Predictors of resilience and quality of life in children with paediatric medical conditions.

Susannah McNulty

Supervised by:

Doctor Catrin Eames (University of Liverpool)

Doctor Victoria Gray (Alder Hey Children's NHS Foundation Trust)

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Chapter 1: Literature Review

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A childhood chronic medical condition is any disease or illness in a child, lasting three months or more (World Health Organisation, 2014). The estimated prevalence of chronic medical conditions in children in the United Kingdom is 15-20% (ONS, 2002). These conditions can have a considerable impact on both physical and psychological functioning and have been associated with higher levels of emotional difficulties across the lifespan (Glazebrook et al., 2003; Phipps, 2007).

Research suggests that in order to promote psychological wellbeing in children and young people with a chronic medical condition there should be an emphasis on resilience and quality of life (Edwards & Titman, 2010). Resilience has been defined as "the relative resistance to environmental risk or the overcoming of stress or adversity" (Rutter, 2006 p.2). Fostering resilience in children may protect against the development of psychological difficulties in adulthood (Seligman, 2000).

Whilst there is an extensive literature base regarding the factors associated with resilience in children; to the authors knowledge there are no reviews to date exclusively focusing on resilience in children with a medical condition. Chapter one aims to explore the current literature pertaining to factors associated with resilience in children with a medical condition. It highlights that family environment and relationship with peers appear to be important factors relating to resilience in children with a medical condition. However, the review demonstrates that there are discrepancies in both the quality and results of the current research base. Furthermore, the studies reviewed tended to focus exclusively on one medical condition, thereby excluding a large number of children with other medical conditions. This limits the conclusions that can be drawn from the review.

There is a large body of evidence highlighting the association between family environment and resilience in children (Benzies & Mychasuik, 2009; Daniel & Wassell, 2002; Garmezy, 1991), and a growing body of literature supporting the relationship between community support and resilience in children (Action for Children, 2007; Alvord & Grados, 2005). A small number of studies have explored the impact of family environment and community support in children with chronic medical conditions including cancer, asthma and dermatitis (Im & Kim, 2012; Kim & Yoo, 2010; Lee et al., 2003; McCubbin et al., 2002). However, to the author's knowledge, there are no studies to date examining these variables in a range of chronic childhood medical conditions. Chapter two presents an empirical study which aims to investigate the impact of both family environment and parental perceived community support on resilience in children with a chronic medical condition.

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Chapter 1: Literature Review

A systematic review of the factors associated with resilience in children with a medical condition

Abstract

Objectives: To conduct a systematic review of the research exploring factors associated with resilience in children with a medical condition. **Methods:** Eight electronic databases were searched using predetermined search terms to identify studies exploring resilience in children with any medical condition. Quantitative studies were included that recruited from both hospital and community samples. Studies were only considered for inclusion in the review if they included a measure of resilience. **Results:** Ten studies were initially identified for inclusion in the review; one was subsequently removed due to poor quality resulting in nine studies in the review. The results identified a number of factors associated with resilience in children with a medical condition, such as relationships with family and peers. However, results across the studies were not consistent and quality varied. **Conclusions:** This review provides some evidence that resilience may be considered a dynamic process involving interaction with family and community factors, rather than an individual trait within children with a medical condition. However, the lack of consistency across the studies and the large degree of variance in quality limit the conclusions that can be drawn from the results. Further research is needed to provide clarity on both the factors associated with resilience and their underlying processes in children with a medical condition.

Keywords: Systematic Review, Resilience, Paediatrics, Children, Medical Conditions

Introduction

A childhood medical condition is a disease or illness occurring between the ages of 0-18 years (WHO, 2014). Conditions range from mild with a limited impact on daily functioning, to life limiting requiring extensive medical intervention (Edwards & Titman, 2010). In the United Kingdom between $15 - 20\%$ of children are living with a chronic condition requiring ongoing medical intervention (ONS, 2002).

Living with a childhood medical condition can have a considerable impact on psychological functioning (Scandlyn, 2000). Children with a chronic medical condition are more likely to experience emotional difficulties than healthy peers (Glazebrook et al., 2003). Between 10-37% of children with a medical condition experience psychological distress, often related to adjustment to their condition (Meltzer et al., 2000). There is a common misconception that children with more life threatening conditions experience greater psychological distress than children with milder conditions. However, the literature elucidates that constructs such as cognitive deficits, pain, visible difference, daily functioning and the child's perception of their condition (Edwards & Titman, 2010) are more significant predictors of psychological distress than illness severity. In addition to factors pertinent to their medical conditions, children's psychological functioning may also be impacted by issues such as poverty, family stress and parental mental health difficulties (Brown et al., 2008). The National Service Framework for Children and Young People (DoH, 2003) advocates that medical services should consider all these factors when providing intervention to a child with a medical condition and not just treat the presenting illness.

Resilience in Children

Resilience can be defined as "the relative resistance to environmental risk or the overcoming of stress or adversity" (Rutter, 2006 p.2). The concept of resilience focuses on strengths as well as deficits and can be understood in terms of both risks and protective factors (Luthar, 2000). This definition stipulates that in order to demonstrate resilience, children must be flourishing despite exposure to adversity (Masten & Powell, 2003). The term resilience does not refer to a personality trait within the child, but a dynamic process (Luthar & Cicchetti, 2000). Masten (2001) contends that resilience is not an inherent quality of unique children; instead that all children are capable of demonstrating resilience if the right mechanisms are in place. Research into resilience has aimed to understand the risks and protective factors predicting resilience and the underlying processes that drive these, in children who have faced adversity.

Initially, the resilience research focused on identifying the individual characteristics that predicted resilience in children (Anthony, 1974). A number of characteristics such as self-regulation, self-efficacy, self-esteem, sense of competence, coping, independence, cognitive skills, optimistic thinking, problem solving skills, and emotional expressiveness have been found to be associated with resilience in children (Alvord & Grados, 2005; Bonanno & Mancini, 2008; Daniel & Wassell, 2002; Eisenberg et al, 2003; Masten, 2001). However, a recent review of children who had been maltreated ascertained that the evidence for the association between individual characteristics and resilience was weak (Afifi & Macmillan, 2011).

As research progressed over time clear associations were established between family environment and resilience in children. Family factors predictive of resilience

include authoritative parenting, warmth, stability, family cohesion, nurturance, emotional expression, parental mental wellbeing and relationships with siblings and grandparents (Afifi & Macmillan, 2011; Alvord & Grados, 2005; Benzies & Mychasuik, 2009; Daniel & Wassell, 2002).

In addition to individual and family factors, an association has been demonstrated between resilience and community factors such as positive peer relationships, non-kin support, community resources and religious and spiritual organisations (Action for Children, 2007; Afifi & Macmillan, 2011; Alvord and Grados, 2005; Obrist et al., 2010). In their review Afifi and Macmillan (2011) determined that supportive relationships with others consistently predicted resilience throughout the research literature.

Resilience in Children with a Medical Condition

Children with a medical condition can be described as "ordinary children confronting extraordinary challenges" (Houghton, 2005, p114), due to the considerable impact of their medical condition on daily functioning. As such, children with a medical condition can be viewed as 'facing adversity'. Exploring resilience in children with a medical condition may have multiple benefits. Edwards and Titman (2010) posit that by focusing on resilience, paediatric medical services could promote better psychological wellbeing. Furthermore, resilience has been associated with improved immune functioning and physical health (Tugade et al., 2004). The majority of the existing resilience research literature refers to child maltreatment and trauma, however over the last decade there has been an increase in resilience research in children with a medical condition. To the author's knowledge

there are no reviews to date exploring the factors associated with resilience in children with a medical condition.

Aims and Objectives

The purpose of this review is to summarise the findings of studies that explore factors contributing to resilience in children with a medical condition. The objectives of this review are to:

- Systematically review and summarise the current empirical research, exploring factors associated to resilience in children with a medical condition.

- Review the quality of the existing research and consider the implications of the findings for future clinical practice and service provision.

Method

The review was primarily conducted by a single researcher. However, a second reviewer also conducted the application of stage two screening criteria, quality assessment and cross-checking of data extraction. A review protocol was developed prior to conducting the literature search, which specified the eligibility criteria and search strategy (see Appendix A).

Eligibility Criteria

Studies were included in the review if they were of quantitative methodology, examined resilience in children aged 0-18 years with any medical condition and utilised a measure of resilience within the core measures of the study. Studies recruiting from both hospital and community samples were considered for inclusion in the review. Studies were only included if full-text articles were available. In an

effort to minimise bias, searching was not restricted to published papers only; dissertations, theses and conference materials were also considered for review.

Exclusion Criteria

Studies were excluded if they were; discussion or review papers, books, case studies or non-English language. Studies of children with an acute injury were excluded from the review. However, studies assessing resilience in children with a brain or burn injury were included due to the pervasive nature of these injuries and level of treatment and follow up care involved.

Information Sources

An electronic search was conducted using eight databases (CINAHL Plus, Global Health, MEDLINE, PsycARTICLES, PsycINFO, ScienceDirect, Scopus and Social Sciences Citation Index) between October and November 2014. All references were exported to EBSCOhost. References of studies included at screening were also hand-searched to ensure a comprehensive review.

Search Strategy

The following predetermined search terms were used to search the keyword list, title and abstract of articles on each database for relevant studies: (child* OR paediatric* OR pediatric*) AND ("chronic illness*" OR "chronic disease*" OR "medical condition*" OR "health condition*") AND (resilien*). References of studies included at screening were hand-searched for relevant titles.

Study Selection

The records identified through database searching were assessed for inclusion in two stages. First, all titles and abstracts obtained through electronic database searching were screened for relevant studies using the eligibility criteria. Any duplicate records were noted and excluded. Reference lists of the studies included at stage one were hand-checked for further relevant papers. In the second stage, full-texts of all the potentially relevant studies identified in stage one were obtained and assessed using the eligibility criteria. Only studies that met the eligibility criteria were included at stage two. Figure 1 presents a flow diagram of the screening procedure reported, in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009).

Quality Assessment Strategy

The PRISMA (Moher et al., 2009) guidelines stipulate that the quality of studies should be assessed as part of a systematic review. Studies chosen for inclusion were assessed for both methodological quality using the Newcastle-Ottawa Scale (NOS; Wells et al., 2012; see appendix B) and reporting quality, using the Strengthening the Reporting of Observational Studies in Epidemiology checklist (STROBE; von Elm et al., 2008). These tools were chosen as the most appropriate as they were devised for non-randomised, observational studies. It was deemed necessary to use both tools as they each served a different function. The NOS examines the quality of the research presented but does not incorporate an assessment of the reporting of research. Whereas the STROBE offers a useful framework for assessing the strength of the reporting of research, but does not assess

the quality of the research design and methodology. The NOS is a widely used quality assessment scale utilising a star scoring system. Two versions of the NOS were used; the case-control version (Wells et al., 2012) and an amended version for cross-sectional studies (Herzog et al., 2013). The case-control version is comprised of eight items with a possible total score of nine stars. The cross-sectional version is comprised of seven items with a possible total score of ten stars. The STROBE checklist provides guidance on how to report observational research and is comprised of 22 items, rated as 'yes', 'no' and not applicable, in this review we gave a maximum score of 26. To ensure reliability, two researchers independently quality assessed eligible papers.

