Hertfordshire. The training was delivered by the Research Team with further specialist support provided by a Family Nurse Partnership Supervisor and a Clinical Psychologist, both of whom were members of the Study Steering Committee.

Figure 5 summarises the content of the training programme and a full copy of the programme is attached as Appendix 7.

- Understanding the aims of the programme,
- Definition of the main constructs, self-efficacy and resilience,
- Emotional coping, practical coping, support networks, you and your child.
- Advanced communications skills and engagement with parents,
- Motivational interviewing techniques (OARS),
- Scaffolding – avoidance of the ‘righting’ reflex.
- The Compassionate Mind approach to emotional strength,
- Bereavement/managing emotions,
- Practical coping and problem solving,
- An introduction to the ENHANCE intervention materials and how to use them,
- The evaluation tools and their use,
- Recruitment of parents and the process of taking informed consent,
- The Action Research Cycle process
- Your role as a Co-Researcher*

*The NC-Rs were also required to complete NIHR Good Clinical Practice (GCP) online training as part of their preparation programme.

Figure 5: Summary content of training programme

Ethical approval

The study was approved by the East of England – Cambridge and Hertfordshire NRES Committee (Ref: 15/EE/0129). Site specific approval was sought and received from Research Governance Departments at the three NHS Trusts sites. The two university-based researchers who undertook the telephone and face-to-face interviews completed GCP training and were issued with NHS Research passports by the Host NHS Trust (on behalf of each of the 3 NHS study sites). The Nurse Co-Researchers also completed GCP training prior to commencing the recruitment of parent participants to the study.

The following documents were included within and were approved as part of the NHS ethics application:

- Parent Participant Information Sheet (Appendix 8).
- Parent Participant Letter (Appendix 9).
- Parent Consent Form (Appendix 10).
- GP advisory letter (Appendix 11).
- Nurse Co-Researcher Consent Form (Appendix 12).
- Parent Interview Schedule – Mid-Point Interview (Appendix 13).
- Parent Interview Schedule – Final Interview (Appendix 14).
- Nurse Interview Schedule (Appendix 15).

ENHANCE materials/tool-kit

Each of the NC-Rs was provided with a folder/tool-kit to support their intervention visits. The folders contained a range of materials which covered both the ENHANCE intervention itself and the pilot study paperwork including:

- Parent participation letters, participant information sheets and parent consent forms (see Appendices 8, 9 and 10) – one set of this paperwork for each participant to be recruited to the study.
- Measurement tools: TOPSE, Distress Thermometer, Resilience Thermometer and Brief Cope Scale.
- Four sets of laminated cards (one for each theme) setting out a short series of prompts/questions (and materials to supplement specific questions)
- Practical exercises to facilitate guided conversations with parents
- Resource sheets/materials to be given to the parent participants – setting out details of national and ‘local’ support networks/contacts.

In addition each parent was provided with a folder which included some background information, a list of the four resilience themes which would form the basis for the intervention visits, a place to store the resource sheets they received during the programme and lined paper for their own notes for themselves or as reflections on the programme for feedback to the research team. A full list of the contents of the folders is included as Appendix 16

Recruitment of parent participants

The NC-Rs were familiarised with the study inclusion and exclusion criteria as set out in the Research Ethics Application (Figure 6). Opportunity was taken to explore with the NC-Rs the rationale behind the establishment of the criteria, including clarification of any outstanding queries raised by the NC-Rs and confirmation that any further advice on recruitment to the study could be obtained from members of the Core University Team if required.

- Participants will be recruited by community children's nurses based in three sites in the East of England.
- These will be the parents of children recently referred to the community children's nursing service
- Child will be under the age of 19 years
- Child will have a recognised disability or complex health need (including long term condition or life-limiting/life threatening illness)
- Child will remain under the care of the community children's nursing service for the duration of the study intervention.
- Because this is a pilot/exploratory study with limited resources, all elements of the study will be undertaken in English. It will therefore be necessary for participants to be able to both read (Consent form and Participant Information Sheet) and converse confidently (intervention and evaluation elements of the study) in English.
- Parents already in receipt of a programme of structured psychological support or therapy (such as formal counselling) or who are receiving ongoing support from a mental health professional may be excluded from the study if there is any possibility of a conflict between the proposed study intervention and that pre-existing support.

Figure 6: Inclusion and exclusion criteria for the ENHANCE Study.

Each NC-R was set a recruitment target of 5 participants to be recruited during a four month period. In total 16 parents were recruited as participants. They were all the main carers for their children and were, in this instance, all mothers. Two participants withdrew during the course of the study but both parents agreed that data collected up to the point of withdrawal could be included within the data analysis. In order to preserve the anonymity of both NC-Rs and parent participants within the study, alpha-numeric identifiers are used throughout the text below. The NC-Rs are identified by the letters A, B, C and D. Parent participants are identified by a two digit code consisting of the letter that corresponds to the NC-R who recruited the parent to the study and a randomly allocated single digit number (e.g. A3, D4 etc). Summary clinical details of the children whose parents were recruited to the study are set out in Table 1.

Child/ Parent Reference Code	Age	Gender	Clinical Detail
A1*	6 years	F	Mitochondrial disease with chronic pain disorder(withdrew from study part way through)
A2	10 months	F	Congenital cardiac disorders and tracheal stenosis
A3	14 months	F	Complex problems associated with premature birth
A4	11 years	M	Hydrocephalus and seizures
A5	6 years	F	Hirschsprungs disease, total parenteral nutrition
B1	6 years	M	Morphea skin disease, weekly injections
B2	2 years	F	Barter Syndrome
B3	15 years	M	Non-Hodgkins lymphoma
B4	5 years	M	Acute lymphoblastic leukaemia
C1*	4 years	M	Did not complete study – Child RIP (data from mid-point interview included within this report with parental permission)
C2	3.5 years	F	Autism
D1	No age recorded	M	Failure to thrive, naso-gastric feeding
D2	14 months	M	Beckwith-Wiedemann syndrome
D3	No age recorded	M	Premature, nasogastric feeding
D4	3.5 years	F	Hydrocephalus, septo-optic dysplasia
D5	15 months	M	Dravet syndrome and seizures

Table 1: Summary clinical details of children whose parents were recruited to the ENHANCE study (* = only partial data collected for study)

Study intervention timeline

Figure 7 provides a summary of the timeline that was followed for each parent recruited to the ENHANCE study. This is purely illustrative as while N-CRs were instructed to start with the ‘support networks’ question A1 (Who would you regard as your social support?) they were then advised that their conversations with each parent should be allowed to follow the most suitable path for that particular parent, with questions introduced in a natural and flowing manner (agenda-matching).

Parents were enrolled on the study for a period of approximately 15 weeks. A ‘pre-recruitment visit’ undertaken by the NC-R provided an opportunity to identify the parent as a potential recruit to the study. If parents responded positively to the suggestion of their possible enrolment in the study, they would be given a copy of the participant information leaflet, letter of introduction and consent form. Approximately 1 week later, the NC-R would make contact by telephone to ascertain whether the parent wished to participate in the study and, if the parent was agreeable, a first intervention visit would be scheduled. On this first visit parents were asked to provide formal written consent and were asked to complete the self-report tools detailed above. Subsequent intervention visits were undertaken at

approximately two weekly intervals for the next 10 weeks. A mid-point telephone interview was conducted by a member of the Research Team in between the 3rd and 4th intervention visits. At the final face-to-face interview with the researcher parents completed the post-intervention self-report tools. This was undertaken, where possible, within two weeks of the final intervention visit. Regular contact was maintained between the Research Team and the Nurse Co-Researchers throughout the intervention/data collection phase of the study. Some slight variations in the intervention timeline arose as a result of planned or unscheduled hospital visits/admissions for the children whose parents were enrolled on the study, family holidays (and NC-R holidays), but these resulted in only minor variations in the planned study timeline for each parent.

	Week 1	Week 3	Week 5	Week 7	Week 8	Week 9	Week 11	Week 13	Week 15
Visit/ Interview Schedule	Pre-recruitment visit	1 st Intervention Visit	2 nd Intervention Visit	3 rd Intervention Visit	Mid-point interview	4 th Intervention Visit	5 th Intervention Visit	6 th Intervention Visit & closure	Final interview
Content of contact/visit	NC-R provides parent with copy of Participant Information Sheet and Consent Form	NC-R provides parent secures written consent from parent. Parent completes pre-intervention Distress/Resilience Thermometer TOPSE and Brief Cope Scale			Semi – structured interview undertaken by University Researcher (telephone).				Semi-structured interview undertaken by University Researcher (face-to-face). Parent completes post-intervention Distress/Resilience Thermometer, TOPSE and Brief Cope Scale
Resilience Themes		Introduce 'Support Networks'	Continue 'Support Networks' Introduce 'Practical Coping'	Continue 'Support Networks' and 'Practical Coping' Introduce 'Emotional Coping'		Continue 'Practical Coping' and 'Emotional Coping' Introduce 'You and Your Child'	Continue 'Emotional Coping' and 'You and Your Child'	Closure of all 4 themes.	

Figure 7: Timeline for study intervention for individual parent participant (for illustrative purposes only).

Findings

The research took a mixed methods approach and the findings are reported in the following order:

- Qualitative data analysis approach
- Findings from the parent interviews
- Quantitative data analysis approach
- Findings from the parent quantitative data analysis
- Findings from Nurse Co-Researcher interviews

Qualitative data analysis approach

All recorded interviews were transcribed. Qualitative data analysis was undertaken using MAXQDA data analysis software. Analysis of both parent participant and nurse co-researcher interviews took a thematic approach with themes added as they emerged. Coding initially focused, on the questions within the four theme areas and practical aspects of the delivery of the intervention, e.g. Was the timing of delivery of the intervention appropriate? Were the themes correct? etc. However, the number of themes was expanded in order to incorporate other areas that arose in conversation. For example, parents were not explicitly questioned about their relationship with their NC-R, nonetheless this was a subject raised many times by parents and this resulted in the addition of two further themes: “valued conversations” and “developing relationships with the nurse”.

