Quality of Life in Children with Headache

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Abstract

The investigation into headache-related quality of life (QoL) in children and adolescents has only recently started and there have been calls to help unravel this complex relationship by several authors. This dissertation therefore aimed to contribute to this set objective. Firstly, the review paper examined the existing literature on the relationship between headache in children and QoL, and the variables that might influence such a relationship. It was found that children with headache were likely to experience some degree of impairment in terms of psychological, physical and social functioning. Initial findings illustrated that adolescents with headache experienced a poorer overall QoL compared to headache-free peers and those with other painful conditions. Yet, given the currently limited number of studies available, several avenues for further research into the QoL of children with headache were highlighted. The empirical paper subsequently focused on investigating some of these avenues. The results revealed that a clinical group of children and adolescents with headache reported a poorer QoL compared to age- and gender-matched peers without headache. Parents generally reported a more positive picture compared to their children. Depression, global self-esteem and coping responses were found to be mediators of the headache-QoL link. It was therefore possible to suggest treatment plans that might act to improve the QoL of children with headache and to outline future research topics.

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Quality of Life in Children with Headache: A Review

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Abstract

Objective: To examine the existing literature on the relationship between headache in children and quality of life (QoL), and the variables that may influence such a relationship.

Methods: The issues raised by our current conceptualisation of headache and QoL in relation to a young age group were considered. The functioning of children with headache in terms of separate QoL domains and overall QoL was then reviewed. Variables that might influence the headache-QoL relationship were also highlighted. The resulting implications for researchers and clinicians were then outlined.

Results: Children with headache were likely to experience some degree of impairment in terms of psychological, physical and social functioning. Initial findings illustrated that adolescents with headache experienced a poorer overall QoL compared to headache-free peers and those with other painful conditions.

Conclusions: The QoL of young people with headache is likely to be adversely affected, yet given the limited number of studies available at this time, continued research investigating the QoL of children with headache in a multidimensional manner is needed.

Key words: quality of life; children and adolescents; headache; chronic pain.

Introduction

Headache in children and adolescents has been described as "the most common, clinically significant, recurrent pain" (McGrath & Larsson, 1997, p. 843). Yet the important effects of this pain on young people have not been well recognised, researched or managed (McGrath, 1999). Headache is often viewed as less significant compared to other chronic medical conditions, perhaps due to its subjective nature and the frequent lack of organic findings (Solomon, Skobieranda, & Gragg, 1993). For similar reasons the impact of headache is not well evaluated by traditional objective clinical outcomes such as mortality, changes in physiological markers or diagnostic images (Mannix, Chandurkar, Rybicki, Tusek, & Solomon, 1999). The burden of headache is therefore at risk of being underestimated (Essink-Bot, van Royen, Krabbe, Bonsel, & Rutten, 1995).

Increasingly, quality of life (QoL) has been presented as an alternative to these traditional outcome measures, as many believe it has the potential to represent the ultimate standard against which to judge the impact of children's experiences and the effectiveness of any intervention (e.g., Wallander, Schmitt, & Koot, 2001). Langeveld and Passchier (2001) outline several reasons to measure QoL in young people with headache. Firstly, it presents a systematic and reproducible method of evaluating a largely subjective experience. Secondly, it offers the clinician and researcher the opportunity to select and evaluate treatment options, from which to stimulate health care in an appropriate way. As such, QoL is fast becoming the major outcome measure for the impact of headache and its treatment (Bandell-Hoekstra, Abdu-Saad, Passchier, & Knipschild, 2000).

A limited and tentative literature has started to reveal that chronic pain including headache has a strong, negative effect on children's QoL (e.g., Hunfeld, Perquin, et al., 2001). However the use and knowledge of the notion of QoL as applied to children is

still at an early stage of development (Wallander et al., 2001). Likewise, the investigation into headache-related QoL in this age group has only recently started and there have been calls to help unravel this complex relationship (e.g., Bandell-Hoekstra et al., 2000). Therefore the aim of this paper is to examine the relationship between headache in children and adolescents and QoL, and the variables that may influence such a relationship. This will be done by first considering our current conceptualisation of headache and QoL in relation to a young age group. The functioning of children with headache in terms of separate QoL domains and then overall QoL will be reviewed. Variables that may influence the headache-QoL relationship will also be highlighted. The resulting implications for researchers and clinicians will then be outlined. The main conclusion drawn will be that the QoL of young people with headache is likely to be adversely affected. Finally, future research topics will be summarised.

Prevalence and Conceptualisations

This review will focus on the majority of young people who present with headache – those with chronic, non-malignant pain. The term 'children' will be used throughout to refer to both children and adolescents, although developmental issues will be highlighted where necessary.

Chronic Pain in Children

Chronic pain is defined as pain that is continuous or recurrent (including pain-free intervals) for 3 months or longer, although this is felt to be too long by some authors considering acute pain is defined as lasting less than 4 weeks (see Carr & Mann, 2000). Complaints of pain occurring at least once a week are made by as many as 30 to 40% of children (Kristjansdottir, 1997; McGrath, 1990). Chronic pain in adults is also

recognised as a major health problem and a relatively large percentage of adults with headache report initial onset of symptoms early in life (Solomon, Lipton, & Newman, 1992). This indicates the potential long-term effects of misunderstood and untreated pain in children.

Pain cannot be easily separated into organic or non-organic categories. The private, subjective experience of pain is the result of a number of physiological, psychological, social and cultural factors, some known, some yet to be identified (Horn & Munafo, 1997). Consequently, individual differences in pain perception and behaviour in children will be affected by factors including cognitive-developmental level; the meaning they ascribe to the pain; previous pain experiences; their perceived and actual ability to cope with the pain and family influences that may provide reinforcement and models for pain response (McGrath, 1990; Siegel & Conte, 2001).

This multidimensional conceptualisation is consistent with Gate Control Theory (Melzack & Wall, 1988) - one of the most influential theories of pain whereby cognitive and psychosocial variables effectively modulate the experience of painful stimuli at the spinal cord. Lask and Fosson (1989) have brought this theory to life in a way that is readily applicable to paediatric headache. This is summarised as follows. When a series of painful impulses are brought to the level of conscious awareness, children initiate an investigation by paying enhanced attention to these sensations. This information is then filtered through their current emotional state, determined largely by their social context, and their past experience as they attempt to assign significance to the signal.

The child usually informs an adult about the internal pain, which is then filtered through the adult's current emotional state, attitudes and past experience. The adult's response moulds the child's subsequent attitude towards internal sensations. In a similar manner, the medical expert's opinions and actions are also determined by training,

personal attributes, past experience of such clinical cases and external factors such as parental concern. In chronic pain syndromes, further medical investigations can reinforce the anxieties of the parent and child, resulting in an increase in communications of pain.

Headache in Children

Headache in children is extremely common and has even increased in prevalence over the past 20 years (Sillanpää & Anttila, 1996). Large epidemiological studies have estimated that 75% of children (aged 15 or younger) have experienced clinically significant headache, with weekly headaches occurring in more than 15% of 10 to 17 year olds (Passchier & Orlebeke, 1985). Egger, Angold, and Costello (1998) have also suggested that 10 to 30% of children and adolescents report weekly or frequent headaches. However, incidence rates can range from 3 to 82% (Goodman & McGrath, 1991) and it is acknowledged that estimates vary according to age and gender mix, definition of headache and method of data collection (Fearon & Hotopf, 2001).

Although headache is rare before the age of 4, its prevalence increases throughout childhood reaching a peak at about age 13 (Fearon & Hotopf, 2001). This may reflect hormonal and developmental factors as well as the academic and social pressures building at this time (Bener et al., 2000). With regards to gender, headaches tend to be more prevalent among boys before the age of 12, but more frequent in adolescent girls. Rhee (2000) discusses this finding in terms of the effect of female hormones, increased susceptibility to emotional disorders and threat appraisal, and differential use of coping strategies.

In general, the prevalence of headache has been shown to be similar across different parts of the world (Bener et al. 2000). Meanwhile, studies examining racial

differences in headache prevalence in children are very limited. Rhee (2000) appears to have been the first to demonstrate that white adolescents are more prone to headaches than black adolescents, although American Indians were found to have the highest rate of headache complaints overall. In contrast, no relationship has been found between socio-economic status (SES) and headache prevalence so far (Rhee, 2000; Zuckerman, Stevenson, & Bailey, 1987). However further studies are required that use alternative measures of SES and samples with a broader age-band.

Headache can be categorised in several ways. The International Headache Society (IHS, 1988) has developed a detailed classification system that is widely adopted for research as well as clinical purposes. Its well-defined criteria represent a major advance in this field (Lipton, Silberstein, & Stewart, 1994). The migraine and the tension headache represent the two most commonly diagnosed headaches in children (Siegel, 1998). As the names suggest, each type is presumed to originate from a different pathophysiological source, the former from excessive response of the cranial and cerebral arteries and the latter from sustained contraction of muscles of the face, scalp and neck (Bakal, 1975). Whilst migraine is described as periodic, severe, unilateral and accompanied by aura, nausea, vomiting and a positive family history; tension headaches are described as very frequent, bilateral and like a 'band, heavy weight or fullness' with associated dizziness (Garralda, 1992).