Results

Database searching resulted in 1147 articles and 6 further studies were identified through references of studies included at screening. Following the removal of 345 duplicates, 802 articles were screened at the initial stage. Screening excluded 748 articles and identified 54 potentially eligible studies based on the eligibility criteria. The full-text papers of these studies were obtained through the University of Liverpool's electronic library system. The second stage of selection excluded 44 papers and 10 papers were selected for inclusion in the review. Due to poor reporting quality and statistical analysis, the results of the Firoozi et al. (2013) paper were difficult to infer. Therefore, the researchers agreed that the paper was not of sufficient quality to be included in the review synthesis. This resulted in a total of nine papers for final inclusion in the review. One of the studies identified for inclusion at the second stage of selection explored resilience in children and young people aged 10-26 years (Haase et al., 2014). Although this exceeded the upper age

bracket, the decision was made to include the study in the final review due to the large quantity of data it provided regarding children under 18. One of the final papers included in the review stated it was part one of a two part study (Haase et al., 2014). In order to exhaust the available literature the researcher contacted the author by email; however part two of the study was yet to be completed and was therefore not available for inclusion in this review.

Data were extracted from the studies on design, population characteristics and outcomes by the researcher and independently checked for accuracy by the second researcher. Data extraction databases were set up using Microsoft Excel spreadsheets. The final papers are discussed in a narrative synthesis.
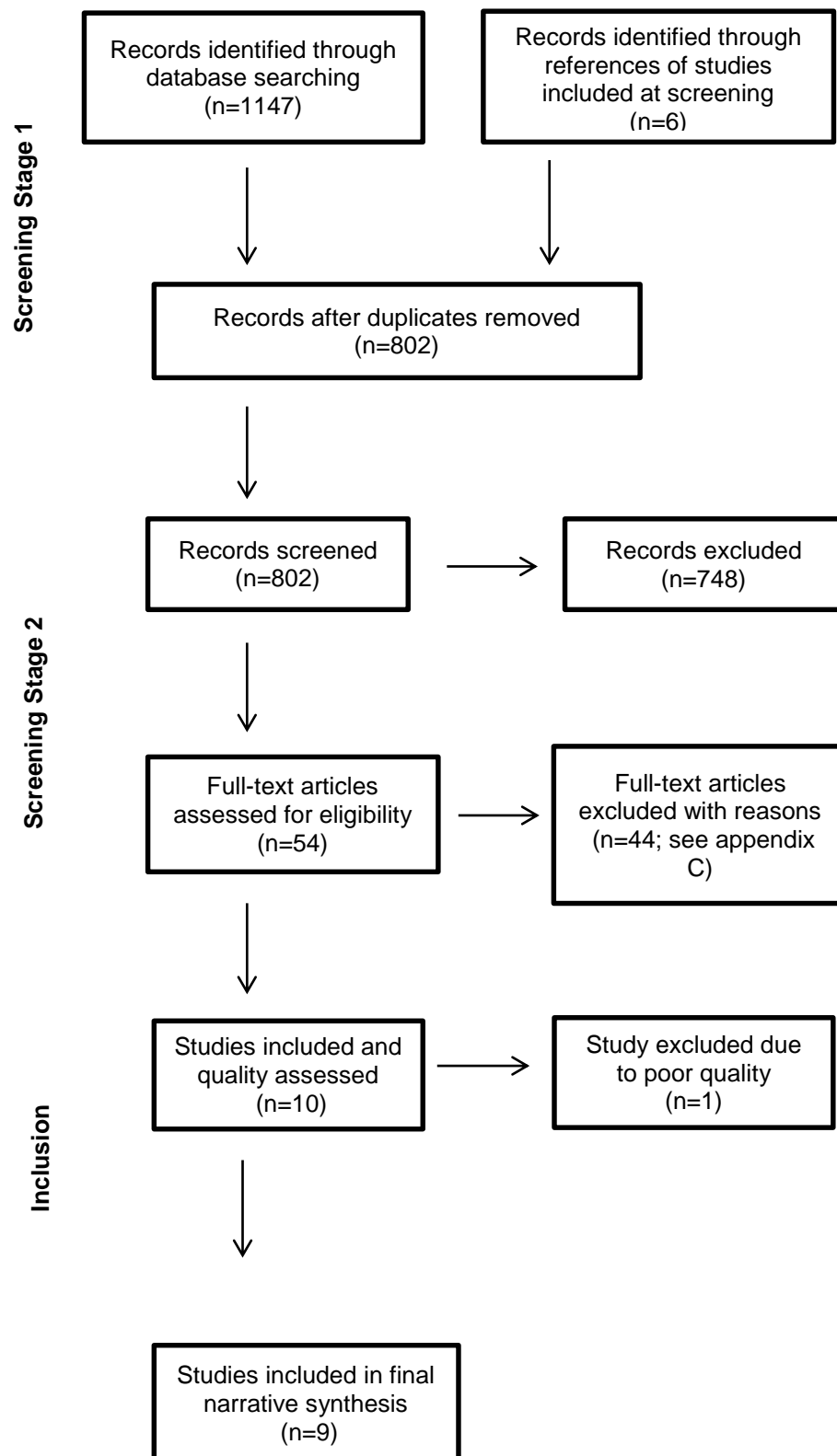
Figure 1. Flow diagram of studies included in the systematic review, based on the PRISMA guidelines.

Study Characteristics

Details of study characteristics are presented in Table 1. The studies were published between 2007 and 2014. Two of the studies utilised a case-control design (Chen et al., 2014; Tonks et al., 2011), whereas the other seven studies utilised a cross-sectional design (Haase et al., 2014; Harper et al., 2012; Im & Kim, 2012; Kim & Yoo, 2007; Kim & Yoo 2010; Powers, 2011; Wu et al., 2013). The studies were conducted in four different countries; USA, South Korea, Taiwan and UK and between 1999 and 2010, although two of the studies did not report dates of participant recruitment (Powers, 2011; Tonks et al., 2011). Sample size varied from 20 to 202 participants and age of participants ranged from 3 to 26 years-old across the studies. Five studies recruited from a community outpatient sample (Chen et al., 2014; Im & Kim 2012; Kim & Yoo 2007; Kim & Yoo 2010; Tonks et al., 2011), one recruited from a hospital inpatient sample (Harper et al., 2012), two from both community and hospital inpatient samples (Haase et al., 2014; Wu et al., 2013) and one from a burns camp (Powers, 2011). Five of the studies explored children affected by cancer (Chen et al., 2014; Haase et al., 2014; Harper et al., 2012; Kim & Yoo, 2010; Wu et al., 2013). The remaining four studies investigated children with atopic dermatitis (Im & Kim, 2012), asthma (Kim & Yoo, 2007), burn injury (Powers, 2011) and brain injury (Tonks et al., 2011).

Table 1. Study Characteristics

Author	Year	Country	Medical Condition	Age Range	Study *N*	Design	Total Quality Assessment Score
Chen et al	2014	Taiwan	Brain Tumour	13 – 18	180	Case-control	30/36
Haase et al	2014	USA	Cancer	10 – 26	202	Cross-sectional & Repeated measures*	25/35
Harper et al	2012	USA	Cancer	3 – 12	41	Cross-sectional	26/35
Im et al	2012	South Korea	Atopic Dermatitis	7 – 15	102	Cross-sectional	24/35
Kim et al	2007	South Korea	Asthma	10 – 15	86	Cross-sectional	18/35
Kim et al	2010	South Korea	Cancer	10 – 15	74	Cross-sectional	26/35
Powers	2011	USA	Burn Injury	9 – 18	20	Cross-sectional	24/35
Tonks et al	2011	UK	Brain Injury	9 – 15	91	Case-control	22/36
Wu et al	2013	Taiwan	Cancer	11 – 19	131	Cross-sectional	27/35

*In this study Haase et al (2014) combined the results of two studies; one of cross-sectional design and one of repeated measures design.

Overview of the Quality of Included Studies

Ten studies were quality assessed independently by two researchers. The total scores are presented in Table 1. Total scores were derived from the summation of the scores from both quality assessment measures. As the quality of reporting is integral to the assessment of methodological quality, the two scores were combined to provide an overview of the overall quality of each paper. One paper was subsequently removed from the review (Firoozi et al., 2013) as a result of poor quality, resulting in nine papers in the final analysis. The interclass correlation coefficient for the NOS was .99 and for the STROBE it was .98; indicating that inter-rater reliability was high. Cohen's K was also calculated for both the NOS ($K=$ .63, $p<.001$) and STROBE ($K=$ .43, $p<.05$). A kappa value of over .40 represents moderate strength of agreement. The quality of the papers varied, with Chen et al. (2014) ranking the highest on both the NOS and STROBE. The average score on the NOS was six; ranging from four (Powers, 2011; Tonks et al., 2011) to nine (Chen at al., 2014). The average score on the STROBE checklist of reporting quality was 18; ranging from 13 (Kim & Yoo, 2007) to 21 (Chen et al., 2014; Wu et al., 2013). Due to the variance in quality it was hard to draw firm conclusions regarding the overall quality of the studies included for review.

Resilience

All of the included studies explored factors associated with resilience; however identifying these factors was the main aim of only three of the studies (Haase et al., 2014; Im & Kim, 2012; Kim & Yoo, 2010). One study explored predictors of both resilience and anxiety (Wu et al., 2013). Two of the studies compared resilience outcomes in children with a medical condition to healthy

controls (Chen et al., 2014; Tonks et al., 2011). One study explored the association

between resilience and pain and distress ratings during medical treatment (Harper et

al., 2012). Kim and Yoo (2007) explored the relationship between depression and

resilience in children with asthma, and Powers (2011) examined the relationship

between resilience and post-traumatic stress symptoms in children with burn

injuries. As this paper aims to review the factors associated with resilience in

children with a medical condition, the synthesis of results will focus on these

outcomes and not necessarily the main outcome of the study.

All nine of the studies included in the synthesis utilised a measure of

resilience. Four different measures of resilience were used across the studies. Chen

and colleagues (2014), Haase and colleagues (2014) and Wu and colleagues (2013)

included the Haase Adolescent Resilience in Illness Scale (HARIS; Haase 2004).

Two studies employed the Resiliency Scales for Children and Adolescents (RSCA;

Price-Embury, 2007) (Powers, 2011; Tonks et al., 2011). Harper et al., (2012)

utilised the Eisenberg Resilience Scale (Eisenberg et al., 2003). The South Korean

papers (Im & Kim, 2012; Kim & Yoo, 2007; Kim & Yoo, 2010) used a measure

developed by one of the authors (Kim, 2002). Table 2 outlines the main findings for

each of the included studies.