Findings from the parent interviews

Data from the parent mid-point and final interviews are combined within the discussion below.

Understanding parental experiences prior to ENHANCE

The children, their complex health needs and disabilities

As noted above, the Nurse Co-Researchers, who had been familiarised with the study inclusion and exclusion criteria during their training programme, were asked to identify children who were new or recent referrals to their services. In addition, the NC-Rs were asked specifically to identify parents or families of children with complex need and disabilities whom they considered had the potential to build their resilience in the context of the proposed intervention.

The clinical diagnosis and nursing care required by the children of the parents recruited to the study were very varied with many children having particularly complex needs. The majority of children were either diagnosed at birth or shortly afterwards, though for some, the complex health need only became apparent some

years later (see Table 1 for a summary of the medical conditions of the children within the study).

The complexity of the health needs of the children within the study was reflected in the length of time that a number of them had previously spent in hospital, with some requiring surgery: *“she went for the first stage of heart surgery”* (A2); *“... had to have four brain operations”* (A4); *“she was in theatre for six and half hours at three days old”* (A5) or admission for paediatric medical investigation and treatment. In some instances children spent many months in hospital before being well enough to be cared for at home: *“from about six months, more than six months she’s home”* (B2); *“from there we spent the next seven months in hospital”* (A5).

When providing information about their child’s condition many parents offered an insight into their own experiences, responsibilities and potential challenges to their own resilience in relation to caring for their child. Parents identified that they have had to learn how to care for or to ‘nurse’ their child: *“I’m like a nurse to her basically”* (A1); *“we ... have to keep an eye on [our child] for clinical signs that there may be a shunt issue”* (A4). In addition parents provided details of specific ‘clinical’ skills which they had been required to learn:

“we have to administer Methotrexate injections every week so we were trained with the nurse.” (B1).

“from the moment I get up I draw up medication, I become sterile(sic), I disconnect her line ...” (A5).

Parents expressed a sense of loss of ‘normality’ and this was a recurring theme. Parents recognise that their lives are different and that caring for children with complex health issues impacts on everyday life and activities for both the child and the family, including the study child’s siblings:

“before ... I could say ‘...would you mind coming and looking after the boys’ ... now we’re more restricted.” (D5) (with reference to the loss of spontaneity and the ability to go out with her husband).

“It was so hard practically getting her out of the house and doing stuff with her like a normal parent would do with a baby.” (A2).

“some days I don’t get out with her.” (A1).

“Last time we [the family] all went away he [the child] ended up in PICU.” (Paediatric Intensive Care Unit) (D5).

“I have to think about [sibling], it’s not just the sick one.” (B4).

One parent described the challenge for their child to see themselves as ‘normal’:

"I didn't want her isolated any more than she already is... ..we've had a few incidents with tears, you know and she says she doesn't want to be special anymore ...' I [the child] want to be normal'." (A5).

Being resilient is not easy when emotional turmoil, lack of emotional and physical support and lack of sleep are part of everyday life. Many children with complex health needs and disabilities require care throughout the 24 hour day:

"the sleep deprivation for me is just an absolute nightmare because I'm up constantly with [child]." (A1).

" ... constant emotional turmoil and lack of sleep and everything, how it can just really chip away at your resilience." (A4).

"I haven't slept properly for six years." (A5).

"yeah, I mean the emotional effect and everything else it can have on people is just ... it's horrific ... (D1).

Some of the parents reported that in coping with the realities of caring for a child with complex needs, they struggle to maintain their own relationships.

"Because with everything with [child], her dad and I broke up during that time" (A3).

"... because I had so much going on in the first year year 'cos [child] was diagnosed with leukaemia, me and [child's father] split up." (B4).

"...my now ex-partner ... me and my partner separated last year. The task of looking after her isn't now between two of us, I do all the work." (A5).

However, one parent was able to view her separation from her child's father in a positive light in that it enabled them both to have a break:

" ... he'll be here for the weekend and then he'll go back to his Dad's and we just take it in turns. Because, you know, obviously his Dad needs a break as well and so we try and do it so we're both around when we need to be but, you know, and it's worked well. It does work well." (B3).

Sense of being alone

When talking about their experience before the ENHANCE study, a number of parents referred to the additional caring responsibilities in terms of how it contributed to their sense of being alone. Problems of communicating with people who may not understand, a feeling of constant emotional turmoil, time spent away from home, in hospital and the relative rarity of the children's medical condition all seemed to add to this sense of isolation:

"I don't know anyone else that has it ..." (D5).

"It's like right, that's it (being discharged from hospital), you're on your own." (D1).

“You feel a little bit like you’re in a different world because I mean friends of mine have had babies and their lives were completely different.” (D2).

Family support

Alongside these comments about isolation and loneliness, the majority of participants identified family and friends as being important in their lives and the lives of their child. A number of the parents recognised the value of the support that family and friends were able to provide, however some of the parents reported that they discovered who their friends really were! Emotional support and practical support was important, although leaving their child with someone else, even family, caused anxiety to many parents:

“Family and friends can be there to talk to but they can’t look after... [child]” (A1).

“You’re thrown into this whole new world and you suddenly find out which of your friends and family are still, you know, there for you, they’re still comfortable, they’re comfortable with your new situation and which of your friends and family aren’t and , you know..., which can hurt ...” (A4).

“I have a very large family and they are all actively involved in [child’s] life.” (A5).

“I’ve got a lot of support i.e. family, friends, groups.” (D4).

“Well my mum comes up, she’s up a couple of days a week, but that’s it really in terms of family.” (C2).

“I’ve lived in this area most of my life so I’ve got a lot of circle of friends here, so I’ve got quite a good support network.” (D5).

Support networks

Additional support outside of family and close friends was viewed in a variety of ways. Some parents acknowledged that they struggled to leave their child with other people, even professionals, although they also noted that they needed a break and should accept help when it is offered:

“... as for respite and the hospice we don’t, I don’t tend to use them because I am, I don’t like leaving her with anyone ...” however this mother went on to say “I do need a break.” (A5).

“I like to keep myself to myself and to trust people is really difficult.” (D3).

Emotional support through talking to other families in the same situation as themselves was seen as being very valuable, this may be through support groups or social media. Having someone to talk to who potentially understand the circumstance that a family finds themselves in was recognised as being important:

“ ...my hospital mums they understand ...” (A1).

“ And like, with the support groups and stuff like that, a year on support groups, yeah they’re probably helpful to some people...” (B4).

One parent suggested that an online forum for parents on the ENHANCE programme could be useful for this purpose. The use of social media was identified as beneficial by some parents:

“I’m on a Facebook® [group], which is a special one for ... it’s only people with ALL (Acute Lymphoblastic Leukaemia) ... that’s quite good.” (B4).

“We use Facebook®, there’s lots of pages on there where you get a lot of, a lot of support and you can see what other ... everybody else is going through similar to what you’re going through and you can exchange ideas and things like that, it’s been brilliant.” (D1).

However the use of social media was not always seen in such a positive light:

“is it just something he’s gonna grow out of ... a bit wary about sort of stumbling across something that’s not, maybe someone else’s scare story might not be your story, so I’ve kept away from that sort of social media side of things.” (D5).

One parent who described herself as having a ‘big family’ indicated that as a result of this she felt that the focus in the study intervention on support networks was of less relevance to her situation.

The impacts and outcomes of ENHANCE

The overall reaction from parents to the ENHANCE programme was positive with comments including ‘good’, ‘useful’, ‘fantastic idea’, and ‘informative’. They welcomed the guidance and support provided by the NC-Rs and emphasised how *“beneficial it is for people to realise how strong they actually are”* (A3). Parents described how they felt that they should take on coping all by themselves and would be reluctant to ask for help, so a programme like ENHANCE where the support was offered was invaluable. One parent echoed a number of participants’ comments in suggesting: *“I think everybody should do it”* (D1).

Rapport with the Nurse Co-Researchers

One of the key findings within the analysis related to the rapport that developed and grew between the parent and the NC-R. This added to the potential impact of the intervention in that it made the experience enjoyable and was a factor in supporting the ‘scaffolding’ idea behind the ENHANCE programme. Indeed one parent laughed about the fact that she had a good relationship with the NC-R who *“asks me questions that she knows I don’t want to answer”* (A5). She acknowledged the questions were very productive for her as it helped her to address issues that she had been avoiding.

Parents described the NC-R as someone who is always very supportive, both of them and their child and someone who would see the child *“as an individual, not just as a child with special needs and that’s important”* (C2). At the same time they recognised and appreciated that the NC-Rs were there for them as well as for their children and indicated that without the ENHANCE programme there would have been far less focus on the parents themselves during the NC-R visits, simply due to time constraints.

“...a community nurse already comes ... they just do their job and just go.” (B2).

The individual NC-R’s approach and the manner of delivery was central to developing rapport with the parents, one of whom identified this as a particularly positive experience:

“It was very informal, and you know ... the nurse made you feel very at ease so you could easily open up. There was no pressure, it wasn’t formal .. it was quite a friendly atmosphere you know, ... the right length of time, wasn’t too intrusive, but it felt like, as well, that there was someone there to support you and you could speak to them.” (C2).