However in practice differentiation is often not clear-cut. Both headache types may co-exist in the same patient (Garralda, 1996), high levels of tension in the head and neck and vasoconstriction of the scalp arteries have been observed in both (Siegel, 1998) and they do not appear to respond differently to various forms of psychological treatment (see Martin, Milech, & Nathan, 1993). Consequently, some authors have proposed a pain severity continuum as an alternative to discrete entities (e.g., Schade,

1997). Headaches can also be categorised by their frequency (daily, weekly, monthly), duration and severity rather than location and symptom complex alone (Egger et al., 1998).

Moreover, criteria specifically designed to describe the full range of children's headaches have not been delineated (Wober-Bingol, Wober, & Wagner-Ennsgraber, 1996). Several authors debate the applicability of IHS criteria to childhood headache. It has been suggested that childhood headache types may differ from those in adults. For example, migraine attacks are commonly much shorter in children and most likely change with advancing age (Guidetti & Galli, 2001). Specific migraine symptoms are often absent in children and their stage of intellectual development may hamper subtle reports, nausea, vomiting and abdominal pain are often more prominent than in adults and head pain is often bilateral rather than unilateral (see Langeveld & Passchier, 2001). Winner, Martinez, Mate, and Bello (1995) have therefore proposed modifications for young patients relating to duration, location, quality of intensity and symptomatology. Indeed, it is understood that the IHS are soon to publish a new edition which updates diagnostic parameters for children. McGrath and Larsson (1997) also finds the American Psychiatric Association's (1994) classification system unhelpful, as several diagnostic categories exist that might be applied to children with headache, including somatization disorder, pain disorder and hypochondriasis.

Organic or psychological?

Under 20% of young headache patients have symptoms secondary to neurological, trauma or viral-related illness (Guidetti & Galli, 2001). Therefore in practice, headache without a demonstrable medical cause may often be dismissed as a manifestation of a psychiatric disorder (McGrath & Larson, 1997). This reflects the reductionism and

dualism that characterises a purely biomedical perspective (Drossman, 1998). In this way, illness *with* disease is viewed as understandable or 'rightful', whilst illness *without* disease is labelled as 'psychosomatic', a term which implicitly queries the credibility of the symptoms even though they are very real to the patient.

Alternatively, the biopsychosocial model as proposed by Engel (1977), accepts the interaction of biological, psychological and environmental factors in explaining health, disease, illness and outcome. Similarly, Wood (2001) refers to the 'biopsychosocial balance' incorporating these three overlapping realms of functioning. She has described how dysfunction in any one realm can undermine function in the other two realms. For instance, as will be discussed later, recurrent headache in children has been associated with stressors within the family and school context, as well as higher anxiety and depression symptom levels (see Carlsson, Larsson, & Mark, 1996). Equally, strength in one of the domains can assist in boosting a child's well-being in the other domains. The concept of linear and circular causality is also relevant here. The reality is that states of health and illness are the result of a complex, reciprocal interaction between cause and effect (Lask & Fosson, 1989). For example, it may be too simplistic to claim that anxiety leads to headache, as the anxiety caused by headache also has the potential of maintaining the pain or triggering pain at a later date.

Psychosocial factors are therefore seen as potentially contributing to the progression of virtually any physical condition (Garralda, 1992; Lask & Fosson, 1989). Moreover, it is recognised that the relative contribution of these factors "varies from disease to disease, from person to person, and from one episode of the same disease in the same person to another episode" (Lipowiski, 1977, p. 234). Several authors therefore argue that posing a dichotomous question which separates physical and emotional health is simplistic, misleading and outdated (e.g., Siegel, 1998; Wood, 2001). In the clinical

setting of course, organic disease such as cerebral tumours, hypertension and short-sightedness are causes of headache needing exclusion (Lask & Fosson, 1989).

Bringing this picture together, some authors propose that we think in terms of a continuum of illness stretching from predominantly organic influence to predominantly psychosocial influence (e.g., Lask & Fosson, 1989; Wood, 2001). For example, a clearly structural disorder such as congenital heart disease might be placed at the organic end of the spectrum, whilst a behavioural problem such as school phobia might be placed at the other extreme. The whereabouts of headache on the continuum is not immediately clear. A limited number of studies have provided some insight into the various psychosocial factors thought to be influential in paediatric headache, although contradictory results have been documented (Egger et al., 1998; Martin-Herz, Smith, & McMahon, 1999). Its exact position would perhaps vary according to the relative contribution of factors for a particular child at a particular point in time. Overall, this model still appears to offer a more helpful perspective from which to view paediatric headache by allowing for a more sophisticated appreciation of the complex factors involved and a more effective multi-modal treatment approach.

Quality of Life

The increasing interest and importance attached to QoL as an outcome measure reflects contemporary views already outlined about the critical link between physical and mental health (Eiser & Morse, 2001). It also highlights the progression from a biologically based curative model to a more holistic approach which aims to treat 'the whole child' (Harding, 2001). Yet Wallander and her colleagues (2001) have observed that this interest has developed without careful attention to methodological and conceptual issues.

QoL is an evolving concept (Harding, 2001). Many early models were largely concerned with function, applying a deficit-centred perspective to children with chronic conditions (Eiser, 1996). QoL has also been used interchangeably with terms such as health status, standard of living and adjustment (Harding, 2001). Currently there is no universally accepted definition of QoL. Such a multitude of definitions, content and criteria have been proposed that it has been described as almost researcher-specific (Borthwick-Duffy, 1996). Alternatively, it has been argued that QoL should be viewed as an organising construct rather than a directly measurable entity (e.g., Schalock, 1996). Despite these obstacles Koot (2001, p. 6) has submitted the following definition for children with chronic conditions: "Quality of life is the combination of objectively and subjectively indicated well-being in multiple domains of life considered salient in one's culture and time, while adhering to universal standards of human rights". This definition although broad, seems applicable to children with recurrent headache, yet QoL clearly needs further clarification as a construct.

Most definitions include the following common issues. Firstly, QoL is understood as a personal, subjective concept based on an individual's unique perspective (Bandell-Hoekstra et al., 2000). Secondly, it is a multidimensional concept which in principle encompasses all domains of a person's life (Koot, 2001), although the ultimate content may vary according to purpose and perspective. From a patient's perspective at least the domains of psychological, physical and social functioning should be included since each may be affected by chronic conditions (Koot, 2001). This is exemplified in Spilker's (1996) multi-level model of QoL. The three levels of QoL have been described as the individual's overall satisfaction with life, broad domains of QoL (e.g., psychological) and specific components of each domain (e.g., anxiety and depression). Thirdly, QoL is a double-sided concept incorporating positive and negative aspects of

well-being and life (Bandell-Hoekstra et al., 2000). Fourthly, it is a dynamic, fluid concept that changes as the child, family, culture and circumstances change (Hanson, 2001).

More recently, health-related QoL (HRQoL) has been distinguished from overall QoL. The former has also been ascribed a range of definitions from the impact of illness or treatment (Eiser, 1996) to QoL from a patient's perspective (Ravens-Sieberer & Bullinger, 1998). HRQoL measures are categorised as either generic or specific. The former are designed to assess all areas of functioning deemed to be affected by illness and treatment, whereas the latter assess QoL within the context of a specified disease (Spieth, 2001) such as the Quality of Life Headache in Youth questionnaire (Langeveld, Koot, Loonen, Hazebroek, & Passchier, 1996). Neither approach is inherently superior and may be used in a complimentary fashion (Spieth, 2001). In practice the terms QoL and HRQoL have been used interchangeably in the literature, perhaps because it can be misleading to try to separate what is influenced by disease from that which is influenced by all past and current experiences (Wallander et al., 2001).

Harding (2001) has noted a recent shift in the conceptualisation of QoL in children to include not only the child's perception of his/her ability to function in various areas, but an estimation of his/her satisfaction with these aspects. In this way qualitative differences in QoL might be found between a sporty child who breaks a leg compared to a more artistic child who may not be so adversely affected. Although our understanding of this aspect is still quite limited, it may help to shed more light on related concepts such as preference, compensation, resilience and coping (Harding, 2001). For example, children might adopt certain coping styles that serve to protect or shield them from the effects of a chronic illness allowing them to maintain QoL.

Special issues relating to the measurement of QoL of children.

Psychometric properties such as reliability and validity are of course relevant to assessing QoL in children with chronic conditions (Koot, 2001). In a recent review of 137 papers, Eiser and Morse (2001) concluded that only three generic and two disease-specific measures fulfilled basic psychometric criteria. Indeed, the task of developing adequate QoL instruments for use with children is far from complete (Koot, 2001; Loonen, Derkx, & Otley, 2001). Moreover, informant and developmental considerations pose challenges in QoL assessment that are more specific to a younger age group (Koot, 2001).

Early attempts to rate children's QoL were based on maternal reports as children were often regarded as unreliable respondents (Eiser & Morse, 2001). It is now well recognised that children can provide unique and reliable information about the quality of their lives (Spieth & Harris, 1996), although informant variance remains a problem (Koot, 2001). There tends to be poor agreement between carer's (e.g., parents, doctors, teachers) and children's ratings of pain, anxiety, depression and QoL (see Harding, 2001; Koot, 2001; Theunissen et al., 1998). Yet agreement amongst raters differs as a result of factors such as child gender, age and condition (Verhulst & Van der Ende, 1992), as well as according to the type of measure used and age of respondent (Harding, 2001). Proxies may be influenced by the development of other children they know, their expectations and hopes for the child, additional life stresses and their own mental health (Eiser & Morse, 2001). Indeed, parents of children with headache are recognised as having an increased risk for psychological maladjustment (Fearon & Hotopf, 2001) which may influence their ratings.