Table 2. Main Findings of Included Studies

Author	Year	Aim	Resilience Measure	Summary of Main Findings
Chen et al.	2014	Compare resilience of adolescent survivors of brain tumours with healthy controls	Haase Resilience in Illness Scale (HARIS)	No sig. difference in resilience between ASBTs and controls. Emotional problems, religion and educational achievement sig. predicted resilience
Haase et al.	2014	Evaluate their Resilience in Illness Model in children with cancer	Haase Resilience in Illness Scale (HARIS)	Hope-derived meaning and courageous coping directly predict resilience
Harper et al.	2012	Examine relationships between children's positive attributes, pain/distress and parents empathic responses during cancer treatment	Eisenberg Resilience Scale	Children's pain/distress was sig. negatively correlated with resilience. Parent's empathic responses mediated the relationship between children's resilience and pain/distress
Im et al.	2012	Identify factors associated with resilience in children with atopic dermatitis	Kim Resilience Measure	Duration of illness and relationship with friend's sig. predicted resilience in children with atopic dermatitis
Kim et al.	2007	Examine the relationship between depression and resilience in children with asthma	Kim Resilience Measure	Depression scores were sig. negatively correlated with resilience. Affectionate and permissive parenting was sig. positively correlated with resilience.
Kim et al.	2010	Identify factors associated with resilience in children with cancer	Kim Resilience Measure	Family functioning and relationship with friends sig. predicted resilience in children with cancer
Powers	2011	Examine the relationship between resilience QoL and PTSS in burn injury	Resiliency Scales for Children and Adolescents (RSCA)	PTSS were sig. negatively correlated with resilience scores. psychosocial and physical quality of life were sig. positively correlated with resilience.
Tonks et al.	2011	Compare resilience in children with an ABI to healthy controls	Resiliency Scale for Children and Adolescents (RSCA)	Children with an ABI had lower resilience scores than controls. Anxiety and Depression scores were sig. negatively correlated with resilience in children with an ABI.
Wu et al.	2013	Examine the relationships between coping, anxiety and resilience in children with cancer.	Haase Resilience in Illness Scale (HARIS)	Cognitive coping and defensive coping sig. predicted resilience in children with cancer.

Note: Abbreviations: QoL – quality of life, PTSS – post traumatic stress symptoms, ABI – acquired brain injury, ASBTs – adolescent survivors of brain tumours.

Cross-sectional Study Outcomes

Haase and colleagues (2014) conducted an evaluation of their Resilience in Illness Model for adolescents with cancer. They combined the results of two separate studies and the sample consisted of both children and young adults (aged 10-26 years). The authors used the Haase Resilience in Illness Scale (HARIS; Haase, 2004). The study measured a large number of variables through the following scales; The Symptom Distress Scale (McCorkle, 1987), the Perceived Social Support from Friends (Procidano & Heller, 1983), The Family Adaptability and Cohesion Scale II (FACES II; Olsen, 1985), the Coping Scale-Revised (Jalowiec;1984), the Hope Index (Hearth; 1991), the Spiritual Perspective Scale (Reed; 1986) and the Self-transcendence Scale (Reed; 1989). There were a number of significant positive relationships with resilience including; spirituality ($r=$ .49, $p<$ .01), support from friends ($r=$ .32, $p<$ .01), support from family ($r=$ .42, $p<$ .01), family cohesion ($r=$ .40, $p<$ .01), family adaptability ($r=$ .46, $p<$ .01), family communication ($r=$.43, $p<$ .01), confrontive coping ($r=$ .31, $p<$ .01), optimistic coping ($r=$ .43, $p<$ .01), supportant coping ($r=$ .30, $p<$ .01), derived meaning: positive readiness/expectancy ($r=$ .69, $p<$ .01) and derived meaning: interconnectedness ($r=$ .61, $p<$ .01). There was a significant negative association between uncertainty in illness and resilience ($r=$ -.32, $p<$ .01); the higher the uncertainty in illness score, the lower the resilience score. Structural equation modelling was used to develop an exploratory model; this highlighted that only hope-derived meaning ($R^2=$ .76) and courageous coping ($R^2=$ .52) directly predicted resilience, whilst the other factors indirectly predicted resilience via these two concepts. It must be noted that 11.7% of the sample in this study were aged 20-26 years and the findings did not differentiate between child and

adult participants; as such this study is not homogenous with the other studies in the review.

Harper and colleagues (2012) assessed pain and distress in children aged 3-12 years, undergoing cancer treatment. They utilised the Eisenberg Resilience Measure (Eisenberg et al., 2003), adaptability, approach and persistence scales of the Carey Temperament Scales (Carey & McDevitt, 1997) prior to treatment. They also explored parent's empathic responses using the state subscale of the State Trait Anxiety Inventory (STAI; Speilberger, 1977) and six items from the Empathic Responses Questionnaire (Batson & Oleson, 1991). The difference in these two scores was calculated to provide an empathic affective response score. Children's pain and distress was measured using the Faces Scale (Wong & Baker, 1988) and rated by the children, parents, nurses and a trained observer. Children's pain ($r = -.36$, $p < .05$) and distress ($r = -.43$, $p < .01$) were significantly negatively correlated to resilience scores; the higher the resilience score, the lower the pain and distress. However, there was no significant relationship between children's temperament and their pain and distress ratings. Parent's empathic affective responses were significantly positively associated with resilience ($r = .41$, $p < .01$). Mediation analysis demonstrated that parent's empathic affective responses significantly mediated the relationship between child resilience and pain and distress ratings by trained observers ($F (1, 35) = 8.96$, $p = .01$, total $R^2 = .34$).

In their cross-sectional study, Im and Kim (2012) employed the Kim (2002) Resilience Measure to identify factors associated with resilience in children aged 7-15 years, with atopic dermatitis. They employed the Childrearing Behaviour Questionnaire (Park, 1995) to measure parenting practices; 14-items of the Personal Relationship Measurement (Kim, 1992) to measure friendships and 8-items from the

School Adjustment Test (Im, 1993) to assess relationships with teachers. Demographic variables including perceived academic performance, duration of illness and dermatitis severity were also collected. Duration of illness ($r = -.31$, $p < .05$), and disease severity ($r = -.35$, $p < .05$) were significantly negatively correlated with resilience; the shorter the illness duration and lesser the severity of illness, the higher the resilience scores. There was also a significant positive relationship between both mother's ($r = .38$, $p < .01$) and father's ($r = .36$, $p < .01$) warmth-acceptance and resilience scores. Relationship with friends ($r = .34$, $p < .01$) and teachers ($r = .35$, $p < .01$) were positively correlated with resilience scores. There was no significant relationship between mother's or father's rejection-restriction or permissiveness-non-intervention and resilience scores. Multivariate analysis showed that of all these correlations, only duration of illness ($\beta = .39$, $p < .01$) and relationship with friends ($\beta = .30$, $p < .01$) significantly predicted resilience in children with atopic dermatitis.

Kim and Yoo (2007) measured resilience alongside parenting attitude and depression in children aged 10-15 years, with asthma. They utilised the Kim (2002) Resilience Measure, Kwak's (1994) Parenting Attitude Questionnaire and a translated version of the Child Depression Inventory (Kovacs, 1985). Demographic variables collected included duration of illness and academic performance. The study reported that parenting attitude was positively correlated to resilience ($r = .46$, $p < .01$), specifically children whose parents scored higher on affection and permissiveness had higher resilience scores. Depression was negatively related to resilience ($r = -.52$, $p < .01$), children with lower depression scores had higher scores for resilience. In contrast to Im and Kim (2012) there was no significant correlation between duration of illness and resilience, although there was a significant

association between duration of illness and depression ($r=$ .27, $p <$.01). Multivariate analysis demonstrated that lower resilience scores predicted higher depression scores in the sample ($\beta=$ -.38, $p<$ .01).

In their study of factors associated to resilience in children aged 10-15 years with cancer, Kim and Yoo (2010) measured resilience, family functioning and relationship with friends and teachers. They employed the Kim (2002) Resilience Measure, the Family Adaptability and Cohesion Scale (FACES III; Lim et al., 1990), 14-items of the Personal Relationship Measurement (Kim, 1992) and 8-items from the School Adjustment Test (Im, 1993). Demographic variables included diagnosis and duration of illness. Both family adaptability ($r=$ .47, $p<$ .01) and family cohesion ($r=$ .51, $p<$ .01) were significantly positively correlated with resilience. Relationship with friends ($r=$ .52, $p<$ .01) and teachers ($r=$ .32, $p<$ .01) were also significantly associated with resilience. Multivariate analysis demonstrated that family function (family adaptability and cohesion; $\beta=$ .26, $p<$ .05) and relationship with friends ($\beta=$ .58, $p<$ .01) were significant predictors of resilience in children with cancer. However, relationship with teachers did not predict resilience despite a positive correlation.

Powers (2011) utilised the Resiliency Scales for Children and Adolescents (RSCA; Price-Embury, 2007) to measure resilience in children aged 9-18 years, with burn injuries. The questionnaire consists of three self-report subscales that measure sense of relatedness, mastery and emotional reactivity. The study also employed the University of California Los Angeles Post Traumatic Stress Disorder Reaction Index (Pynoos et al., 1998) to measure post-traumatic stress symptoms and the Pediatric Quality of Life Inventory (Varni et al., 1998). Information regarding the burn injury was sought from the child's medical records. The study found that post-traumatic

stress symptoms were significantly negatively correlated with relatedness (*r*= -.49, *p*< .05) and significantly positively correlated with emotional reactivity (*r*= .67, *p*< .01); the higher the post-traumatic stress symptoms the lower the relatedness score and higher the emotional reactivity score. Psychosocial quality of life was significantly positively correlated with both mastery (*r*= .76, *p*< .01) and relatedness (*r*= .80, *p*< .01) and significantly negatively correlated with emotional reactivity (*r*= -.74, *p*< .01). Physical quality of life was also significantly positively correlated with both mastery (*r*= .73, *p*< .01) and relatedness (*r*= .61, *p*< .01) and significantly negatively correlated with emotional reactivity (*r*= -.60, *p*< .01). The study was correlational only and did not conduct any multivariate analysis.

In their study of predictors of anxiety and resilience in children aged 11-19 years with cancer, Wu and colleagues (2013) employed the Haase Adolescent Resilience in Illness Scale (HARIS; Haase, 2004), the Revised Children's Manifest Anxiety Scale (RCMAS-2; Reynolds & Richmond, 2008) and the Paediatric Cancer Coping Scale (PCCS; Wu et al., 2011). All three types of coping; cognitive coping (*r*= .71, *p*< .001), problem oriented coping (*r*= .58, *p*< .001) and defensive coping (*r*= .25, *p*< .001) were significantly positively related to resilience. Total anxiety (*r*= -.23, *p*< .05), physical anxiety (*r*= -.21, *p*< .05) and social anxiety (*r*= -.30, *p*< .001) were significantly negatively associated with resilience; the lower the anxiety scores, the higher the resilience scores. However, there was no significant relationship between worry and resilience. Stepwise multiple regression analysis showed that cognitive coping (*β*= .75, *p*< .01) and defensive coping (*β*= -.17, *p*< .01) were significant predictors of resilience in children with cancer.