Parents identified a particular benefit of the new relationship with their NC-R, whom they considered had developed a greater awareness and understanding of the family situation - *“so with this programme they understand more about ... the family”* (B2). This was perceived as having a positive impact on how the NC-R might be able to address their needs and was echoed by many of the participants in the study. It was clearly important to them. This was very much a two-way process, with some parents indicating that they had learned more about both the NC-R’s role and that of the Community Children’s Nursing Team in general. One parent talked about the emotional impact of having a baby with additional needs and the importance of the relationships with the professionals who visited their child at home:

“it’s horrific and I don’t think people realise but I think you need those relationships with the people that come into your home ... To begin with, with (nurse co-researcher) we didn’t have that. I mean she was great but we just didn’t have that relationship and it’s only been because of this (the intervention) that we now have that relationship and I just think everybody should be able to benefit from it ...” (D1).

A number of parents talked about the need to off-load and valued the NC-R in this role in particular, especially as the nurse has a *‘medical’* background. This had particular added-value for the parents as the NC-Rs were considered to be outside of the family and peer group, and were perceived as non-judgemental.

“before I never used to have any support like that and you don’t always want to talk to family.” (A1).

"I can kind of talk about the stresses of that week and even if she can't advise me on anything, just the fact that I can sit and speak about it and not hold it all within myself and argue with myself what I should be doing and advice, and just to get it out and vent is really nice and that is lovely." (A5).

"I mean I don't need psychological help if you know what I mean, but just to have somebody to talk to I think makes all the difference." (D1).

"it's just another person to care really and also easy to talk to sometimes because they're not someone very close to you so it's just a stranger really coming in, you know, and you can sort of offload a little bit really which is lovely. So yeah, I think it's very valuable, yeah, it was a lovely experience and I'll miss her." (D2).

It is clearly evident from the analysis of the parental interviews that this aspect of the ENHANCE programme – the relationship with the NC-R - was greatly appreciated. As one participant observed:

"I think everybody should have the opportunity to have their nurse for half an hour/an hour to talk." (D1).

Becoming emotionally strong

Parents reported that the intervention visits had helped them to reflect on all that they had been through and that, as a result of this, they were able to feel pride that they had coped as well as they had. This, in turn, gave them emotional strength. Ten of the 15 participants indicated that as a direct result of their participation in the programme they felt greater emotional strength including enhanced skills in dealing with emotional situations. These mothers talked in terms of having greater self-esteem and self-belief, getting a '*confidence boost*'. For one parent this led her to being able to assert herself more now and to argue a point with a '*patronising*' consultant (A3).

Analysis of the interviews indicated that this positive outcome was often related in the context of how parents described giving greater consideration to themselves and their needs.

"given me a confidence boost in a sense that I've thought about myself more rather than thinking about him all the time and his needs and to ensure that ... my needs are met as well as his and obviously if I'm okay than he will be okay" (D2).

Another mother talked about her appreciation that the ENHANCE programme focused on the parents, rather than just purely the child:

"it makes you feel important as well, you know, as the child and so that makes you, you know, it gives you a bit more self-esteem, a bit of a boost, just the fact that it's even target at that, I do think that's, that's good." (C2).

Seeing things differently

12 out of 15 of the parent participants reported that the ENHANCE programme had encouraged them to see things differently. A key element of this was the opportunity it provided to take a step back from their situation, as one mother said:

"...you're in your own little bubble you can lose focus of, you know, some of those more obvious things... ...(it) makes you stop and think about these things and I think if you sit and do that proactively it then helps you in your day-to-day coping." (A4).

Parents described how the programme had helped them to challenge the way they think about things, from being asked *"questions you might not think of yourself"* (D2), to forcing *"myself to think[ing] about these questions and answer them honestly"* (A5). They also appreciated being *"taught to kind of flip things back round for the better"* (A4) so that *"It just helps you reframe really"* (C2).

Whilst some parents made reference to 'seeing things differently' as an outcome of the overall ENHANCE programme, others were able to relate this to particular themes, questions or activities. Parents offered several insights into how they perceived this to be helpful:

"making me realise ... how much that I have coped with and that I need to be proud about that and ... knowing that it wasn't my fault." (A3).

"... just made me think about things in a different way and not be so emotionally driven by everything all the time." (C1).

"I realise that I don't always have to cope." (D4).

Specific benefits from taking part in ENHANCE

One mother provides an excellent illustration of how taking part in the ENHANCE programme resulted in a range of positive outcomes. Her confidence, emotional strength and self-belief have all increased.

"... it's made me realise more about myself that I didn't really know, I didn't really believe in myself, so it has helped me." (A3).

She has also begun to reframe situations positively and now enjoys: *"flipping things over, you know, to be on the positive rather than the negative"* (A3). Moreover she has returned to education with the long-term view of training to be a nurse. She posited that this was as a direct result of the ENHANCE programme and the support of the nurse co re-researcher who *"took the time to ask someone to come over and discuss it with me, and you know, made me believe in myself".* (A3).

Analysis of the interviews revealed a number of practical examples provided by parents of how their self-belief and confidence had increased as a result of the intervention. For example, a normally shy mother described how she is now taking her child to a physiotherapy group once a week as a result of increased confidence.

She was keen to report the benefits of the programme as well as her regret at not going along earlier because of her lack of confidence. Another mother described herself as *“being a bit more articulate and able to say that I need help and knowing where I can go.”* (C1).

Parents reported various positive emotional outcomes from taking part in the study. For example, one mother who reported how unsupported she had felt over a number of years:

“had nothing in ten years so kind of constantly in emotional turmoil, so I think it was, you know, very valuable to be able to sort of sit down and have these questions that sort of, you know, make you put, sort of put things in boxes a bit more and, you know, then you can carry on a little bit more calmly.” (A4).

She talked about how *“this constant emotional turmoil”* and lack of sleep can *“really just chip away at your resilience”* but felt that as a result of the ENHANCE programme she was now better able to manage this:

“I take things very much to heart but I had the skill to just kind of stop and take a breath and think, no, I need to protect myself actually and that’s not going to upset me ... so I’ve definitely recognised improvement in that.” (A4).

Another mother who was worried about the possible return of postnatal depression, which she had experienced previously, felt that the opportunity to talk to her NC-R was a key factor in avoiding this: *“because I could be so open with her, I think since this programme’s started I’ve had a lot less down days as well because I feel I can talk”* (D1). The mother offered additional insight into the rapport she had built with the NC-R: *“I’m sure if I rung her up one day and I didn’t sound like the normal me, she would know”* (D1).

Emotional strength was also gained indirectly through the learning of ‘practical’ techniques and strategies which had been introduced by the Nurse C-Researchers during the intervention visits. One mother who reported that *“before I started this programme we weren’t coping at all practically”* (C1), described how the family had previously applied for funding for a wheelchair for the child and this had been turned down. The mother then explained how she had adopted the POET technique to work out more objectively, and less emotionally, how to approach the problem and was successful in obtaining the funding when she applied a second time. She described how she had....

“... dealt with that situation much better than probably I would have done prior to this ...I didn’t get stressed at all throughout the whole thing so that was good.” (C1).

Another mother also considered that she was less stressed as a result of ENHANCE:

"It's made me realise that I don't have to get worked up straight away, I don't have to get in a strop straight away, I can sit down and think about it more rather than just losing my rag a bit ... so that really helped, yeah." (D3).

The ENHANCE intervention appeared to help parents to become more accepting of their situation and to realise that there was no blame to attach to their child's condition, either to themselves or to others. It also enabled them to reflect on where they were and how grateful they were to have got to that point *"I'm so thankful and grateful that she's here"* (A3) and, specifically, to recognise their child's abilities rather than their disabilities:

"I think my coping with him more because he's got a silent cry he makes these weird noises and this will sound really horrible but sometimes they're annoying in a way because you can't really help him. And I think it's made me cope more with his ways of doing things, where I used to get really upset "oh why isn't he doing it like a normal child?" and I think what, talking to (nurse) a bit and these little appointments I think it's made me realise that he is a normal child who does things differently." (D3).

"and our nurse has sort of reiterated that ... we can do anything really and so practically, yeah, we don't hold back and we do anything that a normal child would really, whatever 'normal' is" (D2).

Parents welcomed the information that had been provided by the nurse co-researchers within the resource sheets. For example with regards to accessing sources of financial support:

"... help with finances was quite useful, you know, knowing where you could go to get help." (B3).

"Just things that I wouldn't have known about before really ... like the Family Fund(ing)." (C2).

"at the time we was going for some funding for a car seat, one of the ones that we was suggested actually helped us, we got in touch with them (the Family Fund) and they are actually the ones that helped us fund a car seat. Without that information, I would never have known, so that one was really beneficial, that one." (D4).

The resource sheets were also helpful in directing families towards sources of social support. Parents reported that they had made use of it and were now "signed up" to various networks and support agencies. Social support was clearly important, several participants described their isolation and difficulties experienced in trying to discuss their child with their peers who do not understand the child's condition or the parent's situation.

One mother who had had negative experiences when taking her son out in the community observed: *"I've got dirty looks and remarks because of the way he is."* (D3) The mother welcomed the information provided through her nurse co-researcher about possible support groups for her to attend: *"it's nice to go to these other groups and get support from people that know my situation"* (D3). Another

reported positively that the NC-R had facilitated contact between herself and another mother of a child with a similar condition to her own son.

For some parents simply being asked a straightforward question – but one which they might not think to ask themselves - by someone outside the family circle (the NC-R) had helped to bring clarity to specific situations or issues. For example, for one mother this was demonstrated in a greater understanding of her social support. It meant, as she succinctly put it, that she could:

“...highlight who I can turn to ... and highlight who I can't so maybe stop kind of banging my head on a brick wall with certain people and value the people who I can turn to” (A4).

The ability to apply a more objective approach as a result of the use of the ENHANCE prompt-questions was replicated across the themes. Within the ‘You and your child’ theme, a question which was focussed upon how parents took care of themselves, appeared to be particularly powerful, prompting many comments from the participants. A number of parents specifically identified how they now felt more able to step back and consider their own needs and how they would address them. One mother, who had been woken from her sleep every hour each night for the past six years, described how she had finally recognised, as a direct consequence of the intervention questions that she needs to have a break and take care of herself. She observed that if you can:

“... just go and relax and take yourself out of the situation, even for a small amount of time, it just changes how you can then deal with things.” (A5).