However, both child and proxy ratings of QoL provide valuable information and the latter cannot be discarded (Eiser & Morse, 2001; Koot, 2001). Parent and teacher

ratings of behavioural and emotional difficulties remain valid indicators of later child outcomes (e.g., Verhulst, Koot, & Van der Ende, 1994). Proxy reports may even be indispensable when a person is too young or too ill to reliably report on his/her own condition (Koot, 2001). Therefore, Eiser and Morse (2001) have suggested that QoL measures that provide parallel forms for completion by both child and proxy are measures of choice where possible. The currently limited number of such measures therefore needs addressing.

Several authors have referred to developmental aspects in relation to the measurement of children's QoL. Fundamentally, the quality of a child's self-report will be affected by developmental changes in expressive and receptive language abilities, attention span, time perception, memory and understanding of health, illness and QoL concepts (Koot, 2001; Wallander et al., 2001). Secondly, developmental tasks vary by age in a given culture and so dimensions which are important for QoL may also vary across the age-span (Harding, 2001; Koot, 2001). QoL is also experienced in different ways at different ages (Wallander et al., 2001). Therefore, parents and family life might be more important to young children, whereas peer groups might be important later on as adolescents strive for acceptance and autonomy (Titman, Smith, & Graham, 1997). Moreover, the impact of illness and its treatment may be age-specific (Levi & Drotar, 1998). For example, adolescents may be more concerned with the visibility of a condition and less focused on adherence to treatment.

In summary, QoL measures for children should be multi-respondent and reflect the child's level of understanding as well as the dimensions of QoL which are important for them (Harding, 2001). In practice however, little is actually known about the relative importance that children attach to different life states, which cannot be assumed to reflect adult opinions (Wallander et al., 2001). This highlights a concluding point

expressed by Koot (2001) that although it would be wise to draw upon the experience of two decades of QoL research with adults, it would be 'unforgivable' not to apply basic developmental principles. This confirms the need to investigate children's QoL in its own right, which has been under-researched compared to that in adults. Equally, Guidetti and Gallo (2001) remind us that the child with headache is not simply a 'little adult' and one should avoid an overly adult-focused approach.

Functioning of Children with Headache in Separate QoL Domains

The literature on QoL in childhood headache is fairly new and quite limited. Therefore this review will begin with an examination of the functioning of children with headache in several areas pertinent to QoL. These studies can contribute to our accumulating knowledge of the impact of childhood headache where it is clear that they are addressing relevant dimensions of QoL, even though it may not appear as a named construct (French, 2001). This approach is also consistent with Spilker's (1996) multi-level model of QoL described earlier.

Psychological Functioning

Several studies document maladaptive behavioural and psychological functioning in children with headache (Andrasik & Passchier, 1993). For example, children with headache have been found to score higher on anxiety when compared to healthy controls and also subjects with irritable bowel syndrome (Engström, 1992). Children with migraine have also been found to be significantly more depressed when compared to no-headache peers matched for age, gender and social class (Andrasik et al., 1988). Similar results have been shown by other authors (e.g., Martin-Herz et al., 1999) and by parental report (Larsson, 1988).

However, not all studies confirm these findings (e.g., Cunningham et al., 1987) and mean scores often remain below the clinical level. This may be because many studies tend to involve a non-clinical sample. Children attending medical or specialist clinics may be expected to show greater psychological disturbance (Carlsson et al., 1996). This could be due to a tendency for such children to have more severe/complex symptomatology or increased health anxiety itself reinforced by clinic attendance. Kaiser (1992) has also identified a response bias which may lead to self-report measures under-estimating the severity of symptoms compared to clinical interview. At the same time, we are reminded that even borderline clinical levels of depression negatively affect functioning in adults (Levine et al., 1996).

The effect of headache may also differ according to different affective states. For example, depressed girls with headaches were found to have more frequent headaches, miss more school and take more medication than girls with headaches who were not depressed; whereas anxious girls with headaches missed fewer days of school and took less medication than girls with headaches but without an anxiety disorder (Egger et al., 1998). Thus the experience of pain plus depression may specifically intensify the morbidity of headaches (Egger et al., 1998).

Age and gender effects have also been documented. In children with recurrent headaches, the level of anxiety increases from childhood through adolescence (Martin & Smith, 1995). Likewise, younger children with headache scored twice whilst adolescents scored three times as high on depression ratings compared to controls (Andrasik et al., 1988). The greater distress of older children may be partly due to the greater disruptive effects of pain for this age group, both in terms of academic and social developmental tasks (Andrasik et al., 1988).

Strong gender differences have been shown in terms of the associations between headaches and psychopathology. Headache in girls has been linked with emotional disorders and low self-esteem, but with disruptive behaviour in boys (Egger et al., 1998; Egger, Costello, Erkanli, & Angold, 1999; Rhee, 2000). Hormonal, environmental and cultural stresses and expectations may be pertinent here (Egger et al., 1999). For example, young males with headache may be bound by masculine role expectations which make outward expressions of pain behaviour appear less permissible and so result in alternatives such as aggression (Andrasik et al., 1988).

The nature of the headache experienced may also influence psychological functioning. For example, Hunfeld, Perquin, et al. (2001) found pain intensity to be the strongest predictor of psychological functioning in children with chronic pain. Likewise, headache severity has been related to the psychological functioning of children with migraine (Cunningham et al., 1987). Adolescents with frequent headache also report greater emotional and behavioural risk than those with infrequent headache (Beiter, Ingersoll, Ganser, & Orr, 1991). In contrast, Andrasik et al. (1988) reported that psychological distress in children with migraine was unrelated to headache severity or chronicity. This would suggest that some children are able to maintain reasonably high levels of function despite high levels of pain (Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001).

With regard to headache type, Carlsson et al. (1987) usefully compared the psychosocial functioning of children with four headache diagnoses. Although few statistical differences were found, a consistent pattern emerged in that children with migraine were least distressed and those with chronic tension-type headache or with co-existing migraine were most negatively affected. These results support the headache density hypothesis which is consistent with findings with adult samples (McGrath &

Larsson, 1997). Yet the opposite effect has also been documented (Lanzi et al., 2001) and many studies have reported no significant differences between migraine and tension type headache (Hunfeld, Passchier, et al., 2001). These inconsistencies mean that the role of pain parameters on psychological functioning is far from clear (McGrath & Larsson, 1997).

Several authors conclude that there is a unique relationship between headache and personality traits and psychological functioning. The early literature certainly acclaimed to a 'headache personality' or 'psychological constitution' characterised by increased anxiety, sensitivity, caution, vulnerability to frustration, obstinacy, stubbornness and inflexibility (e.g., Billie, 1962; Wolf, 1937). However, a poorly described control group (or its complete absence) and unstandardised rating scales are amongst numerous methodological weaknesses of these studies (Andrasik et al., 1988). Yet even some of the more recent literature continues to conclude that children with headache "show common traits..... peculiar to cephalagic subjects" without the use of a comparison group (Lanzi et al., 2001, p. 59).

Consequently, the notion of a specific personality in children with headache has been discredited (McGrath, 1999). In contrast, it has been suggested that the personality and behavioural features of paediatric headache subjects may instead result from the common chronic pain experience. In this way, Cunningham et al. (1987) compared children with migraine to a 'no-pain' control group matched on age and gender, in addition to a 'pain' control group who were also matched on pain parameters. The psychological characteristics of children with migraine were not found to be distinctive when compared to children with musculoskeletal pain.

Finally, it should be cautioned that the exact nature of the relationship between psychological distress and pain is controversial. For example, depression may result in a

child developing headaches; depression may develop as a result of recurrent headaches or the relationship may be bi-directional (Bandell-Hoekstra et al., 2000). The relationship might even be an artefact especially if somatic symptoms are part of the depression measure. Correlational studies tend to hypothesise that psychological elevations are more a result than a cause of headache pain (e.g., Andrasik et al., 1988; Cunningham et al., 1987). Yet, this is largely speculation as no causal directions can be firmly concluded from these studies of linear association (Andrasik et al., 1988). Meanwhile, in a one year longitudinal study on adolescents with headache, Rhee (2000) found that depression was more likely to trigger headache rather than vice versa, although only in girls. This inconsistency has led many to propose that complex circular pathways may be involved (e.g., Palermo, 2000; Rhee, 2000).

In summary, recurrent headache does not seem to be associated with major psychopathology. Rather, the psychological functioning of children with headache appears to be affected in a more subtle and complex manner, with important interactions with age, gender, sample, the specific affective disorder studied and the assessment method used. Pain parameters may influence the amount of disruption to psychological functioning, although inconsistencies prevent firm conclusions from being drawn at present. Meanwhile, the psychological characteristics of children with headache are not necessarily unique to those with headache, but may be reflective of children with a chronic pain disorder in general. Finally, it is recognised that the association between psychological distress and headache may be bi-directional rather than linear. To place these findings into a broader context, it is also known that children with headache continue to be at risk of psychiatric symptoms into adulthood (Fearon & Hotopf, 2001).