Case-control Study Outcomes

Chen and colleagues (2014) utilised a case-control design to compare the resilience of adolescent survivors of brain tumour (ASBTs) aged 13-18 years, with age-matched healthy controls. They employed the Haase Adolescent Resilience in Illness Scale (HARIS; Haase, 2004), a Chinese-version of the Health Utility Index Mark 2 (HUI2; Torrance et al., 1996) to measure health status. Demographic variables included education and religion. For ASBT participants, demographic variables also included diagnosis date, pathology and location of tumour and concurrent medical problems. The study found no significant difference between the resilience of ASBT participants and age-matched control participants. However, being classified as 'having emotional problems' was significantly predictive of resilience regardless of group (β= -.43, p< .01), indicating the higher the score for emotional problems the lower the resilience score. The study also found that having a religion (β= .16, p< .05) and being in the top two-thirds for educational achievement (β= .20, p< .01) were significant predictors of resilience. This contrasts with the results of other studies in this review who did not find a significant association between academic achievement or religion and resilience (Im & Kim, 2012; Kim & Yoo, 2007; Kim & Yoo, 2010). When considering the results of this study it is important to consider that the case group were survivors of brain tumours and therefore may present differently to those children who are currently under treatment for a chronic health condition.

Tonks and colleagues (2011) compared the resilience of children with an acquired brain injury (ABI) aged 9-15 years, with age-matched controls. They utilised the Resiliency Scales for Children and Adolescents (RSCA; Price-Embury, 2007) alongside the Beck Inventory for Youth (BYI-II; Beck et al., 2005) The study

found that children with an ABI scored lower for resilience than controls ($t_{89} = 2.35$, $p = .021$). Anxiety ($r = -.40$, $p < .05$) and depression ($r = -.50$, $p < .05$) scores were significantly negatively correlated with resilience scores in the ABI group, whereas only depression scores were associated to resilience in the control group ($r = .30$, $p < .01$). Mediation analysis demonstrated that the relationship between resilience and socio-emotional behavioural functioning was mediated by executive functioning (Sobel: $z = 4.74$, $p < .001$).

Discussion

In this review, empirical literature pertaining to resilience in children with a medical condition was systematically reviewed. Nine studies were included in the final review. A range of variables were found to be associated with resilience across the studies. In line with previous resilience literature (Alvord & Grados, 2005; Masten, 2001) individual child characteristics such as coping and academic attainment were associated with resilience in three of the studies (Chen et al., 2014; Haase et al., 2014; Wu et al., 2013). Furthermore, emotional difficulties were found to be negatively associated with resilience in four of the studies (Chen et al., 2014; Kim & Yoo, 2007; Powers, 2011; Tonks et al., 2011). In accord with previous resilience research (Afifi & Macmillan, 2011; Benzies & Mychasuik, 2009), family factors such as cohesiveness and parent's empathic responses were found to be associated with resilience in four of the studies (Harper et al., 2012; Im & Kim, 2012; Kim & Yoo, 2007; Kim & Yoo, 2007). Relationship with friends was also significantly associated with resilience in two studies (Im & Kim, 2012; Kim & Yoo, 2010).

Haase and colleagues (2014) suggest that family factors and support from friends are indirectly rather than directly associated with resilience, and that this is mediated by courageous coping and hope-derived meaning. However, all of the studies that assessed family and peer factors found some association with resilience. It could be argued that individual traits such as coping and meaning making are shaped by relationships with others and therefore intrinsically interlinked with family and community factors (Luthar & Cicchetti, 2000). Masten (2007) stated that resilience variables at different levels are interdependent on one another; this may also partly explain why the majority of correlations across the study were small to moderate.

Finally, variables such as duration of illness, pain and physical quality of life were associated with resilience in a number of the studies. However, this finding was not replicated in two studies (Kim & Yoo, 2007; Kim & Yoo, 2010). The divergence in the results of the studies makes a conclusive association difficult.

Limitations of Included Studies

There are a number of limitations within the studies included in this review that need to be considered when interpreting the results. As previously stated the quality of the included studies varied in terms of both study and reporting quality and average quality assessment scores were relatively low. This may partly explain why the majority of studies only found small to moderate correlations between the variables. Whilst each of the studies had individual limitations, there were common limitations across the studies. The studies were of cross-sectional design and as such only provided a snapshot of children's resilience at the point in time when they participated in the study. This is especially pertinent as resilience is seen as a

dynamic process that may change over time (Luthar et al., 2000). Longitudinal research needs to assess whether the resilience of children with a medical condition changes over time following diagnosis. The majority of included studies utilised correlational methods to identify factors associated with resilience; this does not prove causation. For example it could perhaps manifest that children who demonstrate resilience are better able to establish and maintain friendships as opposed to relationship with friends predicting resilience.

None of the studies reported information regarding power analysis and study sample sizes varied from 20-202 participants. This made it difficult to ascertain whether the studies comprised enough participants in order to detect significant differences. The majority of studies utilised a convenience sampling methodology for recruitment. This may have introduced bias into the sample as certain groups of people may have been more motivated to participate in the study; therefore it cannot be said that the samples were truly representative and generalisation may be somewhat limited.

Generalisation may be further limited due to the studies focusing on sole medical conditions, with six out of ten of the studies exploring resilience in children with cancer. Research is needed to explore resilience in children with other medical conditions. Furthermore, in two of the studies (Chen et al., 2014; Wu et al., 2013) the majority of participants were in remission. Although these participants are likely to have ongoing medical intervention due to the possibility of recurrence, this may have confounded results as resilience may differ between children currently facing medical symptoms and those in remission. It may also partly explain the variance in results across the studies.

Finally, a number of studies utilised a measure of resilience developed by their research team (Im & Kim, 2012; Kim & Yoo 2007; Kim & Yoo 2010). This could potentially introduce bias into interpretation of the results. Furthermore, this measure is not well validated, therefore it is difficult to assess whether it accurately measures the concept of resilience. These studies and the two Taiwanese studies (Chen et al., 2014; Wu et al., 2013) also translated the language of well validated measures and changed certain items, thus rendering their versions non-validated.

Limitations of the Review

First, only nine studies met the criteria for final inclusion in the review. This is a small number of papers given the wealth of research into resilience in children. As a result, it was not deemed appropriate to conduct a meta-analysis. The small number of papers achieved in this review may reflect the stringent application of the inclusion criteria. The resilience literature is complex and there have been various debates regarding the concept. Two such debates being; whether or not resilience is a concept that overlaps with other psychological processes and whether resilience is the opposite of vulnerability (Kaplan, 2013). This paper takes the view that resilience is not merely the absence of psychosocial difficulties (Rutter, 2006). As such, studies were excluded if they used problem checklists to measure resilience. Furthermore, in order to keep the review homogenous, studies were excluded if they measured concepts that may overlap with resilience such as adaptation or ego-resiliency. This ensured that the review was focused.

Second, the quality assessment tools utilised in this review had some limitations. The cross-sectional version of the NOS used is not validated by the NOS research team but adapted independently by Herzog and colleagues (2013). As such,

the rating systems are slightly different resulting in different overall scores making comparison of case-control and cross-sectional studies difficult. Furthermore, scoring system quality assessment tools are not as accurate as checklists as they do not ensure the same level of detail. For this reason, and because the NOS does not reflect the quality of the reporting, the STROBE checklist was used in addition to the NOS. Although this provided useful information regarding reporting quality, it must be noted that the STROBE is not a quality assessment tool.

Third, there may be publication bias in the studies included in the review. Although the author made an effort to include unpublished works such as dissertations (Powers, 2011), non-English language papers and qualitative studies were excluded from the review. Therefore it is possible that relevant studies were missed in the review. Additionally, resilience is defined as "the relative resistance to environmental risk or the overcoming of stress or adversity" (Rutter, 2006 p.2). Therefore by definition studies may not necessarily have to use a measure of resilience in order for resilience outcomes to be demonstrated. Studies that did not use a measure of resilience were excluded and this may have excluded important information. However, if the review did not implement this as an exclusion criterion the validity of the concept of resilience may have been undermined.

Finally, the review included one paper with a population that included children and young adults up to the age of 26 years (Haase et al., 2014). The focus of this review was children and young people and it is possible that factors associated with resilience in young adults may differ to those of children. Therefore the results of the Haase and colleagues (2014) paper cannot be generalised just to children. Nevertheless, it was thought that the study included important information regarding factors associated with resilience in children with a medical condition and therefore

it was chosen for inclusion. It is important to consider the bias that this study may introduce when interpreting the results of the review as a whole.

Clinical Implications and Future Research

The results of this review suggest that it is important to assess wider familial and community factors such as relationship with family and peers when exploring resilience in children with a medical condition. It may be helpful to consider these wider influences when thinking about building resilience in children with a medical condition rather than focusing interventions on the individual child.

Second, the studies that correlated emotional difficulties such as anxiety and depression with resilience all found a negative relationship (Chen et al., 2014; Kim & Yoo, 2007; Powers, 2011; Tonks et al., 2011). This suggests that children with higher resilience scores demonstrated lower emotional difficulties. This reaffirms the importance of exploring resilience in children with a medical condition; building resilience in children and families may increase wellbeing, and may decrease the association with the development of emotional difficulties.

Additionally the results suggest a small association between illness-related variables such as duration of illness and pain and resilience in children with a medical condition (Harper et al., 2012; Im & Kim, 2012). Furthermore, physical quality of life was found to be positively associated with resilience (Powers, 2011). It may be important to consider the impact of resilience over time following diagnosis of a medical condition. However, duration of illness was not found to be significantly related to resilience in three of the studies (Kim & Yoo, 2007; Kim & Yoo, 2010; Wu et al., 2013). Longitudinal research is needed to explore whether or not resilience in children with a medical condition changes over time; for example

following initial diagnosis or changes to functioning or quality of life. Furthermore, longitudinal research may further our understanding of the impact of pertinent time points such as adolescence on resilience and how family and peers influence resilience over time. This information may elucidate further the most appropriate interventions for promoting resilience and the timing for them.

Conclusions

Despite the variance in quality and findings, the results of this review support the existing child resilience research (Action for Children, 2007; Alvord & Grados, 2005), that posits there are a multiplicity of factors associated with resilience in children. Significant factors for children with a medical condition appear to be present at the level of the individual child, the family and the community. Coping, family and peer relationships were found to predict resilience across a number of studies of children with a variety of medical conditions. This provides further evidence that resilience is a complex multifactorial concept rather than an internal trait of the child. Although there were common themes across the studies, the findings and quality were varied and contradictory. It is therefore difficult to draw conclusive findings from this review. It is important that further high-quality research is conducted to clarify the factors involved in resilience in children with a greater variety of medical conditions. Furthermore, it is necessary to develop a greater understanding of the processes underlying individual, family and community factors in order to inform resilience building interventions.