As a result, she has now started to share her daughter’s care with the child’s estranged father on alternate weekends and is also thinking about employing professional nursing services, something that she would not have considered in the past.

“Since this programme I understand that I am going to worry, it’s natural to worry when you’re not with your children anyway but I can go out and do something for me as a person, not just as her mum, and I can feel okay doing that now.” (A5).

This particular question appeared to resonate with many of the parents who suggested that this had given them the opportunity, often for the first time since their child’s birth, to think about themselves and their needs. One mother’s comment summed up the experiences of a number of the parents: *“when he came along with his problems as well, his medical needs, it just all sort of completely took over.” (D2).*

Practical and emotional coping post-ENHANCE

Parents found taking part in the ENHANCE programme valuable in terms of helping them to cope both emotionally and practically. In respect of emotional coping, the programme appeared to help some parents come to terms with their child’s condition:

“I think that helped me accept what’s happened and it helped me understand that it wasn’t anyone’s fault.” (A2).

“It’s been kind of a relief to actually accept these emotions and, you know, it’s fine, you’re allowed to grieve for a healthy child because you don’t have a healthy child ...” (A5).

Parents reported feeling stronger emotionally, having “a confidence boost” (D2) and being more able to recognise their strengths: “*making me realise ... how much that I have coped with and that I need to be proud about that*” (A3). Several parents specifically highlighted that they felt that emotional coping was a particularly valuable focus for the ENHANCE study, identifying how prior to the intervention, their own emotional situation had been inextricably linked with their child’s condition and health status. Taking part in the study had provided them with the opportunity to discuss things that they had either not thought about directly, had avoided thinking about or had not had someone independent in whom they felt able to confide.

“with absolutely everything that I couldn’t talk to anybody about before, I think was a massive help because it was things that I hadn’t even faced myself before, thinking I’d dealt with it all, I’d just got on with it.” (D1).

This mother went on to comment that since taking part in the ENHANCE programme she’s had “*a lot less down days as well because I feel like I can talk*” (D1).

Several parents made particular reference to one of the ‘practical’ coping activities – using the problem solving mnemonic POET – when discussing strategies that were helping them to cope emotionally. POET provided them with a coping skill that was intended to assist them in breaking problems down into manageable, focused parts, and as a result this allowed them to be more objective and less emotional when dealing with problems and difficult situations. Although some of the parents were not able to recall the specific word, POET, during the interview, they were still able to remember the process and this was clearly a help to them and something they saw as helping them to cope emotionally.

“now I can’t remember the word, is it the respect, how we look at a situation and maybe look at it so rather than getting emotional by it all and thinking, you know, how can we actually look at it and think about it logically and maybe work through that.” (C1).

“it’s more manageable, like more manageable chunks, so an issue wouldn’t feel overwhelming if you kind of remember ... to break it down and tackle one thing at a time. I’d say that was ... more helpful.” (C2).

“There was a really good problem solving diagram that our nurse gave us ... A diagram thing that you can follow about the problem solving and go back to and, yeah, I have used it so it’s been very helpful.” (D2).

“sit down, calm down and go step-by-step.” (D3).

Referring to the programme as a whole one parent summed it up as having “*put me in a good mind-set for dealing with things that will come up and are coming up.*” (D5).

Resilience post-ENHANCE

The final questions of the interviews directly related to the overall effect of taking part in the ENHANCE programme – about parents' resilience at the end of the intervention and whether it had affected how they were coping emotionally and practically.

Of the 15 study participants, 1 failed to respond, and 10 responded positively when asked whether they felt more resilient. Those who did not regard themselves as more resilient as a result of the programme indicated that they felt they were already resilient anyway.

Participants' response to the ENHANCE process

The study themes

Parents were asked to consider each of the four study themes ('you and your child', 'emotional coping', 'practical coping' and 'support networks') in turn and were also asked whether they felt that, when considering all four themes in-the-round, the intervention focus was the right focus.

You and your child

The interviews provided insight into how parents had valued the opportunity to discuss the relationship between themselves and their child with the nurse co-researchers. Parents described how the conversations had provided an opportunity for positive reflection on what they and their child had achieved together, and the progress the child had made. A number of parents acknowledged that this was in contrast to the sometimes negative view that they had previously taken of things that the child had not been able to achieve and their own personal responsibility for their "failure." (D3).

There was also insight into parental perspective in terms of how the child's health needs had impacted upon their own health and wellbeing, with a number of parent acknowledging that this had become a secondary consideration – their principal responsibility was to care for their child – "so you kind of forget about yourself..." (B4).

The intervention visits clearly provided parents with an opportunity to think about themselves and their own needs;

"I do need time for myself and I do need to step back and have some sort of normality" (A5).

"So actually having somebody there saying to you 'are you making time for yourself and are you having some exercise?'" (A4).

"Maybe I need to be a bit more aware of me and where I off-load, I suppose and giving time for me." (C1).

Parents also provided a number of specific examples of how this aspect of the intervention had prompted them to take some "me-time."

"She (the NC-R) took some time to ask someone to come over and discuss it with me, and you know, made me believe in myself. So I'm now at college, do my GCSEs... and then I am going to do my Access Course." (A3).

"I'm just going to sit here and watch rubbish TV and catch up with the soaps." (A5).

"And I have now, I've started doing some Zumba classes and getting myself back into shape a little bit which was nice, it kind of made me think twice." (D2).

"I probably do more in the day, so I probably, you know, I will meet for a coffee with a friend and so on and it's quite nice, you know." (D5).

Practical coping

Analysis of the parental interview revealed that the focus on practical coping was an area that some parents found to be very helpful indeed, whereas others reported no specific benefit from this aspect of the study intervention. One parent described this as "*probably the best one, probably the most beneficial*" (D3) and a number of others offered examples of how they now felt that they were now able to take a more practical problem-solving approach, for example in seeking out support and help. A number of the parents related the development of this more practical approach in terms of how it had supported their emotional coping – and vice-versa.

Emotional coping

Analysis of the parental interview revealed the complexity of the emotional journeys which many of the parents had travelled (and were still travelling).

"You know, prior to this project and a very short course of counselling last year, I'd had nothing in ten years, so kind of constantly in emotional turmoil, so I think it was, you know, very valuable...." (A4).

Parents valued the opportunity and encouragement by the nurse co-researchers to engage in a discussion about emotional coping. For some this had cathartic value in itself:

"So it's been kind of a relief to actually accept these emotions." (A5).

"It helped, well just for me to help point out how I'm feeling at the current time about everything." (A3).

"With absolutely everything that I couldn't talk to anybody about before, I think was a massive help, because it was things I hadn't even faced myself before." (D1).

Suppressing emotions, particularly in front of their child, was important to a number of parents *“I don’t really show that to (child) because as I say he is not really aware of it and I want it to stay that way.”* (B1). One parent observed that even though she considered herself to be an emotionally strong person anyway, it was still valuable to be provided with an opportunity to explore emotional coping. Other parents identified particular elements of their own prior experience which helped them with emotional coping, for instance having a supportive partner or just simply *“being strong”* (B3).

A number of parents placed particular value on the relationship that they had established with the nurse co-researchers in the specific context of discussing emotional coping: *“The relationship between me and the nurse is brilliant.”* (D1). Several parents described how the intervention conversations introduced them to a range of techniques and activities as well as specific resources within the tool-kit which they felt had allowed them to find practical strategies and actions to take which helped to support them with emotional coping:

“So we went to meditation techniques, mindfulness that was really good, just trying to zone out sometimes.” (A2).

“How am I going to do that? Sit down, calm down and go step-by-step.” (D3).

Support networks

In discussing the support network them within the study intervention specifically, parents identified family and friends as a significant source of support. For some this provided them with someone to talk to, though not necessarily to provide practical help with caring for their child. Relationships with members of both the nuclear and extended family were recognised as a particularly strong source of support, and clearly many of these relationships were already well established before the child’s health and care needs became evident. However, a number of parents observed how having a child with complex needs impacted upon friendships and some family relationships:

“...but you’re thrown into a whole new world and you suddenly sort of find out which of your friends and family are still, you know, there for you, ... and which of your friends and family aren’t and, you know, which can hurt..” (A4).

As part of the intervention tool-kit, the nurse co-researchers had provided a printed-list of possible support groups with which parents might make contact. Several of the parents commented positively on the value of engagement with families who were in similar situations to their own, and a number of parents commented on both how valuable this had been in their own experience and of the potential this offered for support in the future. Meeting with families, through formal support groups was described as a very positive experience by a number of the study parents. In addition, several parents highlighted the use of social media, particularly Facebook®

as a valuable source of support. Parents were very positive about the suggestion of making possible contact with other parents who had undertaken the ENHANCE programme, but also wondered about how the issue of confidentiality of patient contact information might be overcome. One parent (A4) commented on the need to have somewhere to 'go to' for emotional support at the end of the intervention and how the support network might be helpful in this respect. One parent suggested that an online forum for parents on the ENHANCE programme could be useful in the provision of mutual support.

Were the study themes correct?

Parents were asked for their views on whether the four theme topics were the correct areas upon which to focus within the intervention visits. The responses to this question were universally positive and concurred with responses from the parent reference group: "*Yeah, absolutely*" (A2), "*Definitely, definitely*" (A4); "*I think they are the right areas, yeah, definitely*" (C2); "*It's thought provoking for every area*" (D2). One parent commented that she found it particularly helpful to know in advance the proposed content of the intervention visits:

"So it's nice to say 'Right, today we're gonna talk about this and then the following week you talk about this'.... it helps you think..." (B4).