Physical Functioning

Children with headache generally report poorer physical health and evaluate their health as less satisfactory compared to no-headache controls (Martin-Herz et al., 1999; van den Bree, Passchier, & Emmen, 1990). In several controlled clinical studies, children with headaches also self-report more somatic concerns compared to control children (e.g., Andrasik et al., 1988; Carlsson et al., 1996). Moreover, Cunningham and colleagues (1987) found that the somatic concern scores of children with headache fell within the clinical range. This particularly high level of somatic complaints also differentiated children with migraine from musculoskeletal pains, although the authors felt this was to be expected as symptoms such as nausea and dizziness are part of the inclusion criteria for headache. However, children with frequent headache have higher levels of somatisation in addition to their headache-related symptoms, compared to those with infrequent or no headache (Martin-Herz et al., 1999).

In particular, children with headache experience other types of (non-malignant) pain more often than headache-free subjects (Carlsson et al., 1996). Anttila, Metsähonkala, Mikkelsson, Helenius, and Sillanpää (2001) documented that throat pain was reported sometimes or often by 64% of children with headache, limb pain by 59%, recurrent abdominal pain by 50%, neck-shoulder pain by 29% and back pain by 14%. These pains were reported to occur significantly more often in children with migrainous compared to non-migrainous headaches. The authors suggest that pain sensitisation mechanisms could be involved. Indeed, children with headache have been described by their parents as being more sensitive to pain than control individuals (Aromaa, Sillanpää, Rautava, & Helenius, 2000). Anttila et al. (2001) were also aware that depressed individuals for example, are more prone to feel pain in all parts of the body (Alfven, 1997).

Increased tiredness is also reported by children with recurrent headaches (Aromaa et al., 2000; Carlsson et al., 1996; Larsson, 1988). This may be linked to sleep disturbance, involving poor sleep quality, night wakening, nocturnal symptoms and daytime sleepiness that has been found to frequently occur in children who experience headaches (Bruni et al., 1997). However, a direct causal link between pain and poor sleep in children is not yet fully established, especially as sleep disturbance has also been reported on pain-free days (Palermo, 2000).

A retrospective case-note review of 58 attenders of a paediatric neurology outpatient clinic revealed that children with headaches were more overweight than the population average, with girls larger than boys and a trend towards increasing weight with older age in both (Velmurugan, Ong, & Pike, 2001). Indeed, exercise may be restricted or avoided due to a perceived exacerbation in pain (Waldie, 2001). This is contrasted with Waldie's own finding that despite having normal body mass indexes children with headache were particularly likely to report feeling overweight during adolescence. A high level of stress about bodily changes was also present. She speculates that the resulting self-consciousness could increase stress levels and susceptibility to headache. Conversely, some level of weight concern or difficulty is also suggested by more frequent self-reports of appetite loss compared to headache-free controls (Carlsson et al., 1996). It is also interesting to note that compared to illness-free parent and child dyads, children of chronic headache sufferers not only experience more headaches per month but appear to be more concerned with their health, bodily functions and body image (Mikail & von Baeyer, 1990).

In conjunction with various other somatic complaints such as 'breathing problems', 'eye tiredness' and 'feeling chilly' more often than control children, it has therefore been concluded that children with headache are more somatically focused

(Carlsson et al., 1996). Several sources of this internal focus have been put forward. From a cognitive-perceptual perspective, attending to one's internal states serves to enhance the perceived intensity of physical symptoms, so that individuals tend to experience even normal physiological sensations as disturbing and respond with hypervigilance (see Siegel, 1998). This process is heightened during adolescence - a period of increased introspection which leads to greater awareness of one's physical sensations and emotions (Hansell & Mechanic, 1985). It has also been proposed that this heightened concern with health status may be either a reaction to, or a means of coping with ongoing stress (Carlsson et al., 1996; Mikail & von Baeyer, 1990).

Finally, gender could again be an influential factor in the physical functioning of children with headache. A population-based, prospective study of adolescents with headache indicated sex differences in co-morbid associations (Sillanpää & Aro, 2000). In this way, allergies, asthma, diabetes and stomach-ache were more common in boys with headache, whilst psychiatric symptoms and sleep disturbance were present more commonly in girls with headache. The mechanisms for this difference are not immediately clear, but it appears that boys with headache are more likely to experience various physical conditions. Meanwhile, Hunfeld, Perquin et al. (2001) found that girls exhibited more intense and frequent pain in general. They discussed this finding in terms of adult studies that show greater pain stimulus thresholds and pain tolerance in males and a greater tendency to report negative affect in females.

In summary, children with headache show particularly high levels of somatic complaints, including other pains, fatigue, sleep disturbance and weight problems or at least increased concerns about their body image. These children appear to be more concerned with their health in general and are said to be more somatically focused. Gender may influence the pattern of physical functioning in children with headache,

although no comprehensive conclusions have been drawn. Placing these findings into a broader context, children with headache remain at risk for multiple physical symptoms including headache, into adulthood (Fearon & Hotopf 2001).

Social Functioning

Disrupted functioning in both the school and home setting are frequently referred to in children with headache. For instance, in an American population it has been estimated that several thousand school days are missed each month due to severe headache (Stang & Osterhaus, 1993). Children with headache have been found to be absent from school (due to illness) significantly more often than headache-free controls (Carlsson et al., 1996), and children with other chronic pains (Hunfeld, Passchier, et al., 2001). Newacheck and Taylor (1992) demonstrated that in comparison to other chronic disorders, only asthma had a significantly greater impact on school attendance than frequent headache. Children with headache are also less happy at school than their peers (Cunningham et al., 1987).

There is some indication that gender, headache type and chronological age may be influential here. In this way, adolescent girls with recurrent headaches report missing more school than those with infrequent or no headaches (Martin-Herz et al., 1999). This is a pattern not seen in boys (Billie, 1962). Martin-Herz and colleagues have suggested that this may be because girls in this age group are more likely to express their discomfort. With regards to headache type, children with migraine or migraine coexisting with tension-type headaches have higher absence rates than those with tension-type headaches only (Carlsson et al., 1996). It is perhaps pertinent then that in a prospective population-based study, children with migraine feared their teacher and failure at school more than those with non-migrainous headache (Anttila, Metsähonkala,

Helenius, & Sillanpää, 2000). It is to be remembered that headache is not known to adversely affect cognitive and intellectual functioning (Billie, 1962; Andrasik et al., 1988). However, problems with concentration when learning and working on the computer are more likely to be described by adolescents with headache compared to those with other chronic pains (Hunfeld et al., 2002).

Developmentally, older children with headache and their parents report significantly more interference with school (White, Alday, & Spirito, 2001). This makes sense in the context of a culture where the amount of educational pressure tends to build with increasing age. This is also consistent with the knowledge that headaches are particularly common during the exam season (Bener et al., 2000). Parents may also affect the social functioning of their child with chronic pain by lowering their expectations for functioning in normal social roles (Palermo, 2000). For example, school absence may be a function of parental factors, such as discouragement of active coping (Dunn-Geier, McGrath, Rourke, Latter, & D'Astous, 1986).

Cunningham and colleagues (1987) found that children with headache showed less social participation compared to pain-free children. Adolescents have themselves reported a significant impact of head pain on the amount of leisure time spent with peers (Langeveld, Koot, & Passchier, 1997). It is unknown exactly why these children participate in fewer peer activities. It may be that they self-limit all activities due to pain and fatigue, or perhaps develop social anxiety and so avoid contact with their peers (Palermo, 2000). Upon interview, Hunfeld et al.'s (2002) non-clinical sample were more inclined to withdraw from social activities because they could not bear noise or bustle when in pain. Regardless, the potential consequences including lowered self-esteem and lessened opportunity to develop healthy peer relationships should not be underestimated (Martin-Herz et al., 1999).

Indeed, children with headache have been shown to be less socially skilled than children with no pain (Cunningham et al., 1987). Bullying and truancy have also been associated with frequent headache in children (Beiter et al., 1991; Williams, Chambers, Logan, & Robinson, 1996). This may reflect the difficulties with peer and social relationships experienced by these children. However, others have reported no difference in social skills or peer relations compared to children without headache (e.g., Andrasik et al., 1988; Cooper, Bawden, Camfield, & Camfield, 1987).

Children with headache are likely to experience a range of family problems which systemic theory tells us can have a negative reciprocal effect. For example, adolescents with recurrent headaches are more likely to have parents who are divorced than headache-free controls (Larsson, 1988). A less happy family environment and a more distant relationship between parents have been noted in children with tension-type headache compared to migraine (Aromaa et al., 2000). However, such a distinction is not clear-cut as the reverse has also been documented (e.g., Anttila et al., 2000).

In terms of illness, a family history of headache is frequently noted reflecting both genetic and environmental factors (see Bandell-Hoekstra et al., 2000). In addition, children with headache are more likely to have a mother with a chronic physical illness that began before the child was 11, as well as mental illness in a family member (Fearon & Hotopf, 2001). In particular, a history of maternal depression is considered a predisposing factor for headache in childhood (Mortimer, Kay, Jaron, & Good, 1992). However, such family factors may not be as strong an influence as for childhood recurrent abdominal pain (Stevenson, Simpson, & Bailey, 1988).

Meanwhile, there is little written on the burden of childhood headache on family functioning. According to mothers, chronic pain including headache has been shown to have a significant negative impact on family life, especially in social terms (Hunfeld,

Perquin, et al., 2001). Breslau, Strauch, and Mortimer (1982) would perhaps describe this as 'perceived role restriction' exhibited in parents raising a child with a disabling disease. This implies that the perceived ability of both the child and his or her family to use their social support networks may be impaired (Langeveld & Passchier, 2001).