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Chapter 2: Empirical Paper

Family environment and perceived community support: the impact on paediatric resilience[1]

Abstract

Objectives: To examine the impact of family environment and parental perceived community support on resilience and quality of life in children with a chronic medical condition. **Methods:** The Family Environment Scale (Moos & Moos, 2002), the Perceived Community Support Questionnaire (Gracia & Herrero, 2006), Resiliency Scales for Children and Adolescents (Price-Embury, 2007) and the Pediatric Quality of Life Inventory (Varni, 1998) were administered in a cross-sectional design to 139 families attending inpatient wards or outpatient clinics at a children's hospital in North West England, UK. **Results:** Multiple regression analysis indicated that high family cohesion and low family conflict somewhat predicted resilience but not quality of life in children with a chronic medical condition. Family expressiveness and parental perceived community support were not significantly associated with resilience or quality of life. Demographic variables including age and whether the child had accessed mental health services also significantly predicted both resilience and quality of life. **Conclusions:** The findings of this study suggest that higher levels of family cohesion could be a protective factor for resilience but not quality of life in children with a chronic medical condition. High family conflict may be a risk factor for lower resilience in children with a chronic medical condition. Clinical implications and further research are discussed.

Keywords: Resilience, Paediatrics, Quality of Life, Family Environment, Community Support.

Introduction

Resilience

Resilience is defined as "the relative resistance to environmental risk or the overcoming of stress or adversity" (Rutter, 2006 p.2). It encompasses two underlying constructs: adversity and positive adaptation; adversity representing negative life experiences such as living with a chronic medical condition, and positive adaptation referring to success or competency in certain tasks (Luthar & Cicchetti, 2000). Historically, resilience was postulated as an exceptional trait in children who thrived despite facing adversity (Anthony, 1974). However, more recent researchers such as Masten (2001) have described resilience as 'ordinary magic'. Masten advocates that resilience is not a personality trait of exceptional children, but a dynamic process that all children are capable of experiencing if the right systems are in place.

The dominance of the medical model in psychiatry has resulted in an emphasis on pathology and deficits in understanding psychological difficulties. Masten and Curtis (2000) maintain that by focusing on deficits, positive aspects of functioning may be neglected. An emphasis on resilience enables us to move away from a pathological language towards the promotion of strengths. Seligman (2000) posits that fostering competency rather than modifying areas of weakness is vital in the prevention of psychological difficulties. As such, building resilience in children may protect against later psychological difficulties and the development of stigma (Seligman, 2000).

Children with a Chronic Medical Condition

Children with a chronic medical condition can be described as facing adversity. In addition to the physical impact of their chronic illness, these children may encounter invasive treatment regimes, visible difference, treatment side-effects, separation from family and peers and disruption of education (Phipps, 2007). Edwards and Titman (2010) call for an emphasis on improving quality of life and wellbeing for children with a chronic illness in addition to caring for their medical needs. They postulate that this would enable children to adjust positively to any challenges resulting from their medical condition. The paediatric literature has traditionally focused on outcomes of quality of life whilst the mental health literature has assessed resilience (Lawford & Eiser, 2001). Quality of life can be defined as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (WHO Quality of Life Group, 1994). The present study aims to extend the paediatric literature by focusing on resilience as well as quality of life.

Multiple Levels of Resilience

The resilience literature has historically centred on identifying individual characteristics predictive of resilience in children. Coping skills, problem solving, self-efficacy, self-regulation, expressiveness, reflectiveness, sense of competence, optimism, autonomy, cognitive skills, temperament and communication skills have all been identified as predictive of resilience in children (Alvord & Grados, 2005; Bonanno & Mancini, 2008; Daniel & Wassell, 2002; Masten, 2001). However, more recent research suggests that resilience operates at multiple levels and that family

and community factors are also integral (Landau, 2010). Furthermore, these levels interact with and impact one another (Masten, 2007). Masten (2001) suggests that individual resilience factors may be a product of family and community factors, for example self-regulation manifesting through attachment processes (Fonagy, 2003). Goldstein and Brooks (2013) advocate that resilience research should centre on the interaction between the child and their social environment.

Family Environment

Family environment has repeatedly been found to be predictive of resilience in children. Pertinent family factors include cohesion and warmth, emotional support, emotional expressiveness, secure attachment style, encouragement of independence and stability (Alvord & Grados, 2005; Benzies & Mychasuik, 2009; Daniel & Wassell, 2002).

A wealth of research has demonstrated the importance of family environment in children with a chronic medical condition. A more supportive family environment is predictive of better adjustment in children with medical conditions such as atopic eczema and burn injuries (Dennis et al., 2006; LeDoux et al., 1998), whilst family cohesion has been found to be correlated with support seeking in children with sickle cell disease (Kliewer & Lewis, 1995). Inversely, the family environment may also impact on a child's medical condition. Malhi and Singh (2002) established that children with juvenile arthritis reported less pain if they judged their families to be more supportive. Moreover, family environment has been correlated with treatment compliance in children with cystic fibrosis and chronic kidney disorders (Soliday, 2001; Standen et al., 1985).

A number of studies have demonstrated an association between family environment and resilience in children with chronic medical conditions such as cancer (Kim & Yoo, 2010). A study of children with asthma reported that affectionate and permissive parenting style was associated with resilience in the child (Kim & Yoo, 2007). Furthermore, Harper and colleagues (2012) established that parental empathy mediated the relationship between children with cancer's resilience and their levels of pain and distress. Other factors such as parental warmth and acceptance, family cohesion and expressiveness have been found to be associated with resilience in children with a chronic medical condition (Lee et al., 2003; McCubbin et al., 2002).

Community Support

In addition to individual and family factors; community support has also been found to be predictive of resilience in children. Obrist and colleagues (2010) contend that an individual's success is partly dependent on the resources and success of their community. Ungar (2011) further developed this by suggesting that resilience could be understood as the ability of individuals to access the resources they need from the community to establish and maintain their wellbeing.

The construct of 'sense of community' can be understood as the perception of belongingness and feeling that you are part of a larger structure (McMillan & Chavis, 1986). A strong sense of community has been associated with increased feelings of psychological wellbeing (Herrero & Gracia, 2007). People who are more socially integrated are more likely to have higher quality social interactions and be less reactive to stress (Cohen et al., 2000). Interestingly, it is the level of perceived community support rather than actual measured support that seems to predict

wellbeing (Jackson & Warren, 2000). Runyan and colleagues (1998) suggest that even young children directly benefit from the extent of their parent's community support.

A number of studies have demonstrated the relationship between community support and resilience in children. Factors such as positive relationships with non-kin adults, good peer relations, safe neighbourhoods, religious organisations and relevant support and recreational facilities are all associated with increased resilience in children (Action for Children, 2007; Alvord & Grados, 2005; Wright et al., 1997).

A small number of studies have explored the impact of community support on resilience in children with a chronic medical condition. Relationship with friends has been identified as an important predictor of resilience in children with atopic dermatitis (Im & Kim, 2012) and cancer (Kim & Yoo, 2010). Social environment has also been found to be associated with resilience in children with Duchenne's muscular dystrophy (Fee & Hinton, 2011). Two qualitative studies of resilience in children with cancer also suggest that support from the community is vital in fostering resilience in the child (Lee et al., 2003; McCubbin et al., 2002).

Given that both family environment and perceived community support are predictive of resilience in children, it seems appropriate to extend the literature to children with a chronic medical condition. Previous research in this area has focused on sole medical conditions rather than exploring the predictors of resilience across medical conditions. A better understanding of the impact of family environment and parental perceived community support on resilience in this population may contribute to and inform clinical interventions to foster and maintain resilience in children with chronic medical conditions.

Aims and Hypothesis

The aims of this study are to explore the impact of both family environment and parental perceived community support on the resilience and quality of life of children with a chronic medical condition. It is hypothesised that 1) family cohesion will be positively correlated with resilience, 2) family cohesion will be positively correlated with quality of life, 3) family expressiveness will be positively correlated with resilience, 4) family expressiveness will be positively correlated with quality of life, 5) family conflict will be negatively correlated with resilience, 6) family conflict will be negatively correlated with quality of life, 7) higher parental perceived community support will be positively correlated with resilience 8) higher parental perceived community support will be positively correlated with quality of life, 9) family environment and parental perceived community support will predict resilience, 10) family environment and perceived parental community support will predict quality of life. The study aims to identify the strongest predictors of resilience in children with a chronic medical condition. Finally, the study will consider any other pertinent demographic predictors of resilience in children with a chronic medical condition, particularly time since diagnosis and the presence of multiple medical conditions.

Method

Participants

A total of 139 children with a chronic medical condition and their parents were recruited from a children's hospital, in the North West of England, UK between August 2014 and March 2015. Families were eligible to participate if they met the following criteria: the child was a) aged 9-18 years (due to the self-report

nature of the questionnaires), b) had a medical condition lasting three months or longer, c) an inpatient or outpatient of the hospital, d) the child and at least one parent agreed to participate, e) both the child and participating parent(s) could understand written English. A total of 142 questionnaires were returned and final analysis was conducted on 139 questionnaires as three were excluded due to extensive missing data. Children ranged in age from 9-18 years (M= 13.62 years, SD= 2.36). Over half of the child participants were female (N= 61.9%) and 94.2% of the participants identified as White British. Almost three quarters of parents reported that they were currently working (N= 103) and 71.2% of parents were married or co-habiting with their partner. A total of 33.1% of the child participants (N= 46) and 17.3% of the parents had accessed mental health services (N= 24). The average time since diagnosis of the child's medical condition was 4.7 years. Eleven of the children were inpatients at the time of recruitment and 128 were outpatients attending a clinic appointment. The percentage of children with multiple medical conditions was 30.9% (see Table 2 for details of medical specialities).

Power and Precision

G-Power calculations (Faul et al., 2007) were used to estimate the minimum number of participants required to detect medium effects at .80 power at an alpha of .05, as recommended by Cohen (1988). One hundred and thirty one participants were required for hierarchical multiple regression ($f^2 = 0.15$), based on thirteen predictors, to achieve .80 power at an alpha of .05. The minimum estimated sample size for the study was surpassed (actual $N = 139$) and achieved power was .83.

Design

The research design was of cross-sectional methodology, utilising paper-based questionnaires.

Measures

Parent measures

Demographic questionnaire. Participant demographic information was collected, including child's gender and age, number of siblings, ethnic group, religion, marital status, social economic status as measured by postcode deprivation index, child's medical condition, time since diagnosis, number of school absences, number of inpatient admissions and whether the child or parent had accessed mental health services.