The intervention tool-kit

As noted above, the intervention visits were supported by the provision of a tool-kit, a set of materials which included practical exercises and resource materials. The NC-Rs provided each parent with a ring-binder folder during the first intervention visit and materials were added to the folder as they were introduced during subsequent visits. Copies of some of the materials are included in Appendix 17.

A number of the parents offered positive general comments about the provision of the resource folder, observing that it had already been used as an *aide memoire*, had the potential to be used as a resource in the future "*it will be something I will refer back to, rather than something I would necessarily refer to regularly*" (D5) or as something that could be shared with a partner. Other parents indicated that they had only used the folders during the sessions. Included within the folders were a number of information/resource sheets. These included resources provided by the University Research Team as well as 'bespoke' contact lists that had been populated by the NC-Rs based upon their knowledge of the specific child. A number of the parents commented that some of the resources were previously unknown to them (two parents specifically mentioned the Family Fund) or that the resource sheet prompted them to access a resource that they were previously aware of, but had not tried to access.

"The most useful thing was having the sheet with all the numbers on it. And obviously the contact numbers for others, you know, societies and things that might help." (B3).

“(nurse co-researcher) gave me a big printout of all the different websites and stuff and I found that quite useful, just sort of going through all the websites... ..a lot of these networks and support agencies are all on Facebook® and that’s something I use every day, so I signed up to those.” (C1).

The tool-kit (Appendix 17) included a number of practical and word-based exercises. Parents expressed a range of views on the exercises and materials with some reporting that they found them more valuable than others. Several parents described the exercises themselves as a positive or enjoyable experience. A number of parents identified how the word-based exercises had allowed them to identify words to describe their feelings or emotions: *“It helped, well just for me to help point out how I’m feeling at the current time about everything.” (A3).* One parent helpfully suggested other words that might be added: *‘confused’* and *‘helpless/hopeless’* (B3). Several of the parents commented positively on how they had been able to use the word-based exercises including the POET Tool (Appendix 17) in dealing with practical problems/situations, identifying how the exercises had helped with problem solving, looking at things from a different point of view or reflecting on situations:

“I found that it’s about making you look at situations in, from perhaps another perspective and breaking, breaking things down, issues, problems.” (C2).

“It did make you think about how to do things, so it sort of made you slow down the way you do things, yeah.” (D5).

“...and rather than feeling, like, why is nothing working, to go back to the beginning and thing well, look at the situation, what needs doing, what’s the best way to resolve it? That sort of thing.” (D3).

“Like, if I’m having a bad day I can look at that, and that helps me, because I find I can’t talk things out on my own, I need someone to tell me what to do, kind of thing, ‘cos I do get a bit scrambled...” (B4).

“...and you think ‘right, okay, how am I going to break this down?’ so I’m not trying to be so emotionally... make decision on an emotional point of view if you like.” (C1).

One parent, the mother of a child with a long-established condition, who reported that she had not found the exercises to be helpful commented: *“It would definitely help people especially early on because a lot of problems occur when you first come out of hospital or when you first find out about conditions.” (A5).*

Focus on the parents’ needs

Parents welcomed the fact that the study intervention focused explicitly on them and their needs: *“to know that there is somebody interested in what I have been through as well” (D1), “focussing on the parents, from that perspective, rather than purely the child’s needs” (C2)* and has *“given me a confidence boost in a sense that I’ve*

thought about myself more rather than thinking about him all the time and his needs.” (D2). “I think it kind of clicked that I need to be looking after myself.” (A2).

A number of the parents commented on how the individual scripted questions that were asked of them by the NC-Rs afforded them permission to think specifically about their own situation:

“...but the questions have made me rethink a lot about how everything affects us, little bits, do we take time, enough time-out for ourselves? Just to, kind of, reflect on actually how I’m coping emotionally.” (A5).

“It was very useful to have somebody to, you know, take you through questions to sort of, again it’s kind of making you stop and think about these things and I think if you sit and do that proactively it then helps you in your day to day coping.” (A4).

One mother commented on how the focus within the intervention upon her own needs had encouraged her to think about the potential value of engaging with other parents who had been involved in the ENHANCE project.

Parents identified how focussing on this subject area within the intervention had impacted positively upon their relationship with the NC-R.

“If we hadn’t done this, I wouldn’t have had the relationship that I’ve got with my community nurse now and it’s like because I’ve got so much trust in her and everything else because we’ve built that relationship I can ring her up at any point and ask her anything, even if it’s like irrelevant, if you like to (child’s name).” (C2).

“I mean, she (NC-R) was great but we just didn’t have that relationship and it is only because of this (intervention) that we now have this relationship.” (D1).

Establishing structure and ‘objectivity’

Parents described how the intervention had helped them to apply both structure and objectivity to thinking about their situation. A number of specific elements were identified:

- *The independent perspective of the NC-R (A2).*
- *Creating mental space (A4).*
- *Taking time (A4, A5).*
- *Stopping/pausing/stepping back to think/reflecting (A3, A4, A5, C2, D1 D2).*
- *Re-evaluating and re-adjusting (A4).*
- *Being more objective (C1).*
- *Looking at things another way (C2, A5).*

A valued conversation

The intervention visits were highly valued by parents many of whom specifically highlighted that this was an opportunity for a conversation with somebody who was not a member of the family or a friend. A number of the parents related that they had found it valuable simply “to talk” and to have somebody “to listen.” Parents commented positively on the particular skills and abilities of the NC-Rs in conducting the conversations:

“The nurse made you feel very at ease, so you could easily open up.” (C2).

“I think (NC-R) is very good at not just sticking to all the questions.” (A2).

“You know what, I think everybody should have the opportunity to have their nurse for half an hour or an hour to talk to.” (D1).

One parent made a particularly powerful observation:

“..being able to talk about everything I had been through with my pregnancy, with absolutely everything that I couldn’t talk to anybody about before, I think was a massive help because I think it was things I hadn’t even faced myself before, thinking I’d dealt with it all. I’d just got on with it and you don’t actually realise that you don’t, you don’t actually... you do need to reflect back on it.” (D1).

Learning emotional and practical coping

Parents particularly valued the focus within the intervention upon both emotional and practical coping specifically in relation to how it had helped them to learn and develop their own coping abilities and strategies.

Many of the parents used the words “skill”, “technique”, “mechanism” or ‘strategy’ when relating how they felt that the intervention had enhanced their coping abilities.

This was often supported with an illustrative example:

“Like the little cards and the little speech bubbles that (NC-R) has shown me. I seem to be reflecting back more on that ... using that more, look ahead of me and think well, rather than getting all ‘Oh, how am I going to do this? How am I going to do that?’...Sit down, calm down and go step-by-step” (D3). (see Appendix 17 for POET mnemonic referred to here)

“So it’s been kind of a relief to actually accept these emotions and, you know, it’s fine, you’re allowed to grieve for a healthy child because you don’t have a healthy child, and accept what’s going on around you and it’s kind of nice to look at everything from a, from a different sort of point of view.” (A5).

Frequency and timing of the ENHANCE intervention

The views of parents were sought in relation to aspects of the structure and process of the ENHANCE programme. The research team were particularly keen to ascertain parental opinions about the programme itself (the number of visits, the

length of those visits and the time intervals between visits). In addition, as noted previously, a number of the parents who were enrolled in this study had already experienced several years of parenting a child with complex health needs and the research team were interested to understand from parents whether the timing of the ENHANCE intervention was appropriate in terms of their own time-line.

Parents reported that they found the length of the intervention visits (approximately 30 minutes) to be appropriate. One participant suggested that the visits could have been completed more quickly than this, though several others indicated that they were happy for the interviews to run for longer – perhaps up to an hour. A number of visits were reported to have been longer than the suggested 30 minutes, particularly the initial visit during which the parents were required to complete the quantitative self-report tools. Parents appreciated the ‘discipline’ of knowing the anticipated duration of the visit in advance – though they also valued the flexibility shown by the nurses to allow the intervention visit to reach a ‘natural’ end. Parents did, however identify that they were already dealing with multiple clinical appointments for their child and that some additional flexibility with the timing of the visits (rather than a rigid fortnightly intervention) might help with the scheduling of those appointments. It was, however, evident from both the Nurse and parent interviews that the Nurses had been very responsive to parental wishes in the scheduling of visits.

In respect of the child and family time-line, parents provided some very strong perspective and insight based upon their own personal journeys. Parents identified very clearly the need for the programme to be delivered at times to suit each individual family. There was some discussion about the possible delivery at around the time of a child’s diagnosis, alongside an acknowledgement that diagnosis itself was not altogether straightforward. However, Figure 8 illustrates the variability in parental responses to the question about the timing of the delivery of the ENHANCE intervention. Most parents indicated that they would have liked to receive the programme earlier, possibly during the first year of the child’s journey, after discharge from hospital and once a diagnosis had been confirmed, but this was by no means a consistent view from the participants.

A number of the parents suggested that they would have liked the course to be slightly longer (a slight increase in the number of visits) and one parent specifically requested that an additional visit be included perhaps 4-6 months later to check that all was well and that the parents were continuing to make use of the resources and strategies to which they had been introduced within the programme. This was discussed both in the general terms by parents who felt that they would like to ‘touch base’ with the NC-R and also in anticipation of possible change (or worsening) of the child’s health status.



Figure 8: Parent participant views on the timing of the ENHANCE intervention.

Learning points from the study

Parents were asked for their views on the overall relevance of the study intervention to their situation. Most reported that they found the intervention to be relevant and appropriate to their situation, though, as noted above, a number of the parents felt that they would have liked to receive the programme earlier in their/their child's journey. However, this could perhaps be because some of the participants had been coping for some time with their situation, e.g. one parent for 6 years, and another for 11 years.