In summary, the school attendance of children with headache appears to be gravely affected, especially for girls, those with migraine or combination headaches and older children. In terms of peer relationships, children with headache show less social participation and may have weaker social skills than controls. Paediatric headache is also associated with various family problems, including divorce, disharmony in the home, physical and mental health difficulties in family members and a restricted family social life. A full discussion of these models is beyond the scope of this review, however these systemic factors can be expected to reduce the QoL of children with headache in terms of their social and family role functioning (Langeveld & Passchier, 2001).

Overall QoL in Children with Headache

Only four studies to-date have investigated the QoL of children with headache in a multidimensional manner. Three further studies have investigated the QoL of children with chronic pain inclusive of headache. Salient results from these studies will be drawn upon here. In their 1996 paper, Langeveld and colleagues compared adolescent students familiar with headache to headache-free controls using their newly developed Quality of Life Headache-Youth (QLH-Y) questionnaire. This appears to be the only such comparison in the literature to-date. They found that adolescents with recurrent headache reported a comparatively poorer overall QoL, consisting of worse psychological functioning, more physical symptoms, a poorer functioning status and less satisfaction with life and health. In this way, nearly all QoL domains discriminated

between the headache and non-headache group. This finding is consistent with several adult headache studies documenting poorer QoL compared to the general population (e.g., Essink-Bot et al., 1995; Michel, Dartigues, Lindoulsi, & Henry, 1997; Osterhaus, Townsend, Gandek, & Ware, 1994).

In their comparison of the QoL of an adult migraine sample to the general population, Essink-Bot et al. (1995) found the largest differences to have been in terms of bodily pain, role limitations due to physical health and to emotional problems, social functioning and vitality. Children with migraine particularly report more fatigue and stress (Langeveld et al., 1996), but the pattern of the impact of paediatric headache on QoL compared to controls has not been well delineated.

Several adult studies have found that patients with headache report significantly worse QoL compared to patients with other major chronic conditions (e.g., Solomon et al., 1993). In contrast, the child literature only contains comparison data with a very limited number of other conditions. Hunfeld and colleagues (Perquin et al., 2001; Passchier et al., 2001; 2002) have performed three investigations into the QoL of adolescent students with chronic head, limb, abdominal and back pain. Their assessment incorporated the Quality of Life Pain-Youth (QLP-Y) questionnaire adapted from the QLH-Y to enable application to pain in general. On this measure, a community sample of adolescents with headache were found to have the poorest QoL compared to those with other pains (Hunfeld, Passchier et al., 2001). In their 2002 paper, additional interview data suggested different patterns existed in the consequences for every day life for different pain locations. In this way, adolescents with headache reported more problems with concentration, social activities and physical complaints, compared to back or limb pain where particular problems with physical exertion were noted. However, less differentiation existed when the pain was severe, when most adolescents

tended to report problems with physical activities, sleep, concentration and mood regardless of pain location.

Meanwhile, it is perhaps puzzling to note that the above results of comparatively worse QoL for adolescents with headache existed despite the headache group reporting the least amount of pain (Hunfeld, Passchier, et al., 2001). This suggests that factors other than pain may be also involved in lowering QoL for children with headache. Indeed, although headache has been shown to have an independent effect on adolescent's QoL (Langeveld, Koot, & Passchier, 1999), its presence does not account for a significant part of the variance in QoL (Langeveld et al., 1996). As such, much of the variance in the relationship between paediatric headache and QoL is still to be explained. Therefore variables that may be influential will now be outlined.

Headache type is one such variable that may affect the relationship between headache and QoL. Some of the adult studies have shown that distinct headache diagnoses are marked by unique patterns of impairment and QoL (e.g., Solomon, Skobieranda, & Gragg, 1994). If this is this case, then a patient's diagnosis might help determine the degree and type of impairment they are likely to experience. However, initial evidence suggests that this is not the case for paediatric headache. In their 1999 paper, Langeveld and colleagues found similar patterns of QoL including psychological functioning for both children with migraine and non-migraine headache. This provides further support for the continuum model of headache in children.

Different pain parameters have been found to influence the paediatric headache-QoL relationship. Van den Bree et al. (1990) have documented low correlations between headache frequency, intensity and duration and dimensions of QoL. In their adolescent male student sample, greater headache frequency was associated with lower satisfaction with health; greater duration correlated with lower satisfaction with autonomy, and

greater intensity was associated with lower satisfaction with health, school, home situation and autonomy and satisfaction in general. The narrow sample and unstandardised QoL measure perhaps limits the extrapolation of these findings. However, Langeveld et al. (1997) have since revealed similar results using a multi-measurement design. As such, fluctuations in headache activity in adolescents as measured by a 4-week headache diary, were found to be related to fluctuations in the subjects' functional status, psychological functioning, overall satisfaction with life and health perception as measured by the QLH-Y. Specifically, more intense and frequent headache coincided with a lower self-reported QoL.

Several studies point to stress as a potential factor in determining the relationship between headache and QoL. Stressful life events are considered to be both a risk factor for childhood headache and a consequence (Waldie, 2001). As outlined earlier in this review, children with headache do appear to experience multiple life domain stressors. It may be that they actually experience a greater number of stressful events compared to other children (Carlsson et al., 1996), or that they are just more sensitive to everyday stressors (Andrasik et al., 1988; Anttila et al., 2000; Cooper et al., 1987).

In order to test the role of stress on the interrelation between headache and QoL in adolescents, Langeveld and colleagues (1999) chose to use a diary format to record stressful events over a 4-week period in conjunction with the QLH-Y. They found that subjects high on experienced stress showed a greater impact of headache on their psychological functioning and satisfaction with life and concluded that experienced stress moderates the relationship between headache and QoL in adolescents. It is also useful to note that by far the most instances of experienced stress were related to school.

Meanwhile, in the same analysis Langeveld et al. (1999) discovered that although trait negative affectivity predicted adolescents' physical and psychological

functioning, it did not play a moderating role in the relationship between headache and QoL. The potential role of other emotional and psychological variables has not yet been explored. In particular, Bandell-Hoekstra et al. (2000) propose that depression might be a mediator of the headache-QoL relationship. This is supported by evidence reported on earlier in this review of increased morbidity in girls with depression in addition to headache (Egger et al., 1998). Similarly, low self-esteem may exert a significant impact on headaches via depression (Silberstein, Lipton, & Breslau, 1995).

Finally, in Hunfeld and colleague's (2002) 3-year follow-up study, we are provided with some insight into the longer-term relationship between persistent pain in children and QoL. Contrary to expectations, the authors found that pain-related QoL and the impact on the family remained stable (rather than worsening) across the three assessments. Interview data confirmed that many adolescents adapted to their pain and appeared to become more skilful in coping with their pain. This appears at odds with findings with adult chronic pain patients who are characterised by poor coping (McGrath & Unruh, 1987) and for whom the longer the duration of pain, the poorer their QoL (Skevington, 1998). Yet a comprehensive exploration into the impact of the coping responses employed by children with headache on their QoL has yet to be undertaken.

In summary, the limited number of studies available tell us that adolescents with headache have a poorer QoL when compared to headache-free controls and to adolescents with other chronic pain conditions. However, there may be less differentiation in QoL impairment across conditions when pain levels are high. In adolescents, similar patterns of QoL impairment have been noted across headache diagnoses and across time. While headache has a main effect on QoL, pain parameters and stressful life events are also important players in this relationship. In this way, the more headache and the more stress experienced, the worse the adolescent's QoL. The

potential role of other psychological factors such as emotional functioning and coping responses has yet to be explored.

Meanwhile, it is important to place the above findings within a realistic methodological context. To-date, all seven studies into the overall QoL of young people with headache have been population-based, using only adolescent subjects from Dutch samples. One involved a solely male adolescent population. Six out of the seven include no control comparison and utilise one of two related QoL questionnaires. Although the QLH-Y questionnaire and its adapted version the QLP-Y are a vital and unique step forward in headache research, not all subscales show satisfactory internal consistency (Langeveld et al., 1999). The authors themselves are aware that the measurement of social functioning is less reliable and valid than the other dimensions (Hunfeld et al., 2002).

Theoretical and Clinical Implications

The issues raised in this review have several key implications for researchers and clinicians interested in the QoL of children with headache. Conceptually, this review has highlighted the multidimensional nature of both headache and QoL and the need to employ them as such. This is in contrast with a tendency until recently to study aspects of QoL in isolation and is supportive of the move towards a more comprehensive approach (e.g., Langeveld et al., 1996; 1997; 1999). Alongside there is a need to apply a developmental framework and a child-focused approach to address the special issues for children in the presentation and diagnosis of headache and in the assessment and interpretation of QoL.

The overall picture that has been painted here has been that the QoL of children with headache is likely to be pervasively and persistently affected across physical,

psychological and social life domains. As such, the importance of investigating, assessing and treating the physical in conjunction with the psychological and social aspects of children's lives in an attempt to improve their QoL is underscored. This opposes the use of clinical psychology input as a last resort in some medical settings, where children are only referred after receiving multiple medical work-ups (Kenny & Willoughby, 2001).