The family environment scale (FES; Moos & Moos, 2002: relationship dimension). The FES is a 90-item scale measuring family environment (Moos & Moos, 2002) across three dimensions; relationship, personal growth and system maintenance. Only the relationship dimension of the scale was utilised within the study; which is comprised of three 9-item subscales; cohesion, expressiveness and conflict. Participants respond to statements about families with a 'true' or 'false' response. The scale has been used extensively within family research. The three subscales have good internal consistency ranging from .69 to .78 (Moos & Moos, 2009). In the current study internal consistency ranged from $\alpha = .60$ to .70 across the three subscales.

Perceived community support questionnaire (PCSQ; Gracia and Herrero, 2006). The PCSQ is a 14-item scale of perceived community support. It is comprised of 3 subscales measuring community integration, community

participation and community organisation. It is scored on a 5-point Likert scale, ranging from one (strongly disagree) to five (strongly agree). The PCSQ yields a total score in addition to the three subscale scores. Internal consistency for the whole scale is good ($\alpha > .86$) and ranged from $\alpha = .75$ to .88 for the three subscales (Herrero & Gracia, 2007). In the current study, the Cronbach's alpha coefficient for the overall scale was $\alpha = .92$.

Child measures

The resiliency scales for children and adolescents (RSCA; Price-Embury, 2007). The RSCA is a 64-item measure of child resilience, validated for children aged 9-18 years. It is comprised of 3 subscales; mastery, relatedness and emotional reactivity. Participants respond to items on a 5-point Likert scale regarding frequency, ranging from zero (never) to four (almost always). An overall resource score and vulnerability score can be calculated from the three subscale scores, indicating the level of resilience. A higher score on the mastery and relatedness scales indicates increased mastery and relatedness and therefore higher resilience. Conversely, a lower score on the emotional reactivity scale indicates lower emotional reactivity and therefore higher resilience. Internal consistency for the three scales is rated as good-excellent, ranging from $\alpha = .85$ to .95. Confirmatory factor analysis has demonstrated good validity (Thorne & Kohut, 2007). In the current study internal consistency ranged from $\alpha = .94$ to .96 across the three subscales.

The pediatric quality of life inventory (PedsQL; Varni, 1998). The PedsQL is a 23-item measure of health related quality of life in children. It is composed of four subscales; physical, emotional, social and school functioning. Participants respond to items on a 5-point Likert scale regarding frequency, ranging from zero (never) to

four (almost always). Percentage scores are yielded from the four subscales to provide a Total Quality of Life Score, a Physical Functioning Score and a Psychosocial Functioning Score (a combination of emotional, social and school functioning). Internal consistency in all scales is acceptable ($\alpha = >.70$. In the current study, the Cronbach's alpha was $\alpha = .95$.

Procedure

The study received ethical approval from the National Research Ethics board in May 2014. Study advertisement posters were displayed in clinic waiting rooms and wards across the hospital in order to recruit children with a range of medical conditions. Self-report questionnaire packs were left in clinic waiting rooms and on the wards. Families were directed to complete questionnaire packs by the researcher or clinic/ward staff whilst they were waiting for their appointment or during their inpatient stay. Reasons for non-completion included lack of time and feeling unwell. Standardised information sheets were provided in the questionnaire packs for both child and parent participants. Participants consented to the study by completion and return of the questionnaires. Families had the option to complete the questionnaires in the hospital or return by post; 87.49% of questionnaires were completed whilst in the hospital. Instructions advised that the child complete the child measures independently. The parental measures could be completed by either or both parents together or independently. The questionnaires took approximately 20 minutes to complete.

Statistical Analysis

Preliminary data screening was conducted to check the data for missing values and violations of homogeneity, normality and linearity. Item-mean imputation was utilised in occurrences of <10% of missing data on one measure. The exceptions to this were the Pediatric Quality of Life Inventory as total scores were calculated based on means and the Family Environment Scale as individual item answers were either true or false so an item-mean could not be calculated. Therefore, items on these measures were counted as missing. Two participants were missing more than 10% of items on more than one measure and were subsequently removed from the data. The assumptions of normality were violated by a number of variables and as such parametric analysis could not be conducted. To investigate hypotheses one, two and three, Spearman's correlations were conducted. Due to the number of Spearman's correlational analyses being performed and therefore the risk of Type I error, bonferroni post-hoc correction was calculated to indicate a revised alpha of p <.003. Additionally, point-biserial correlations were performed on a number of dichotomous demographic variables. Hierarchical multiple regression was conducted to examine hypotheses four and five. Regression residuals were examined for homoscedasticity and normality; as these assumptions were not met bootstrapping was utilised. Bootstrapping approximates the features of the distribution from the sample data (Field, 2013). Collinearity diagnostics demonstrated that multicolinearity was not a problem within the data set.

Results

Descriptive Statistics

Means and standard deviations for the main study variables are reported in Table 1. Reported means for all three subscales of the Family Environment Scale were within the expected norms for non-distressed populations. Mean score rankings on the measures of the RSCA were also within the average range. The mean score reported for the PEDSQL in this study was below the expected norm for healthy children, as expected.

Mean scores were calculated for individual medical specialities (Table 2). The mean scores for the resilience resource index were highest in children with cardiology, dermatology, haematology and neurosurgery conditions, whereas the mean scores for the resilience vulnerability index were highest for children with general paediatric, gynaecology, nephrology and neuro-oncology conditions. Mean quality of life scores were highest in children with craniofacial, dermatology, diabetes, endocrinology and respiratory conditions, and lowest in children with cardiology, chronic fatigue, gynaecology, oncology and neuromuscular conditions.

Table 1.
Descriptive statistics for study variables (N =139)

Measure	*Mean*	SD	Range	Expected Norm
FES Cohesion	54.5	11.0	11-65	50
FES Expressiveness	48.6	13.4	22-71	50
FES Conflict	45.7	10.8	33-75	50
PCSQ Total	44.3	11.7	14-69	-*
RSCA Emotional Reactivity	50.5	12.0	23-90	50
RSCA Relatedness	49.4	12.2	1-68	50
RSCA Mastery	47.7	11.8	13-74	50
RSCA Resource Index	48.7	12.1	14-72	50
RSCA Vulnerability Index	51.1	12.3	25-86	50
PEDSQL Total	69.5	20.6	14.13-100	83.84

Note. FES = Family Environment Scale; PCSQ = Perceived Community Support
Questionnaire; RSCA = Resiliency Scales for Children and Adolescents; PEDSQL =
Pediatric Quality of life Inventory. *No norm reported for PCSQ.

Table 2.
Medical speciality of participants and mean for study variables (N=139)

Medical Specialty	N	%	M(SD) RSCA Resource	M(SD) RSCA Vulnerability	M(SD) Peds QL
Allergies	2	1.4	45.5(26.2)	50.0(22.6)	77.7(13.1)
Cardiology	3	2.2	57.7(7.8)	44.3(3.1)	55.6(17.1)
Chronic Fatigue	2	1.4	55.0(8.5)	45.5(4.9)	54.9(19.2)
Chronic Pain	7	5	54.9(9.6)	43.6(10.5)	58.0(25.5)
Craniofacial	1	0.7	45.0	58.0	90.2
Cystic Fibrosis	3	2.2	49.7(12.6)	51.7(12.5)	70.0(6.9)
Dermatology	1	0.7	67.0	31.0	100
Diabetes	14	10.1	50.2(14.6)	47.3(13.0)	82.1(12.8)
Endocrinology	4	2.9	51.8(13.9)	46.0(15.5)	87.2(12.5)
Gastroenterology	13	9.4	52.2(12.6)	50.8(14.2)	75.2(18.8)
General Paediatrics	2	1.4	37.5(23.3)	60.0(19.8)	59.0(51.0)
Gynecology	1	0.7	36.0	76.0	29.4
Haematology	1	0.7	59.0	53.0	77.2
Nephrology	1	0..7	39.0	62.0	68.5
Neuro-oncology	2	1.4	35.5(4.9)	61.0(9.9)	60.3(37.7)
Neurology	13	9.4	44.8(8.2)	54.6(8.2)	59.0(15.2)
Neuromuscular	4	2.9	43.8(9.9)	54.3(8.5)	44.3(7.2)
Neurosurgery	2	1.4	59.0(17.0)	40.0(17.0)	70.3(19.5)
Oncology	4	2.9	39.3(17.4)	56.3(21.0)	54.9(11.7)
Orthopaedics	2	1.4	46.5(2.1)	50.0(2.8)	80.6(15.6)
Orthotics	1	0.7	50.0	54.0	70.7
Plastic Surgery	2	1.4	46.5(0.7)	56.0(0.0)	80.4(10.8)
Respiratory	2	1.4	53.5(4.9)	48.0(9.9)	87.0(4.6)
Rheumatology	33	23.7	49.1(11.4)	50.0(11.2)	70.0(21.2)
Surgery	5	3.6	47.0(10.3)	55.5(8.7)	69.0(10.4)
Urology	14	10.1	49.0(12.2)	51.0(12.3)	69.4(20.6)

Note. RSCA = Resiliency Scales for Children and Adolescents; PEDSQL = Pediatric Quality of life Inventory

Table 3.

Spearman's correlations of examined variables

	RSCA Resource	RSCA Vulnerability	PEDS QL	FES Coh	FES Exp	FES Con	PCSQ	Age	No. of sibs	Postcode depr	Multi med conds	Years since diax	No. Inpx admiss
RSCA Resource													
RSCA Vulnerability	-.894*												
PEDSQL	.566*	-.583*											
FES Coh	.387*	-.397*	.311*										
FES Exp	.193	-.175	.143	.340*									
FES Con	-.323*	.385*	-.222	-.495*	-.203								
PCSQ	.202	-.227	.169	.338*	.236	-.236*							
Age	-.326*	.260*	-.034	-.164	-.038	.109	-.124						
No. of sibs	-.195	.196	-.173	-.140	.068	.169	.027	-.032					
Postcode Deprivation	.157	-.119	.104	.177	.158	-.203	.201	.003	-.098				
Multi med Conditions	-.160	.195	-.285*	-.144	-.064	.100	-.104	.122	-.040	-.093			
Years since Diagnosis	-.170	.152	-.108	-.033	-.155	.121	.055	.166	.017	.091	.211		
No. of inpt Admissions	-.140	.112	-.222	-.121	.033	.015	-.033	.048	-.090	.033	.241	.298*	
Days off School	-.169	.151	.336*	.005	-.055	-.068	.006	.022	-.036	-.041	.063	.118	.361*

Note. RSCA Resource = Resiliency Scales for Children and Adolescents Resource Index; RSCA Vulnerability = Resiliency Scales for Children and Adolescents Vulnerability Index; PEDSQL = Pediatric Quality of Life Inventory; FES Coh = Family Environment Scale Cohesion Subscale FES Exp = Family Environment Scale Expressiveness Subscale; FES Con = Family Environment Scale Conflict Subscale; PCSQ = Perceived Community Support Questionnaire; No. of sibs = Number of siblings; Multi med conditions = Multiple medical conditions; No. of inpt admissions = number of inpatient admissions.