Within the interviews, parents were asked a number of probing questions in order to seek clarity with regard to the relative value of the four study theme

focus areas. When discussing the individual themes, it was clear that parents had different needs and drew accordingly on the themes that were most valuable to them at the time. Some parents identified aspects of the programme that they had personally found to be more valuable than others and one parent felt that the intervention might have been more valuable for her had her child's needs been more complex.

As already noted, all of the principal caregivers in this study were mothers and one mother wondered whether it might be possible to provide something similar to the ENHANCE programme for fathers, ensuring that they, too, have support. The mother observed that while she did not like to generalise about gender, in many families in these circumstances it is likely to be the mother who is the main carer and who attends special needs playgroups and gets to meet other mothers. In discussion after the interview about whether the programme should target both parents at once, she indicated that it is better one-to-one as she really valued the time she had with the nurse by herself and it may be more difficult to be as open as she had been if they had gone through the programme as a couple.

Although it was only evident within one of the ENHANCE interviews, an issue of concern was the possible over-reliance by the parent on the relationship with the nurse co-researcher. This did not appear to be a major issue, however the research team felt that this might be a learning point in relation to the need to ensure clear disengagement by the nurse at the end of the intervention programme.

Quantitative data analysis approach

Quantitative data was collected using 4 self-completed tools:

- Distress Thermometer
- Resilience Thermometer
- Brief COPE Scale
- Tool to measure Parenting Self-Efficacy (TOPSE)

Of the 16 parents recruited to the study, pre-test questionnaires were completed by 15 parents. 14 parents completed both pre-and post-test questionnaires. With such a small sample size, the inferential statistical analysis below should be treated with some caution, particularly with regards to power. The following tables set out the quantitative data for the sample. Data was analysed using SPSS v21, and t-tests were applied to establish significance of the outcomes.

Findings from the parent quantitative data analysis

Distress and resilience thermometers

Scale	T1	(sd)	T2	(sd)	df	sig.p
Distress	5.00	(2.88)	2.43	(2.82)	13	.02*
Resilience	6.00	(2.29)	7.21	(2.28)	13	.22

Table 2: Distress/resilience thermometers - pre- and post-test mean scores (NB: one parent failed to complete the thermometers at T2).

Scores on the Distress Thermometer decreased between T1 and T2 ($m = 5.00$ to 2.43) and a within-groups t-test indicated that this was significant ($t_{(13)} = 2.6, p = .02$). This suggests that participants considered themselves to be less distressed after receiving the ENHANCE intervention.

Scores on the Resilience Thermometer increased between T1 and T2 ($m = 6.00$ to $m = 7.21$), though this change was not significant. A comparison of the qualitative findings with the quantitative results suggest that the measure is not reliable as nearly 50% of verbal responses to the question “*Would you say you are more resilient at the end of and as a result of the programme?*” were inconsistent with changes in the scores between T1 and T2 on the Resilience Thermometer.

Brief COPE Inventory (13 scales)

Scale	T1	(sd)	T2	(sd)	df	sig.p
Self-distraction	4.27	(1.33)	4.13	(1.92)	14	.73
Active coping	5.47	(1.46)	6.47	(1.73)	14	.01**
Denial	2.47	(1.06)	2.53	(0.74)	14	.82
Substance use	2.00	(0)	2.00	(0)	14	n/c
Use of emotional support	5.60	(1.45)	4.93	(1.91)	14	.14
Use of instrumental support	4.40	(1.50)	4.93	(1.62)	14	.18
Behavioural disengagement	2.47	(1.13)	2.13	(0.52)	14	.17
Venting	3.67	(1.35)	3.13	(1.06)	14	.18
Positive reframing	4.87	(1.46)	5.47	(1.85)	14	.11
Planning	4.93	(1.22)	5.47	(2.17)	14	.21
Acceptance	6.47	(1.60)	5.80	(1.86)	14	.31
Religion	2.87	(1.60)	3.13	(1.88)	14	.16
Self-blame	4.07	(1.49)	3.27	(1.62)	14	.05*

Table 3: Brief COPE Inventory – pre- and post-test mean scores.

The scales within the Brief COPE inventory indicate how people are coping with their circumstances. A higher score on any of the scales is representative of a particular behaviour or activity occurring more frequently. For some items on the inventory, higher scores indicate a desirable/positive behaviour change (for example active coping or positive reframing) whereas for other items, higher scores indicate a less desirable/negative behaviour change, (for example denial or substance abuse).

Between T1 and T2, mean parental scores on 9 of the 13 scales moved in the desirable/positive direction, however only two scales yielded statistically significant change (active coping scale, $t_{(14)} = -2.84$, $p = .01$; and the self-blame scale, $t_{(14)} = 2.10$, $p = .05$). This is consistent with findings from the qualitative data analysis.

Scores on three of the scales (denial, use of emotional support and acceptance) changed in the less desirable/negative direction though none of these findings were significant.

There was no change between T1 and T2 in respect of the substance use scale.

TOPSE

Scale	T1	(sd)	T2	(sd)	df	sig.p
Emotion & affection	52.50	(6.43)	55.07	(5.32)	14	.11
Play & enjoyment	53.07	(6.17)	53.20	(7.92)	14	.94
Empathy & understanding	42.79	(16.15)	48.00	(10.93)	14	.04*
Pressures	41.17	(13.21)	41.80	(12.38)	14	.89
Self-acceptance	50.90	(6.15)	53.60	(6.65)	14	.06
Learning & knowledge	48.73	(7.78)	50.00	(7.80)	14	.59
Total TOPSE score	286.30	(29.58)	302.47	(37.28)	14	.09

Table 4: TOPSE - pre- and post-test mean scores

The overall TOPSE score increased by 16 points from T1 to T2 though this was not statistically significant. Scores across all subscales increased between T1 and T2 with a statistically significant difference for two of the subscales: empathy and understanding, $t_{(13)} = -2.32$, $p = .037$, and self-acceptance, $t_{(14)} = -2.09$, $p = .056$. This suggests that parents had more empathy and understanding in relation to their child and were being kinder to themselves. The latter finding echoes that of the Brief COPE Inventory self-blame scale and, as with the Brief COPE scale, is consistent with the qualitative data analysis.

Findings from the Nurse Co-Researcher interviews

The Nurse Co-Researchers were interviewed approximately two weeks after they had completed their final 6th intervention visit. The interviews were undertaken by members of the Research Team in an office setting identified by the individual NC-Rs.

Training

As noted above, the Nurse Co-Researchers were recruited from three NHS Trusts within the CLAHRC East of England region. The NC-Rs undertook a three day introduction/training programme at the University of Hertfordshire, details of the programme are set out in Figure 5/Appendix 7.

The training was very well received by the NC-Rs, all of whom agreed that it was not only an essential part of the programme *“I, 100%, would not have been able to do it without any of the training”* (NC-RB), but it was also informative and enjoyable. They appreciated the opportunity to meet as a group and to get to know their NC-R colleagues and in addition, they valued the motivation they received from the Research Team and other staff who were involved in the delivery of the training programme: *“...very educational, sort of motivating so I think they were really useful”* (NC-RD).

The NC-Rs did, however, identify a number of gaps within the training programme, primarily related to the use of the resource materials within the toolkit, suggesting that they would have found it helpful to be given an opportunity to practice or ‘role-play’ some of the exercises, before using them ‘in the field’.

“I think maybe we could have done in the training some sort of pretend practice sessions on using the actual tools ...” (NC-RB)

“A little bit of role play would have been good to just prepare when we were doing the questions with the families.” (NC-RC)

“I think maybe if we’d done a little bit more perhaps role play about going actually through the files a little bit more.” (NC-RD)

Overall the NC-Rs identified that they were well prepared: *“we were given all the right tools, all the right information and everything we need”* (NC-RB) and that the Research Team had provided good support. They felt that the ENHANCE folder was well organised into different sections, with *“detailed paperwork”* (NC-RC) and was *“very user-friendly”* (NC-RD).

As noted above, during the course of the fieldwork phase of the study, the NC-Rs met with the Research Team on two occasions in order to provide an opportunity for reflective discussion as part of the action research element of the study. All of the NC-Rs reported that they valued the opportunity to meet periodically to discuss progress and learn from each other. These meetings were considered by the NC-Rs to be supportive, as they provided an opportunity to explore problems or issues both in informal ‘networking’ conversations with each other and also within the context of the more formal action research cycle process that was facilitated by members of the Research Team.

The NC-Rs were asked to keep a reflective diary throughout the fieldwork. Each of them did this and reported that in addition to providing a resource for reflection, they also found it a useful exercise for keeping track of where they were up to with each of the parent participants.

Experiences of recruiting participants

The recruitment target for each of the NC-Rs was 6 participants. In fact they each recruited between 3 and 5 participants (See Table 1). The challenges of recruiting to target were highlighted during the interviews. One of the NC-Rs was a special needs community nurse who worked within special schools and identified the particular challenge of recruitment during the long Summer school holiday.

Although the NC-Rs had been provided with details of the study inclusion and exclusion criteria as part of the initial training programme (Figure 6) as well as an opportunity to discuss the criteria in more detail with the Research Team, there remained some anxiety about *“whether I had picked the right family... I felt a bit vague about the criteria ... that was quite difficult because it wasn’t sort of set in stone.... (However)... in the end it worked out okay.”* (NC-RD)

Delivering the ENHANCE intervention

Feedback from the NC-Rs in relation to their ability to deliver the ENHANCE intervention was generally quite positive: *“I felt the programme was, in the main, absolutely fine”*, (NC-RA), a view that was reflected in each of the NC-R interviews. Some NC-Rs made minor changes to the wording of the prompt questions, depending on the parent they were talking to, as they felt this was *“a gentler format of questioning”* (NC-RA) and *“I did tend to reword them a little”* (NC-RD); whereas others used the question script *verbatim*, appreciating that fact that they *“were to the point, there was no wishy-washiness actually you could be quite direct and the parents actually appreciated that”* (NC-RC). All of the NC-Rs reported that they were comfortable working to the parents’ agenda, they felt this was the right approach and something they would normally do within a clinical visit, this was seen as part of their role, supporting parents as necessary.