Meanwhile, at least some aspects of the chronic pain experience seem to impair QoL in similar ways. This implies that findings from one condition may be usefully extrapolated to another and so improve our knowledge and understanding of chronic pain in children in general. Clinically, an effective intervention for headache such as stress management, cognitive behaviour therapy, or relaxation training (McGrath & Larsson, 1997) could be provided for a group of children with a range of chronic pain conditions. This may also help clinicians to manage their limited resources more effectively. Similarly, attempts to characterise and address impairment in QoL for children with headache may be most appropriately based on a continuum model rather than distinct headache types.

The probability of reciprocal causal pathways acting between headache and QoL was also exemplified particularly by consideration of the psychological functioning of children with headache. This highlights the need to address the bias towards correlational data collected to-date. Moreover, with headache itself only accounting for a small proportion of the variance, the relationship between headache in children and QoL is likely to be characterised by a variety of mediating and moderating factors. Some of these factors will be amenable to psychological intervention, so that QoL can also be improved in an indirect manner. For example, as stress is a moderator of the headache-

QoL relationship, interventions directed at improving the QoL of these children should include techniques aimed at enhancing stress-coping skills (Langeveld et al., 1999).

Ending on a cautionary note, our current knowledge base on the overall QoL of children with headache has been shown to be in the early stages of development. This implies that our ability to make sturdy generalisations to younger, clinical, cross-cultural populations may still be limited at present.

Summary and Future Directions

The aim of this review was to examine the relationship between headache in children and adolescents and QoL, and variables that may influence such a relationship. The evidence discussed here together suggests that the QoL of young people with headache is likely to be adversely affected in a pervasive and persistent manner. This confirms the relevance to clinicians and researchers of applying the QoL notion to young people who experience headache (Langeveld & Passchier, 2001). The scene was set by a discussion regarding our current conceptualisation of headache and QoL as applied to children. This emphasised the importance of appreciating and utilising a multidimensional, biopsychosocial model of health, illness, chronic pain and QoL. Specific consideration of informant and developmental issues with regards to QoL assessment and interpretation helped to underline the need to take a child-focused approach where possible.

The functioning of children with headache across three separate QoL domains was then examined. Some degree of impairment was documented in each area. In this way, children with headache tend to show subtle yet important emotional difficulties, they report increased levels of somatic focus and complaints and often exhibit problems within the school, peer and family context. The currently limited literature base on the

overall QoL of children with headache was then summarised. Initial findings illustrate that adolescents with headache experience a poorer QoL compared to headache-free peers and those with other painful conditions. The contributory role of increased pain and stressful life events was highlighted. In the final section, this review considered some of the conceptual and practical implications of the above discussion for researchers and clinicians.

The findings discussed above also demonstrate that continued QoL research is relevant in relation to young headache patients. There are several gaps in the literature that could be usefully filled. Whilst many studies have focused on investigating their functioning in separate QoL domains, our understanding of their QoL as a multidimensional concept needs further development (Bandell-Hoekstra et al., 2000). In particular, it would appear that a well-chosen control group (or groups) might permit greater conviction in making or refuting conclusions. In this way, Langeveld and Passchier (2001) have requested more in-depth comparison with healthy controls and subjects with other chronic diseases. Articulating the impact of cultural differences in illness perception and experience would also be a worthwhile venture (Loonen et al., 2001). Further clarification of the constructs of headache and QoL as applied to children would be beneficial in making research studies more easily comparable.

There is a striking scarcity of studies incorporating a clinical population, especially considering that a high use of health care services has been documented for this group of children (Metsähonkala, Sillanpää, & Tuominen, 1996; Mortimer, Kay, & Jaron, 1992). Preliminary evidence suggests that there are few differences in the QoL as measured by the QLP-Y, of adolescents with chronic pain who consult healthcare services compared to those who do not (Perquin et al., 2001). However, the scope of functional limitations and the subsequent needs of children with headache who present

in our clinics still requires further investigation in its own right, in order to refine the services we deliver.

Reflecting the paucity of QoL instruments for children in general, the headache-specific questionnaire developed by Langeveld et al. (1996) and adapted by Hunfeld, Perquin, et al. (2001) stand alone. Hunfeld and colleagues (2002) have already spoken of their hopes to refine the QLP-Y based on interview data. Further development of alternatives, especially of shorter measurement scales is also desirable (Langeveld & Passchier, 2001). Likewise, no studies in children have been reported in which the QoL of headache subjects is compared with the QoL of no-headache controls employing a purely generic QoL instrument (Langeveld & Passchier, 2001). A proxy scale has also yet to be used with this population, although a preliminary parent version of the QLH-Y questionnaire is apparently becoming available.

The QLH-Y questionnaire was developed to be used on a target population of adolescents between 12 and 18 years of age, and this has effectively limited our knowledge and use of a truly developmental framework at present. The QoL of pre-adolescent children with headache is therefore unknown but no less important or valid. Exploration of the effects of age and also gender in relation to headache and QoL might yet provide us with some useful insights (Bandell-Hoekstra et al., 2000). Meanwhile, greater use of qualitative methods in conjunction with quantitative methods might help to discover 'the story behind the numbers' (e.g., Hunfeld et al., 2002).

The question of causality is raised frequently in the literature, reflecting in part the dominance of cross-sectional studies in this field. Fundamentally, there is uncertainty as to whether headache has an impact on QoL, or poor QoL triggers the onset of headache, or whether the relationship between headache and QoL is of a reciprocal nature (Bandell-Hoekstra et al., 2000). Authors suggestions include using experimental

and treatment designs, as well as more longitudinal and prospective studies to correct this bias and to help establish causality (e.g., Hunfeld et al., 2002; Langeveld et al., 1997; Palermo, 2000).

Research data concerning the impact of head pain is lacking in some areas, such as sleep and parental burden. Moreover, because there is not a unidirectional relationship between pain and QoL, Palermo (2000) has highlighted the need for models that consider complex circular pathways between children's headache, individual and family factors and QoL impairment. The identification of additional potential mediators and moderators of the headache-QoL association such as depression and coping response, would allow for interventions to be targeted on the specific behaviours or emotional processes that will affect most change and improvement in QoL. Risk and resilience factors might also be highlighted providing clues about the young patients who need additional support compared to those who have sufficient resources (Langeveld & Passchier, 2001).

Finally, one important reason to understand QoL impairment associated with paediatric headache is that it is potentially amenable to psychological intervention (Palermo, 2000). Bandell-Hoekstra and colleagues (2000) have noticed that the assessment of QoL has become an outcome measure of pharmacological therapeutic trials in adult patients with headache, but they could only find one published study using QoL as an outcome measure in a non-pharmacological trial. Similarly, Palermo has observed that there has been very little treatment research on paediatric chronic pain specifically focused on functional QoL improvements. Yet she points out that psychological interventions such as cognitive-behaviour therapy need to be used to enhance children's functioning as the primary goal, with reductions in pain as a secondary goal. In this manner, the use of QoL in treatment effect studies may result in a

more detailed evaluation of the effects of headache and psychological intervention on these specific domains (Langeveld & Passchier, 2001). Perhaps as these gaps in our knowledge are filled, the important effects of headache on young people will become better recognised, researched and managed.

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Empirical Paper

Quality of Life in Children and Adolescents with Chronic, Recurrent Headache

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Running head: QUALITY OF LIFE AND PAEDIATRIC HEADACHE

Quality of Life in Children and Adolescents with Chronic, Recurrent Headache

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Abstract

Objective: To determine whether the quality of life (QoL) of a clinical group of children with headache differs from that of children without headache, to examine the potential roles of depression, global self-esteem and coping as mediators in the headache-QoL relationship, and to compare parent and child ratings of QoL.

Methods: Participants were 30 children between 8 and 16 years of age, attending paediatric neurology clinics with chronic, recurrent headache and 30 age- and gender-matched controls without headache. Children were assessed using the Child Health-Related Quality of Life (CQOL), Children's Depression Inventory, Self-Perception Profile for Children and Kidcope. Parents of children with headache completed the parallel version of the CQOL.

Results: Children with headache reported a poorer QoL compared to peers without headache. Depression, self-esteem and older children's coping responses were found to be mediators of the headache-QoL link. Parents generally reported a more positive picture compared to their children.

Conclusions: Children with headache tend to experience lowered QoL. This is partly attributable to psychological factors which may be modifiable.

Key words: quality of life; children and adolescents; headache; chronic pain; clinical sample; pediatric; paediatric; mediators.

Introduction

Headache in children and adolescents has been described as "the most common, clinically significant, recurrent pain" (McGrath & Larsson, 1997, p. 843). Large epidemiological studies have estimated that 75% of children (aged 15 or younger) have experienced clinically significant headache, with weekly headaches occurring in more than 15% of 10 to 17 year olds (Passchier & Orlebeke, 1985). Prevalence increases throughout childhood reaching a peak at about age 13 (Fearon & Hotopf, 2001). With regards to gender, headaches tend to be more prevalent among boys before the age of 12, but more frequent in adolescent girls (Rhee, 2000).

Meanwhile, the effects of headache in young people have not been well recognised, researched or managed (McGrath, 1999). Headache is often viewed as less significant compared to other chronic medical conditions, perhaps due to its subjective nature and the frequent lack of organic findings (Solomon, Skobieranda & Gragg, 1993). For similar reasons the impact of headache is not well evaluated by traditional objective clinical outcomes such as mortality, changes in physiological markers or diagnostic images (Mannix, Chandurkar, Rybicki, Tusek, & Solomon, 1999). The burden of headache is therefore at risk of being underestimated (Essink-Bot, van Royen, Krabbe, Bonsel, & Rutten, 1995).