*p <.003

Correlations between Resilience, Family Environment and Parental Perceived

Community Support

In line with hypothesis one there was a moderate positive correlation between the resilience resource index and family cohesion (r_s = .387, n = 139, p < .003), with higher family cohesion associated with higher resilience. A moderate negative correlation was found between the resilience resource index and family conflict (r_s = -.323, n = 139, p < .003) with higher family conflict associated with lower resilience; providing support to hypothesis five. Similar inverse relationships were observed with these variables and the vulnerability index of the RSCA (see Table 3). There was no statistically significant relationship between family expressiveness or parental perceived community support and either of the resilience indices; therefore hypothesis three and seven are not supported.

A strong positive correlation was observed between the resilience resource index and quality of life (r_s = .566, n = 139, p < .003), with higher perceived quality of life being associated with increased resilience. A number of demographic variables were also significantly correlated with resilience. Point-biserial correlation (see Table 4) demonstrated a moderate relationship between children accessing mental health services and the resilience resource index (r_{pb} = .366, n = 139, p < .01), suggesting that children who had not accessed support from mental health services tended to score higher for resilience. There was a moderate negative relationship between child age and the resilience resource index (r_s = -.326, n = 139, p < .003), indicating that the older participants were, the lower their resilience scores. Having accessed mental health services (r_{pb} = -.405, n = 139, p < .001) and child age (r_s = .260, n = 139, p < .003), were also significantly correlated with the vulnerability index of the RSCA. Additionally, a small statistically significant

correlation was observed between the vulnerability score and parental access to mental health services ($r_{pb} = .196$, $n = 139$, $p < .05$), suggesting that children whose parents had accessed mental health services tended to score higher on the vulnerability index. Socioeconomic status, number of siblings, years since diagnosis, multiple medical conditions, school absences and number of inpatient admissions were not significantly correlated with either the resilience resource or vulnerability indexes.

Table 4.
Point-biserial correlations

	Resilience Resource	Resilience Vulnerability	Quality of Life
Child accessed mental health services	.366**	.405***	.484**
Parent accessed mental health services	.141	.196*	.297**

*$p <.05$, **$p <.01$, ***$p <.001$*

Correlations between Quality of Life, Family Environment and Parental Perceived Community Support

In line with hypothesis two there was a significant moderate positive association between quality of life and family cohesion ($r_s = .311$, $n = 139$, $p < .003$), with higher family cohesion correlating with higher perceived quality of life. No statistically significant relationship was found between quality of life and family expressiveness, family conflict or parental perceived community support, refuting hypotheses four, six and eight. Point-biserial correlation (see Table 4) revealed a strong statistically significant relationship between quality of life and children who had accessed mental health services ($r_{pb} = .484$, $n = 138$, $p < .01$), suggesting that children who had not accessed support from mental health services tended to score higher for quality of life. There was also a moderate association between quality of

life in children and parents who had accessed mental health service ($r_{pb} = .297$, $n = 133$, $p < .01$), indicating that children whose parents had not accessed mental health services tended to score higher on quality of life. A significant moderate negative relationship was observed between number of school absences and quality of life ($r_s = -.336$, $n = 139$, $p < .003$), with increased school absences associated with lower quality of life. A small significant negative relationship was observed between quality of life and multiple medical conditions ($r_s = -.285$, $n = 139$, $p < .01$), indicating that more medical conditions are associated with lower quality of life scores. There was no significant relationship between child age, number of siblings, socioeconomic status, years since diagnosis or number of inpatient admissions and quality of life.

Predictors of Resilience

Hierarchical multiple regression was conducted to examine whether parental perceived community support and family environment predicts resilience in children with a medical condition, after controlling for other instrumental variables either theoretically linked or significantly correlated with resilience. Age and socioeconomic status were entered into the model at Step 1, explaining 13.4% of the variance in resilience (F (2, 130) = 10.06, p <.001). Number of medical conditions, years since diagnosis, school absences, child accessed mental health services and parent accessed mental health services were entered into the model at Step 2, explaining 24.8% of the variance (F (7, 125) = 5.89, p <.001). After entry of the FES and PCSQ at Step 3 the total variance explained by the model as a whole was 33.1%, F (11, 121) = 5.44, p <.001. In line with hypothesis nine, family environment and parental perceived community support explained an additional 8.3% of the variance

in resilience, after controlling for the other variables (R^2 change = .083, F change $(4, 121) = 3.75$, $p <.01$). In the final model only family cohesion, age of child and child accessed mental health services were statistically significant predictors of resilience (FES Coh $\beta = .23$, $p <.05$; age of child $\beta = -1.20$, $p <.01$; accessed mental health services $\beta = 5.60$, $p <.05$).

Hierarchical multiple regression was also conducted to explore whether parental perceived community support and family environment predict the RSCA vulnerability score. Age and socioeconomic status were entered into Step 1 of the model, explaining 8% of the variance ($F_{(2, 130)} = 5.68$, $p < .01$). Number of medical conditions, years since diagnosis, school absences, child accessed mental health services and parent accessed mental health services were entered in Step 2 of the model, explaining 23.2% of the variance ($F_{(7, 125)} = 5.41$, $p < .001$). FES and PCSQ were entered at Step 3 and the total variance explained by the model was 32.8%, $F_{(11, 121)} = 5.38$, $p < .001$. In line with hypothesis nine, family environment and parental perceived community support explained an additional 9.6% of the variance in resilience, after controlling for the other variables (R^2 change = .096, F change $(4, 121) = 4.33$, $p < .01$). In the final model family conflict, age of child and child accessed mental health services were statistically significant predictors of vulnerability (family conflict $\beta = .22$, $p <.05$; age of child $\beta = .84$, $p <.05$; accessed mental health services $\beta = -6.59$, $p <.01.$).

Table 5.
Hierarchical Multiple Regression Model

	Step 1	Step 2	Step 3
Resilience Resource			
R^2	.134	.248	.331
R^2 change	.134	.114	.083
F	10.06	5.89	5.44
p value	.000	.000	.000
Resilience Vulnerability			
R^2	.080	.232	.328
R^2 change	.080	.152	.096
F	5.68	5.41	5.38
p value	.004	.000	.000
Quality of Life			
R^2	.014	.351	.369
R^2 change	.014	.336	.018
F	.95	9.64	6.42
p value	.388	.000	.000

Step 1: Socioeconomic status, Age of Child.
Step 2: Step 1 + Parental access to mental health services, school absences, years since diagnosis, number of medical conditions, child accessed mental health services.
Step 3: Step + Step 2 + FES Expressiveness, FES Cohesion, FES Conflict, Perceived community support.

Predictors of Quality of Life

Finally, hierarchical multiple regression was used to examine family environment and parental perceived community support as predictors of quality of life in children with a medical condition. Age and socioeconomic status were entered into the model at Step 1, explaining 1.4% of the variance ($F (2, 130) = .95$, $p =.388$). Number of medical conditions, years since diagnosis, school absences, child accessed mental health services and parent accessed mental health services were entered into the model at Step 2, explaining 35.1% of the variance ($F (7, 125) = 9.64$, $p <.001$). The FES and PCSQ were entered at Step 3 and the total variance explained by the model was 36.9%, $F (11, 121) = 6.42$, $p <.001$. Family environment

and parental perceived community support only explained an additional 1.8% of the variance in quality of life. After controlling for the other variables, this was not statistically significant (R^2 change = .018, F change (4, 121) = .867, p = .486). Therefore, hypothesis ten could not be supported. In the final model only child accessed mental health services and school absences were statistically significant predictors of quality of life (accessed mental health services β = 14.40 p <. 01, school absences β = -2.48, p <.01).

Discussion

This study was designed to investigate the impact of family environment and parental perceived community support on resilience and quality of life in children with a chronic medical condition. To the best of the author's knowledge this is the first study in which these factors have been explored across children with a range of medical conditions. The main finding was that family environment was predictive of resilience but not of quality of life in children with a chronic medical condition, whereas perceived parental community support was not associated with resilience or quality of life.

In accordance with previous findings (Kim & Yoo, 2007; Kim & Yoo, 2010), family cohesion and family conflict were associated with resilience; such that increased family cohesion was associated with increased resilience and increased family conflict was associated with decreased resilience. This augments the growing body of literature that suggests that family environment is integral to the resilience of children with a chronic medical condition (Kim & Yoo, 2007; Kim & Yoo, 2010). In contrast to previous research (Alvord & Grados, 2005) family expressiveness and parental perceived community support did not appear to be associated with resilience.

In the final regression model only family cohesion was statistically significant in predicting the resilience resource index and family conflict in predicting resilience vulnerability. This suggests that family cohesion may be a protective factor for higher resilience, whilst family conflict may be a risk factor for lower resilience. Family expressiveness was not found to predict resilience. This suggests that family cohesion; the degree to which family members provide support, help and commitment to one another, may be more important in building resilience in children with a chronic medical condition than the extent to which they express their feelings to one another. This could be due to a number of factors. Kennedy (1999) stipulates that family cohesion is also associated with the development of a secure attachment style. If children have a secure attachment style they are more likely to be able to regulate their emotions (Fonagy, 2003) and as a result may score higher for resilience. Finally, family expressiveness may not always present positively; at times of increased stress some families may exhibit high expressed emotion. Indeed the family expressiveness scale includes items such as 'we say anything we want to around home' suggesting both positive and negative expressiveness is represented. Further research is needed to understand the impact of different manifestations of family expressiveness on resilience in children with a chronic medical condition.

The findings of the study also implicate that family environment is more pertinent to resilience than parental perceived community support. This is an interesting finding as a growing body of research has highlighted the association between community support and resilience in children (Alvord & Grados, 2005; Jacelon, 1997; Wright et al., 1997). It is possible that community support was less of a priority to families in the study due to the increased demands of caring for a child

with a chronic medical condition. Masten (2007) suggests that due to the complex multilevel nature of resilience, factors are often interdependent on one another. For example, family support and cohesiveness have been found to predict social competence and support (Bell et al., 2001). Therefore, it is possible that perceived community support impacts resilience indirectly through family environment. Further research is needed to understand this process.

In contrast to resilience, family environment and parental perceived community support did not provide significant predictive value to quality of life in children with a chronic medical condition. The greatest predictive value for quality of life was found at step two of the model, this encompassed medical factors such as multiple medical conditions, school absences and years since diagnosis. However, of these only school absences was a significant independent predictor of quality of life. It is possible that this indirectly relates to community support as children's social networks predominantly arise from school. Therefore children who are absent from school more often may be more socially isolated and as a result score lower for quality of life. Alternatively, children who are more absent from school may suffer increased severity of their medical condition and as a result score lower for quality of life.

Age was also identified as a significant predictor of resilience. The findings indicated that the older the children in the sample were, the lower their resilience. There could be a number of important factors at play here. First, adolescence is a time of developmental change and risk, which can have a significant impact on the wellbeing of young people (Call et al., 2002). Second, cognitive and affective development is ongoing throughout adolescence (Steinberg, 2005), suggesting that older children can understand more complex emotion. It is possible that this

increased level of affect understanding may have impacted the self-report scores of the older children in the sample. Third, in addition to the usual challenges of adolescence, older children with a chronic condition may also have to face the difficulties of taking responsibility for treatment decisions and transition to adult services. Furthermore, children with progressive conditions may face a loss of independence at a time when their peers are gaining more liberation (Edwards & Titman, 2010).