The exercises and resources within the study tool-kit were described in positive terms by the NC-Rs who reported that they also felt that the parents had found them to be valuable. Each of the NC-Rs reported that they had adapted the use of items within the tool-kit according to the needs of the individual parents, however *“we were given all the right tools, all the right information and everything that we needed”* (NC-RB)

Length of visits

The proposed length of time for each of the visits to the families was 30 minutes. The NC-Rs felt this was an appropriate starting point, however in practice visits

varied in length from 20 minutes to an hour and a half: *“it just depended on the family and how they were on that particular day”* (NC-RD). Visits were *“generally longer than 30 minutes I always gave myself an hour ... so I wasn’t rushing and the parents didn’t feel I was rushed”* (NC-RC). All NC-Rs faced challenges with the planned schedule of fortnightly visits as a number of the children were admitted to hospital during the intervention period which increased the length of time between visits. However *“if they were fairly stable and at home then I think every other week was good”* (NC-RD).

The study themes

You and your child

Feedback from the NC-R interviews indicated that the questions/prompts/resources within this theme area required further development. It was generally felt that the questions were not sensitive to the different ages of the children: *“I think we need one for the older children, I felt they didn’t get as much out of these questions”* (NC-RA); the *“you and your child is very age and development specific”* (NC-RB) and *“I found (it) harder with the older child”* (NC-RC).

NC-RD reported that she found this section very beneficial with one particular parent:

“(she) was very good at the caring, practical, you know, the nursing side, doing this that and the other, but actually sitting down and playing with the child that came second because they’re sort of almost carers first and then mum second so it was good to reinforce ... how important it was to have these times of play and enjoyment with the child” (NC-RD).

Practical coping

Overall the questions and exercises related to practical coping were evaluated positively by the NC-Rs. In general this theme provided questions that were easier to ask, and allowed the NC-Rs to offer practical help and support and perhaps to signpost parents or make referrals to other services where appropriate. One NC-R suggested that *“parents don’t often think about how they’re practically coping, it’s always usually about emotion so it was quite good to sit back and reflect with them ...”* (NC-RC).

The questions relating to long-term challenges for the families were met with a variety of responses. The NC-Rs described these as quite difficult questions to ask, but ones that they felt were really useful. One NC-R found this so helpful that she has now introduced the subject of long-term challenges into *“our assessments, when we do them, about what they [the parents] think of as the long term challenges”* (NC-RB), whereas another found that *“parents didn’t want to go there ... “I’m just getting by day-by-day and I don’t want to think of the future too much”* (paraphrasing parent) *.... so I thought that was quite difficult”* (NC-RD).

Emotional coping

In using the set of questions within the emotional coping theme, the NC-Rs reported that they found that the parents did “*open up*” (NC-RD) over a period of time. Conversation around this theme area gave the parents an opportunity to “*pick out ... what they are feeling ... because a lot of parents just go, ‘fine, yes, it’s alright, it’s fine’*” (NC-RB). Each of the NC-Rs reported how the parents are just “*getting on with it*” “*well I’m managing, I have to don’t I?* (paraphrasing parent)” (NC-RD). NC-RC reported that she “*didn’t feel uncomfortable ... when we were talking about emotions and parents seemed to really acknowledge and to have the time to think about them which was good*”. NC-RA specifically commented “*I liked the question about emotional strength*”.

All NC-Rs felt that the study parents had developed increased emotional strength as a result of the programme. This was highlighted by NCR-C who reflected on the comments made by two parents who seemed more in control and didn’t feel frightened of speaking to professionals or acknowledging that they needed to speak to professionals

Support networks

Responses from the NC-Rs in relation to the support networks theme were quite consistent, but reflected the variation in experiences of both the N-CRs and the parents. NC-RB reported that she “*went through the support network things and I put stars by the ones that were relevant for them, so I wasn’t just handing them out, I was sort of, picking out some bits ...*” and that she subsequently referred parents back to the support networks exercises and information sheets repeatedly through the intervention visits, acknowledging that “*families don’t use their support networks, they just, they know that they’re there but they don’t use them*”. This is in marked contrast to NC-RA who felt the families are “*absolutely alone*”:

“they don’t need continuing care, they could do respite here, they don’t meet their criteria, they don’t meet social care’s criteria, they’ve got to wait a month to see their GP. The Health Visitor basically is not able to see them because she is out of her depth of normal health visiting, you know” and “*a sister who lives locally just can’t, is so frightened of the TPN and the complexity, she would freak, she can’t look after her niece*” (NC-RA).

NC-RD thought the “*questions were appropriate and very useful to use*” She advised that she had also adapted the handout to include local sources of support and felt that it would be useful to incorporate a section within the resource sheet to include “*what respite you get*”.

Impact of the programme overall

The NC-Rs felt that overall the intervention visits provided time to talk and build a rapport with parents. This was recognised as a strength by NC-RD who gave an

example of one family who, after the first visit, felt that the mother was already quite resilient but realised this was not the case as when they talked more the mother went on to say *“I wish that, you know, that I’d had this a year ago.”*

The NC-Rs reported that they felt that the programme had improved parents’ practical coping abilities, as illustrated by one particular family identified by NC-RC. The family were experiencing particular difficulties in relation to their child’s wheelchair. The parent reported that she had previously been emotional and defensive she *“broke down crying on the phone and it was his need and they needed it as a family”* (NC-RC) when approaching the professionals in order to resolve the problem. However, as a result of the ENHANCE programme, not only was she now using the POET strategy to help her deal with the professionals she was even using the approach in her personal life. One NC-R observed that for one of the parents she felt that the programme has been *“incredible, it’s helped her so much she’s actually gone back to evening classes ...”* (NC-RA)

The NC-Rs felt that the additional time that they were able to spend with families as a result of delivering the ENHANCE programme was very much valued by the parents: *“actually having that time, I think they trust you more”* (NC-RB). In addition, the NC-Rs commented that they also appreciated the extra time they have been able to give to the families and that this has increased their job satisfaction:

“I mean I think I’ve enjoyed doing it, I think it was a bit daunting to start with ... I just found it really nice to be able to spend the time” (NC-RD).

All four of the NC-Rs reported that they have also been able to use some of the approaches with other families not involved in the study.

Impact on the NC-R overall workload/job

The NC-Rs offered a range of views on how their involvement in the ENHANCE study had impacted on their job role overall. This included comments on engagement with their line managers, other Team colleagues and ‘time’ factors related to their involvement in the project. Generally the managers and colleagues were reported as being supportive of the project though a Senior Manager within one of the NC-R’s NHS Trusts (not the Nurse Manager who had originally formally committed to the study on behalf of the Trust) did voice concern: *“You need to make sure that you’re not taking on too much, it’s not impacting on your workload”* (NC-RD). This particular NC-R said *“I mean the only thing was when we first started doing it we’d gone along to the first I think and the second training workshop, and then our organisation research person sort of called us in and we had a meeting with our manager and it was like we’d gone ahead and done something that perhaps we shouldn’t have done”* (NC-RD).

Overall, however, the NC-Rs reported that their managers were positive about the project and other colleagues were “*very impressed*” (NC-RC) and they “*didn’t seem to find it too much of an issue ... I work autonomously anyway*” (NC-RD).

The time commitment to deliver the ENHANCE intervention was a significant concern, with all of the NC-Rs identifying some issues related to the impact of the time required for the project on their everyday work. However, each of the NC-Rs reported that they found ways to mitigate the impact:

“it did encroach on my work and my time but actually given my job title, it was actually beneficial for families” and “travel was an issue for me.” (NC-RA)

“it wasn’t too bad overall ... I only had four [families]. I think if I’d had more it would have impacted more.” (NC-RB)

“it has been a big issue within school nursing because we’ve been short in our team and we have to be within school and it’s lovely to go out to the parents’ houses and I would have wanted to have done more but I just couldn’t do it in the time restrictions ... I think from a community nurse’s point I think it was easier because they could put into their diary.” (NC-RC)

“I think when I started it was like, oh gosh, I’ve got all these interviews to do ... what I tried to do was perhaps do three families and get the mum finished before I started the next one. It was nice to actually be able to spend that time with families that needed it, and it felt justified because I was doing the study, so it was nice, it was a luxury ...” (NC-RD)

Improvements for the future

The NC-R’s made a range of suggestions about how the programme might be developed in the future: were various recommendations for the future:

- It was suggested that there should be separate sessions / questions for the husbands / partners. The role of the father needs to be recognised: “*if fathers felt more supported and resilience increased would that prevent relationships from ...*” (NC-RA) referring to break down of relationships.
- The recruitment criteria caused some anxiety and was described “*as a bit vague*” (NC-RD). In particular, it was felt that restricting the study to families who had only recently been referred to the Community Nursing Team was: “*a shame ... some of our families that have been on our books for perhaps years, some of the complex families would have really benefitted from this programme*” (NC-RD).
- One NC-R suggested the large folders were rather off-putting for the parents and suggested that little individual pockets would be suitable “*rather than scaring them*” (NC-RB).

- Within the ‘you and your child’ section it was felt that different questions / resources were required for the older child / teenager along with an acknowledgement of the need for transition to adult services
- There was a request for further resources in relation to the compassionate mind and emotional coping.

Resilience

The NC-Rs were asked explicitly whether they felt that all or some of the parents had become more resilient as a result of the ENHANCE programme:

“I would say certainly A2, A3, A4 and A5, I hope A1.” (NC-RA)

“Yes.” (NC-RB)

“I think for two of them yes.” (NC-RC)

“I think it was very much developing resilience, I think the families resilience is up and down depending on how their child is ... I’m hoping it, I hope it helped ...” (NC-RD)

The ENHANCE programme overall

And in terms of your views on the programme overall?