Increasingly, quality of life (QoL) has been presented as an alternative to traditional outcome measures, as many believe it has the potential to represent the ultimate standard against which to judge the impact of children's experiences and the effectiveness of any intervention (e.g., Wallander, Schmitt, & Koot, 2001). This reflects contemporary views about the critical link between physical and mental health and the importance of taking a holistic approach which aims to treat 'the whole child' (Harding, 2001). As such, QoL is fast becoming the major outcome measure for the impact of

headache and its treatment (Bandell-Hoekstra, Abdu-Saad, Passchier, & Knipschild, 2000).

QoL is recognised as a multidimensional concept, which from a patient's perspective should include at least the domains of psychological, physical and social functioning since each may be affected by chronic conditions (Koot, 2001). Studies on separate life domains suggest that children with headache will tend to experience impairment in all three areas. Children with headache have been found to score higher on anxiety and depression measures when compared to healthy controls (Andrasik et al., 1988; Engström, 1992). Children with headache generally report poorer physical health (Martin-Herz, Smith, & McMahon, 1999) and more somatic concerns compared to control children (e.g., Andrasik et al., 1988; Carlsson, Larsson, & Mark, 1996).

Disrupted functioning in both the school and home setting are frequently referred to in children with headache. More frequent absence from school is noted compared to headache-free controls (Carlsson et al., 1996) and children with other chronic pains (Hunfeld, Passchier et al., 2001). Cunningham and colleagues (1987) found that children with headache showed less social participation and were less socially skilled compared to pain-free children. Bullying and truancy have also been allied with frequent headache in children (Beiter, Ingersoll, Ganser, & Orr, 1991; Williams, Chambers, Logan, & Robinson, 1996). Paediatric headache is associated with various family problems, including divorce, disharmony, physical and mental health difficulties, and a restricted family social life. These systemic factors can be expected to reduce the QoL of children with headache in terms of their social and family role functioning (Langeveld & Passchier, 2001).

Meanwhile, only four studies to-date have investigated the overall QoL of children with headache in multidimensional manner. Three further studies have

investigated the QoL of children with chronic pain inclusive of headache. Salient results will be drawn upon here. Using their newly developed Quality of Life Headache-Youth (QLH-Y) questionnaire, Langeveld, Koot, Loonen, Hazebroek, and Passchier (1996) found that compared to headache-free peers, adolescent students with recurrent headache reported a comparatively poorer overall QoL. This appears to be the only such comparison in the literature to-date and the pattern of the impact of paediatric headache on QoL compared to controls has yet to be clearly delineated. Meanwhile, similar patterns of QoL impairment have been noted across headache diagnoses (Langeveld, Koot, & Passchier, 1999) and across time (Hunfeld et al., 2002).

Hunfeld, Passchier, and colleagues (2001) have compared a community sample of adolescent students with head, limb, abdominal and back pain and found those with head pain to report the worst QoL. Yet curiously, the headache group reported the least amount of pain. This suggests that factors other than pain may be also involved in lowering QoL for children with headache. Indeed, although headache has been shown to have an independent effect on adolescent's QoL (Langeveld et al., 1999), its presence does not account for a significant part of the variance in QoL (Langeveld et al., 1996).

In an attempt to explain this variance, Langeveld, Koot, and Passchier (1997) found that fluctuations in headache activity in adolescents as measured by a 4-week headache diary, were related to fluctuations in the subjects' functional status, psychological functioning, overall satisfaction with life and health perception as measured by the QLH-Y questionnaire. Specifically, more intense and frequent headache coincided with a lower self-reported QoL. In their 1999 paper, Langeveld and colleagues also used a diary format to test the role of stress on the interrelation between headache and QoL in adolescents. They found that subjects high on experienced stress showed a greater impact of headache on their psychological functioning and satisfaction

with life and concluded that experienced stress moderates the relationship between headache and QoL in adolescents.

The literature to-date has therefore shown that adolescents with headache have a poorer QoL when compared to headache-free controls and to adolescents with other chronic pain conditions. While headache has a main effect on QoL, pain parameters and stressful life events are also important players in this relationship. In this way, the more headache and the more stress experienced, the worse the adolescent's QoL. However, it is important to place the above findings within a realistic methodological context. All seven studies into the overall QoL of young people with headache have been population-based, using only adolescent subjects from Dutch samples. One involved a solely male adolescent population. Six out of the seven include no control comparison and utilise one of two related QoL questionnaires. Although the QLH-Y and its adapted version the Quality of Life Pain-Youth (QLP-Y) are a vital and unique step forward in headache research, not all subscales show satisfactory internal consistency (Langeveld et al., 1999).

Our ability to generalise may therefore be limited at present. For example, a high use of health care services has been documented for this group of children (Mortimer, Kay, & Jaron, 1992). The association of headache in childhood with a variety of psychosocial factors means that medics refer a substantial number of children with headache to clinical psychology in paediatric and community settings. Yet, there is a striking scarcity of studies using clinical populations about which we need to know more in order to refine the services we deliver. Exploration of the effects of age and gender in relation to headache and QoL has not yet been undertaken (Bandell-Hoekstra et al., 2000). No studies in children have been reported in which the QoL of headache subjects

is compared with the QoL of no-headache controls employing a purely generic QoL instrument (Langeveld & Passchier, 2001).

A proxy scale has also yet to be used with this population. There tends to be poor agreement between carer's and children's ratings of pain, anxiety, depression and QoL (see Harding, 2001; Koot, 2001), with children reporting more problems and lower QoL than their parents report about them (e.g., Theunissen et al., 1998; Verhulst & Van der Ende, 1992). However, proxy ratings could still provide valid and reliable additional information on the QoL of children with headache (Eiser & Morse, 2001).

The potential mediating role of other psychological variables has yet to be explored. For instance, depression might be a key mediator of the headache-QoL relationship (Bandell-Hoekstra et al., 2000; Palermo, 2000). This is supported by the finding that increased morbidity in terms of more frequent headache, more school missed and more medication taken, has been documented for girls with depression in addition to headache (Egger, Angold, & Costello, 1998). Similarly, low self-esteem may exert a significant impact via depression (Silberstein, Lipton, & Breslau, 1995).

Meanwhile, the observed stability (rather than worsening) of pain-related QoL over a 3-year period implies that some adolescents with chronic pain are able to adapt to their pain and even become skilful in managing it (Hunfeld et al., 2002). Indeed, more approach coping (i.e., active and direct attempts to deal with pain and regulate emotions whilst in pain) has been related to less disability in children with headache (Reid, Gilbert, & McGrath, 1998). However, a comprehensive exploration into the influence of the coping responses employed by children with headache on their QoL has yet to be carried out. Further understanding of mediators of the headache-QoL relationship would be beneficial by helping to focus psychological interventions on specific behaviours or emotional processes that will affect most change and improvement in QoL.

Therefore, this study aims to further our knowledge of the impact of chronic recurrent headache on children's QoL and the ways in which this effect occurs. Given the literature outlined above, three main hypotheses can be advanced for testing. Firstly, using a generic instrument, a clinical group of children and adolescents with chronic recurrent headache will have a poorer QoL compared to age- and gender-matched peers without headache. Secondly, depression, self-esteem and coping response will mediate the relationship between headache and QoL. Thirdly, there will be a low agreement between child and parent ratings of children's QoL. Specifically, parents will underestimate the impact of headache on their children's QoL.

Method

Design

To test the first and second hypotheses, a between-group design was employed. The two groups were defined by the presence or absence of headache. The third hypothesis was tested using paired-sample t tests.

Participants

Sample selection.

With regards to the clinical group, a consecutive series of new patients presenting for evaluation of head pain at paediatric neurology outpatient clinics at two general hospitals were considered for participation. Eligibility for the study was established if the patients met the following criteria: headache of at least weekly frequency and 3 months duration without known organic cause; aged between 8 and 16 years; English as their first language; and the absence of any physical or learning disability. The headache parameters of frequency and duration are consistent with current definitions of chronic

pain in children and several previous studies (e.g., Cunningham et al., 1987; Egger, Costello, Erkanli, & Angold, 1999).

The non-headache group attended a local primary and secondary school and were matched on age (in years) and gender. Parents were asked to only consider allowing their child to participate in the study if their child experienced less than one headache per week. On testing, the majority of the control children claimed to experience no headaches at all. A small minority described very infrequent headaches (e.g., one every few months).

Participant cohort.

Forty-five new patients were considered for the study. However, 15 were not approached as 8 failed to attend their clinic appointment, 3 were younger than 8 years of age, 2 experienced headache less frequently than the criteria specified, and 2 had known learning disabilities. Thirty children and their parent(s) were approached at their outpatient appointment and all agreed to participate in the study. This sample size was selected in order to provide 80% power to detect differences between groups of the order of a standard deviation, setting alpha at .05. This effect size was necessary in order for results to be of clinical significance.

Table 1 shows the age distribution of the clinical and non-clinical groups, in addition to the age at which parents completed full-time education. Twenty-one out of the 30 children in the clinical group were subsequently referred on to a paediatric psychology service.