Children in the sample who had accessed mental health services were also more likely to demonstrate lower resilience and quality of life scores. It is likely that these children were referred to mental health services for difficulties with emotional wellbeing. A number of studies have reported an association between emotional difficulties and decreased resilience (Chen et al., 2014; Kim & Yoo, 2007). This is important as it is widely documented that emotional difficulties in childhood can continue into adulthood (Fichter at al., 2009). A number of authors suggest that by fostering resilience in children and young people we can prevent the manifestation of difficulties later in life (Forrest & Riley, 2004).

There was a large significant association between resilience and quality of life in the sample. Collinearity diagnostics (see Appendix I) demonstrated that multicollinearity was not a problem between the two constructs. Although there were some similarities in the variables that predicted both variables, there was also a degree of divergence. The findings suggest that family environment appears to be important in the development of resilience, whereas medical factors appear to be more important in a child's perception of quality of life and that children can still demonstrate resilience despite low medical quality of life. It is possible that whilst overlapping concepts, that there are different pathways to the development of each.

Further research is needed to understand the relationship between resilience and quality of life in children with a chronic medical condition.

Limitations

Several limitations of this study should be noted. First, the study utilised a cross-sectional design, as such causality cannot be inferred from the findings. By exploring just one point in time we cannot fully understand the process of resilience and quality of life in children with a chronic medical condition. Longitudinal research may facilitate a better understanding of the processes involved in both constructs, and the impact of pertinent time points such as treatment commencement and transition. Second, the study employed convenience sample methods. As a result the sample was predominantly white British and recruited from outpatient clinics. Findings may have differed if there had been a higher proportion of inpatient participants. Due to the availability of the researcher a higher proportion of participants were gained from the rheumatology, neurology, diabetes and gastroenterology clinics. Furthermore, a large proportion of the parent participants were employed and either married or cohabiting, as such it may be that families that were more stable were more likely to participate in the study. In summary, this sample may not accurately reflect the paediatric population as a whole, and as such limit generalisability.

Third, the impact of medical condition was not explored in the inferential analysis and as such may be a confounding variable. Although previous research has found no association between illness severity and resilience (Wu et al., 2013) specific features of some medical conditions such as chronic pain, visible difference and mobility may have confounded the results. Efforts were made to analyse medical factors contributing to conditions such as multiple medical conditions,

number of inpatient admissions and school absences. Of these, only school absences were found to significantly predict quality of life in children with a chronic medical condition. Interestingly, mean results indicated that the medical conditions that scored lowest for quality of life did not score lowest on resilience. This may suggest that children with medical conditions that have the greatest impact on quality of life are not necessarily lower in resilience.

Fourth, findings may have differed if child perceived community support had been assessed instead of parental perceived community support. Although research suggests that children directly benefit from their parents social capital (Runyan et al., 1998), it may have been more useful to assess the children's own perception of community support. For example, a child's community resources may come from school and the study did not measure this. Additionally, it may have been useful to measure the child's perception of their family environment, as it is possible that child self-reports of family environment may have differed from parental self-report. Fifth, there is no normative data for the PCSQ as it has not been extensively researched. As a result the validity and reliability of this tool may not be as strong as the other measures in the study. Further independent research is warranted to explore the validity and reliability of the PCSQ in different populations. Sixth, the study did not record which parent/carer completed the parental measures or whether they were completed in consultation with the child. This subtle difference may have had a significant impact on the results, as mothers and fathers have been found to provide different depictions of their family environment (Mikelson, 2008). It would have been beneficial to record which parent completed the measures and whether they included the child when completing the family environment scale. Furthermore, the impact of social desirability bias on the parental measures should be taken into

account when interpreting the results. Seventh, the study did not collect demographic information regarding the type, duration and time point of child access to mental health services. As findings have identified this as an important factor in both child resilience and quality of life, it would have been advantageous to have contextual information to augment the results. It is possible that differences would have arisen between children who had recently been referred to mental health services compared to those who had historically accessed mental health services. Further research is necessitated to unpick the influence of access to mental health services on child resilience and quality of life.

Finally, as resilience pertains to "how effectiveness in the environment is achieved, sustained or recovered, despite adversity" (Masten, 2007, p. 4), it is possible that the RSCA did not fully encompass resilience in all areas. The scales focus on emotional resilience and relatedness to others, however they do not measure academic resilience. Kaplan (2013) postulates that children's resilience may present across a variety of domains; it is possible that whilst not scoring highly for resilience on the RSCA, children in the study may have scored highly on academic resilience. It may have been beneficial to measure academic success as an adjunct to the RSCA.

Clinical Implications

Despite these limitations, findings from the current study have important clinical implications. First, the findings indicate that children who have accessed mental health services and have lower perceived quality of life score lower for resilience. This highlights the importance of health care practitioners assessing and building resilience, strengths and resources in children with a chronic medical

condition. Exploration of resilience and resources may result in improved engagement and outcomes (Geraghty, Wood & Hyland, 2010). A strengths-based resilience approach may be especially useful when working with children with a chronic medical condition as they are facing on-going adversity that may not be directly changeable. Additionally, interventions that focus on managing emotional difficulties may also be crucial in building resilience as it is appears that emotional difficulties may undermine the development of resilience.

Second, the findings suggest that working with families may be an important means of fostering resilience in children with a chronic medical condition. Rather than looking to develop specific resilience building interventions, clinicians could focus on cultivating family cohesiveness and reducing family conflict. Utilisation of families' strengths and resources may facilitate this process. Finally, the findings may also support the wider medical team to identify children who may benefit from interventions to foster resilience, for example older children, or those in families with high conflict and low cohesiveness.

Future Research

In order to address some of the limitations this study should be repeated incorporating a wider geographical population, increased ethnic diversity of participants and increased representation of children with underrepresented medical conditions. Further longitudinal research should aim to explore the process of resilience and quality of life in children with a chronic medical condition across pertinent time periods such as inpatient stays and transition to adult services. The influence of factors associated with medical conditions such as pain, mobility and visible difference on resilience should also be explored. Finally, further research should examine the relationship between family environment and perceived

community support in order to develop theoretical pathways to understanding resilience. This expansion of the literature could not only contribute to further understanding of the factors predicting resilience in children with a chronic medical condition but also our understanding of the construct and process of resilience on a broader level.

Conclusion

In summary the results suggest that family cohesiveness and family conflict are predictive of resilience but not quality of life in children with a chronic medical condition. This study builds on previous research exploring resilience in children. However, in contrast to previous research community support was not found to be predictive of either resilience or quality of life in children with a chronic medical condition. It is possible that community support is indirectly associated with resilience through family environment; this is a key consideration for future research. Age and the child having accessed mental health services also predicted both resilience and quality of life in children with a chronic medical condition. These findings emphasise the importance of assessing resilience in children and young people with a chronic medical condition and suggest that family-based interventions may be beneficial in fostering resilience. Further studies are needed to continue to explore both the predictors and process of resilience and quality of life in children with a chronic medical condition.

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Appendix A

Literature Review Protocol

Title

"What predicts resilience in children with a medical condition?"

Type of Review

Systematic Review

Inclusion Criteria

- Children with a chronic illness (Chronic Illness defined as lasting for 3 months or more, any type of chronic illness, any severity, <18 years old, any time since diagnosis.

- Predicting resilience.

- Resilience in the child with the chronic illness, outcome measures must be measuring resilience in the child, other measures may be used in addition to resilience.

- Hospital or community setting.

Exclusion criteria

Studies not measuring resilience (e.g. those looking at adaptation/ post-traumatic growth), studies with children without a chronic illness, books, review papers, non-English language papers.

Search Strategy

Search Terms

Child/Children, Resilience, Paediatric or Pediatric, Chronic Illness, Chronic Disease, Medical Condition, Health Condition.

Databases

Psycinfo, Medline, Web of Knowledge, Cinahl, Global Health, PsychArticles, Scopus, Science Direct, Social Sciences Citation Index.

Other searches

Follow up references from key texts from database search, personal communication

with key authors from search.

Appendix B

Systematic Review Stage 2 Reasons for Exclusion

Table 1.

Stage 2 reasons for exclusion of studies

Reason for Exclusion	N
Not measuring resilience	30
Not measuring predictors of resilience	3
Inappropriate population	3
Inappropriate design	1
Theoretical paper	4
Literature review	2
Non-English language	1

Appendix C

Testing Assumptions for Statistical Analysis

Prior to statistical analysis, data was screened to examine the parametric assumptions of normality, homoscedasticity and linearity. In order to assess the normality of score distribution, z-scores for skewness and kurtosis were calculated by dividing the values by the standard error. Values that are greater than $1.96 =$ significant $p < .05$ (Field, 2013). The FES Cohesion scale had both a significant skewness ($z = -6.18$, $p < .001$) and kurtosis value ($z = 3.27$, $p < .01$). The FES conflict scale ($z = 2.26$, $p < .05$), RSCA Resource Index ($z = -2.69$, $p < .01$) and PEDSQL ($z = -3.25$, $p < .01$) were all significantly skewed. Whilst the FES expressiveness scale ($z = -2.13$, $p < .05$) and the RSCA Vulnerability Index ($z = 3.08$, $p < .01$) both had significant kurtosis values. The Kolmogorov-Smirnov (K-S) Test was also utilised to examine whether the scores on the measures were significantly different from a normal distribution. The FES cohesion scale ($D(139) = .248$, $p < .001$), FES expressiveness scale ($D(139) = .112$, $p < .001$), FES conflict scale ($D(139) = .157$, $p < .001$) and the PEDSQL ($D(139) = .102$, $p < .001$) were all significantly non-normal. Histogram and P-P plot graphical analysis confirmed that the assumptions of normality were not upheld, and as such parametric analysis could not be conducted.

Appendix D

Collinearity Diagnostics

Multicollinearity can happen when two or more predictor variables in a multiple regression model are highly correlated, leading to one variable being able to linearly predict another (Field, 2013). This can make interpretation of the regression model problematic. Collinearity diagnostics were conducted on the data set to screen for any occurrences of multicollinearity. If the variation inflation factor (VIF) is greater than 10 and the tolerance value is below 0.2 then multicollinearity may be a problem within the data set (Bowerman & O'Connell, 1990; Menard, 1995). In the current data set none of the VIF values were greater than 10 and the tolerance values were all greater than 0.2, indicating that there is no concern regarding multicollinearity in the data set.

Furthermore, collinearity diagnostics were conducted to examine the relationship between resilience and quality of life as they were strongly correlated in correlational analysis. Tolerance and VIF values were again in the expected range suggesting that although strongly correlated that multicollinearity was not a concern.