“I felt the programme was, in the main, absolutely fine, ...” (NC-RA)

“I think it does work. I think sitting down, spending that time, with them, and I think for the families, they appreciate having someone to give them those, to give them the information, to give them the skills and stuff like that, because actually, they just don’t, a lot of the time they’re sent home and that’s it” (NC-RB)

“Definitely think it should continue, I think it’s a really good resource for families ... I think it’s something that we’re lacking as professionals that these families are lacking, they’re not getting this support and it’s needed” (NC-RC)

“I think it was different for each family” (NC-RD) reflecting a view that some parents benefitted more from the practical coping, others the emotional coping and others with respect to how parents could develop stronger support networks.

Summary of findings

The ENHANCE intervention was very positively evaluated by both sets of participants. Parents reported favourably on many aspects of the intervention, including their perceptions of the programme overall, and of the four individual intervention themes. They felt that the questions that formed the basis for the guided conversations were the right ones – ones that they would either not normally think to ask themselves or would even avoid asking - and ones which helped them to bring about changes in the way they thought about their situation. The views of the NC-Rs were also largely positive, with a particularly strong endorsement for the fact that the programme afforded them an opportunity to spend time with and focus upon the needs of the parents.

Experience prior to ENHANCE

The study provided significant insight into the parent and child 'journey' prior to the ENHANCE intervention and, as noted above, this highlighted the particular issue of the timing of the delivery of the intervention within that journey. It was noteworthy in this study that a number of the parents and children were several years down that journey time-line.

In describing their experiences prior to the ENHANCE intervention, parents highlighted various areas where the child's disability or complex health need had impacted upon family life. This included impacts upon relationships with partners, families (including the child's siblings) and friends. Parents reported difficulty in getting out of the house, and in separating from their child. They did not feel confident entrusting their child's care to others.

Parents also identified that they had spent time, sometimes for quite lengthy stays, with their child in hospital. Parents described themselves as being on constant alert and having to act as 'nurses' in administering to their child's care needs, both whilst in hospital and once they returned home. This was both emotionally and physically draining for parents, a number of whom reported long term sleep deprivation, and how this had impacted upon their wellbeing.

Parents identified with a loss of normality and described feelings of isolation and of feeling alone, observing that other parents, those who were not in their situation, found it difficult to understand. However, they also described the value of peer support, particular from others in similar circumstances to their own, including support groups.

The ENHANCE intervention

Parents identified that, as a result of the intervention, they had learned coping strategies, both emotional and practical, and that the development of practical coping strategies also impacted positively on their emotional strength by helping them to approach situations more objectively. The information on resources such as support groups and networks was welcomed as was any further information provided by the Nurse Co-Researchers.

In the post-intervention interviews parents described how they had gained knowledge about themselves and their relationship with their child, and how they now felt better able to accept their situation. They reported increased self-belief and self-confidence as a result of the intervention, and indicated that they felt better supported and emotionally stronger. These testimonies concurred with findings from the quantitative data analysis which identified significant improvements on scores for active coping and self-blame on the brief COPE inventory scale and for empathy and

understanding and self-acceptance on the TOPSE scale. Scores on the self-report Distress Thermometer indicated that parents were less distressed at the end of the intervention period.

Ten parents reported in the post-intervention interviews that they felt more resilient as a result of the intervention. However, this particular finding was not mirrored by the Resilience Thermometer measure, with clear inconsistencies between verbal report and rating on the measure. Further refinement and testing of the Resilience Thermometer will be required if this is to become a useful self-report measure for resilience.

The Nurse Co-Researcher perspective

The Nurse Co-Researchers were generally very positive in their commentary on the ENHANCE intervention and they felt that “it worked”. The Nurse Co-Researchers felt that the timing of the intervention and the pattern of two weekly visits to parents were appropriate. They valued the extra time that they were able to spend with the parents in order to deliver the intervention, and commented that this increased their job satisfaction. They did, however report that the time commitment to deliver the intervention was sometimes an issue for other members of their nursing team, including their managers.

They considered that the tools and the questions provided to support the intervention were good, although they felt that some questions for older children and adolescents should be included. They found the formal training/preparation to be valuable and suggested the inclusion of more role-play within the training programme. Regular meetings with the other Nurse-Co-Researchers (for peer support) was very useful and allowed them to learn from each other. They also reported that they had applied some of the approaches used within the intervention to their work with other families.

Mechanisms and Outcomes

Further analysis of the qualitative data was undertaken specifically in order to identify how the mechanisms which were identified in advance of the study, and which formed the basis for the development of the intervention, were reflected within the findings. In addition the data was analysed in order to identify possible outcome factors as described by both parents and Nurse Co-Researchers – some of these factors were related by participants to specific elements of the intervention whereas others arose within a more generalised discussion of the intervention. This data is summarised in figure 9 below. Analysis suggested that the outcomes were not sufficiently well differentiated to allow them to be linked explicitly to specific mechanisms, however it may be possible to explore these relationships more fully in the future.

Mechanisms	Outcomes
<ul style="list-style-type: none"> • General focus on parents' needs – someone paying attention to their needs (not just their child's needs) • Valued conversations – someone independent of family (& with medical expertise) • Building rapport with their nurse • Relationships with nurse which parents identified as 'different' to their previous experience of relationships with professional staff • Focus on building parent self-esteem – enabling separation – becoming a parent, person and carer (not just carer) • Helping parent to build in 'objectivity' – to pause, step back and look at things differently and to think positively • Getting parent to evaluate what they have and how strong they are • Getting parent to evaluate and think about what's out there to support them • Learning & developing practical skills • Learning and developing emotional coping skills (and being kind to themselves) • The themes • Guided conversations, and getting parent to think about things they may not have thought of, or may have avoided addressing • Provision of information 	<ul style="list-style-type: none"> • Improved self-esteem • Increased self-confidence and self-belief • Ability to separate own identity from that of the child • Recognition of need to take care of themselves in order to be able to properly care for their child • Greater knowledge (of sources of support and of ways of coping) • Calmer • Better able to cope practically • Better able to cope emotionally • Better able to use support networks (social & professional) • Less isolated • Honesty about their situation in a constructive way (acceptance and removal of blame). • Improved emotional resilience • Seeing things differently

Figure 9: Mechanism and outcomes

Considerations for future research

A number of the parents in this study considered themselves to be resilient prior to receiving the ENHANCE intervention. This was reflected in both the qualitative data and in the range of scores on the quantitative measures at T1. This study captured minimal biographical data about the child, parent and family. In a future study, it might be helpful to collect additional information for each child and family including details of the timeline of the emergence of the child's complex health needs or disability and diagnosis. This data could then be incorporated into analysis of the effectiveness of the intervention, in particular to examine this in the context of the child/parent journey timeline. It may also be possible to address the question of whether the intervention is more or less effective for parents of children whose disability/health need was present from birth as compared to children whose problems became evident some time later. A larger sample size might allow for

further analysis of the quantitative data, specifically to make comparisons within the sample, between parents with low or high scores on the quantitative measures at T1.

Enrolment of parents to this study was predicated upon the child being referred to the Community Children's Nursing Services in which the Nurse Co-Researchers were based. Such referrals would be made as the result of the identification of a specific need for nursing care/support to the child. For some families this referral would have been made several years after the child's complex health need or disability became evident. A number of parents in this study indicated that they would have liked to receive the intervention earlier in their child's journey. In a future study it may therefore be helpful to explore the possibility of identifying an earlier entry point.

In order to determine whether the intervention has a lasting effect, it would be helpful to introduce an additional data capture point, perhaps six months post intervention – this could include both quantitative and qualitative data.

The brief COPE scale, TOPSE scale and Distress Thermometer each provided evidence of increased parental resilience as a result of the ENHANCE intervention. In a future study it may be helpful to incorporate additional quantitative measures/tools. The TOPSE scale was originally designed for the parents of young children and feedback from parents of older children in this study indicated that some of the questions within the scale were not relevant for their child. Some of the questions within the scale may need to be adapted in order to address this. The Resilience Thermometer which was adapted for this study from the Distress Thermometer was not a reliable measure of resilience and will require further refinement and re-testing.

Opportunity might be taken in a future study to examine how resilience and self-efficacy might be related to parental health-seeking behaviours – both for themselves and on behalf of their child. It might be reasoned that if parents are more resilient, they are able to be more self-efficacious and more self-reliant, therefore reducing the need to seek professional advice and support. Although the potential health economic impact of reduced health seeking behaviours might be difficult to demonstrate in small samples, with the involvement of a health economist from the outset, aspects of study design and methodology might be developed specifically in order to explore this area.

The ENHANCE intervention was delivered by four Nurse Co-Researchers. The time commitment to deliver the intervention raised a number of concerns in relation to capacity and workload within the Community Children's Nursing Service in which they were based. Each of the Nurses attended a three-day training programme. In addition the nurses participated in two half-day action research workshops. For each child/parent that was enrolled to the study, the Nurse Co-Researchers undertook a total of seven home visits. The Nurse Co-Researchers were also each interviewed by a member of the University research team approximately two weeks after the final intervention visit. This represents a significant time commitment – (30 hours per nurse for training and workshops, approximately 10 hours per parent participant [including allowance for travel] and 1 hour for the research interview. In addition, the Nurse Co-Researchers confirmed that they had spent several hours in self-directed

preparation in advance of the intervention visits. It will be essential to ensure that economic analysis within a future study incorporates a systematic examination of the full costs of all aspects of the delivery of the intervention.

Feedback from the Nurse Co-Researchers in relation to the training programme was generally very positive and included several pointers to how the programme might be developed in the future. This included the suggestion that the programme should include opportunity to 'practice-test' delivery of the intervention through role-play.

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