Insert Table 1 about here

The mean age of the entire sample was 12.53 years (SD = 2.14; range = 8.0 – 16.6). These figures are consistent with reports of peak incidence of headache in children (Fearon & Hotopf, 2001). The two groups did not differ significantly according to the children's ages (t (58) = -.042, p = ns) or according to the age at which their mothers (t (58) = 1.99, p = ns) or fathers (t (58) = 1.48, p = ns) completed full-time education.

Measures

All 60 children completed four measures assessing QoL, depression, global self-esteem and use and efficacy of pain coping strategies. The children in the headache group also rated the typical severity, duration and intensity of their pain. The parents of the headache group also completed a parallel measure of their child's QoL.

QoL.

The Child Health-Related Quality of Life (CQOL; Graham, Stevenson, & Flynn, 1997) was used to assess QoL of the children involved in this study. The CQOL comprises 15 domains: mobility, self-care, continence, school, activities, friends, family, discomfort due to bodily symptoms, worry, depression, sight, communication, eating, sleep and appearance. For each of the domains, the child is given a brief list of various problems in a particular domain that might be shown by a child whose QoL has been adversely affected. They then rate their own functioning over the past month on a 7-point scale. At one end is a rating that the child is better than children of the same age and at the other extreme is the child with a severe functional impairment. Two further 7-point ratings are made to establish firstly how upset, and then how satisfied the child has been with their level of functioning. Finally, a global rating of QoL is made on a single 7-point scale

ranging from better than children of the same age to very poor quality of life. A higher score indicates a poorer outcome.

The measure therefore provides a function, upset and satisfaction rating for each of the 15 domains in addition to an overall QoL rating. Combined scores are also obtained by summating the ratings across the 15 domains separately for function, upset and satisfaction. The authors report acceptable reliability and validity and have demonstrated that the CQOL can discriminate between children with chronic physical disorders, psychiatric disorders and well controls (Graham et al., 1997).

Depression.

Depressive symptoms were evaluated via the Children's Depression Inventory (CDI; Kovacs, 1980). This is a widely used 27-item self-report measure where each set of three sentences pertains to a key symptom of depression. The child is asked to select one of the three sentences that best describes him/her for the preceding 2 weeks. A value is assigned to each sentence from 0 (absence of the symptom) to 2 (clinically severe form of the symptom) from which a summated total score is produced. The CDI has been found to have adequate reliability and validity (Saylor, Finch, Spirito, & Bennett, 1984).

Coping.

The Kidcope (Spirito, Stark, & Williams, 1988) is a widely adopted checklist that assesses children's use of coping responses and their perceived efficacy in relation to a particular stressor. In this study, the stressor was specified so that all children were asked to recall the last time they had pain that bothered them. They were first asked to rate this experience in terms of the distress they felt. The children were then asked

whether or not they used specific coping strategies and if used, how helpful they were during the painful episode.

Both the younger (ages 7 to 12) and older (ages 13 to 19) versions were used. The main scale of the younger version contains 15 items and the older version contains 10 items. The frequency measure is binary for the younger version, but on a 4-point scale for older children. The efficacy rating is on a 3-point scale for younger children and a 5-point scale for older children. A higher score indicates higher frequency and increased efficacy.

With regards to scoring, the distress items were summed to provide an overall indicator of the upset caused by the pain. The main scales provide 10 coping category scores for the frequency and efficacy of various strategies. For categories comprising of more than one item, the mean frequency score was calculated and the highest efficacy rating was used. In this study, the 10 strategies were further grouped into higher order coping constructs based on recommendations by Spirito, Stark, and Tyc (1994) and as previously utilised with children with headache by Holden, Rawlins, and Gladstein (1998). In this way, three overall strategy types were used: avoidant coping (distraction, social withdrawal, wishful thinking and resignation), negative coping (self-criticism and blaming others) and active coping (problem-solving, emotional regulation, cognitive restructuring and social support).

The reliability and validity of Kidcope have been established in previous research with a variety of different populations, including paediatric samples for whom it was originally designed (Spirito, Stark, & Knapp, 1992).

Global self-esteem.

To measure levels of child global self-esteem, the relevant subscale of the Self-Perception Profile for Children (SPPC; Harter, 1982; 1985) was administered. For each of the six items, the child is asked which of two statements is more like themselves and then whether the statement is really true or only sort of true for them. The child's responses are recorded on a 4-point scale from 1 (low perceived competence) to 4 (high perceived competence). Reliability as measured by Chronbach's alpha has been documented at around .73 by the author and others (e.g., Harter, 1985; Hoare, Elton, Greer, & Kerley, 1993). The modified version adapted by Hoare et al. for British children was used in this study for which internal and construct validity have been upheld.

Headache Group Only

Pain parameters.

Three visual analogue scales (VAS) were used to assess the severity, duration and intensity of pain experienced by the headache group. The VAS consisted of horizontal lines of 100 mm with very mild/short/weak and a smiling face on the left ends and very severe/long/strong and a sad face at the right ends. The children were asked to mark a position on each line that best matched the usual experience of their pain. VAS markings were then converted to a score from 0 to 100 by reading off each mark against a millimetre ruler.

The VAS has been shown to be a valid, reliable and versatile measure for the assessment of self-reported pain in adult and child chronic pain patients (e.g., Jensen, Karoly, & Braver, 1986; McGrath, 1986). This has been found to be true of children as young as five years old (Varni, Thompson, & Hanson, 1987). The VAS used in this

particular study were modelled on the well-established Pediatric Pain Questionnaire (PPQ) by Varni and colleagues. The scales were felt to be sufficient measures of pain for the current study as they are considered to be one of the most germane components of the PPQ (Varni, Blount, Waldron & Smith, 1995) and a more in-depth assessment of pain was not necessary here.

CQOL - Parent form.

The almost identical parent version of the CQOL was used to assess the QoL of children with headache from their parent's point of view. The parent is asked to rate how his/her child has been in the area in question and then rate his/her own levels of upset and satisfaction in the same way. The scoring and psychometric properties are as stated earlier. The parent version has been found to discriminate between the mothers of children with learning disabilities, chronic physical disorders and psychiatric disorders (Graham et al., 1997).

Procedure

Approval to conduct the study was obtained from the ethics committees for the University of Southampton and the two hospital trusts involved (Appendix A). Patients and their parent(s) who met the study criteria were approached at the end of their medical appointment so that an organic cause of headache could first be ruled out. A brief verbal description of the study was provided in addition to an information sheet (Appendix B). Written consent was obtained from both the child and a parent (Appendix C).

Measures were administered in the clinic, completed concurrently by child and parent but in separate rooms. Each child was given individual support (according to each

questionnaire's protocol) in completing the measures by the current researcher. In general parents required very little assistance. Where it was not possible to administer the measures in clinic (e.g., at the end of a clinic), they were completed at the child's initial clinical psychology appointment following the same protocol.

Parents of 230 schoolchildren were sent a letter together with an information sheet (Appendix B) and two copies of the consent form (Appendix C). They were asked to return one copy of the consent form (signed by both themselves and their child) by freepost if they were happy for their child to take part. The response rate was 37%, which is consistent with reported parental consent rates (e.g., Audrain, Tercyak, Goldman & Bush, 2002). Age- and gender-matched children were then assessed in the same individual manner as for the clinical group. Testing was carried out during school time and it was therefore not possible to collect further data from parents of the control group. It is acknowledged that it was not possible for the current researcher to be blind to the allocation of the children to the headache or non-headache group.

Data Analysis

Firstly, no effects of age or gender on overall QoL were found, *t*s (58) = -1.86, -.12 respectively, *p*s = *n*s.

Independent *t* tests were used to determine the psychological characteristics of the headache and non-headache groups. A MANOVA was then used to compare the groups in terms of overall QoL and combined functioning, upset and satisfaction. In order to identify where the group differences in QoL lay, Mann-Whitney *U* tests were then employed. Given the number of comparisons involved, Bonferroni's correction was applied (Grove & Andreasen, 1982). An acceptable alpha of .003 was adopted, to reduce the risk of Type I errors.

Associations between pain parameters and QoL were determined by using correlational analyses (Pearson's r).

Correlational analyses were then used to determine whether the proposed mediators (depression, self-esteem and coping) were associated with the dependent variables (overall QoL, combined functioning, upset and satisfaction). Baron and Kenny's (1986) regression model was then used to test the hypothesised mediational relationships. In this regression model, the first step is to establish bivariate relationships between the hypothesised independent variable (group), mediator and dependent variable. If all of the bivariate relationships achieve statistical significance, the mediational relationship is tested by determining whether removing the variance in the dependent variable that is attributable to the mediator variables reduces or completely removes the variance in the dependent variable that is attributable to the independent variable. A substantial reduction in the strength of the independent-dependent relationship indicates a partial mediation effect, whereas a perfect mediation effect is seen where the independent-dependent relationship is rendered non-significant (Baron & Kenny, 1986). Forced entry methods were subsequently used to test for the best predictors of QoL. Group was entered in the first step, followed by variables shown to be mediators from the above analysis in a second step.

The associations between the child and parent forms of the CQOL were calculated using paired-sample t tests because the data are paired and the scales are equivalent. Additional investigations involved using MANOVAs to determine the relationship between age and gender and QoL, and t tests to compare the QoL of children subsequently referred and not referred on to clinical psychology. An alpha level of .05 was used for all statistical tests except where specified.

Results

Characteristics of the Headache and Non-Headache Groups

Table 2 summarises the children's mean scores and independent t test results for depression, global self-esteem and coping. Children with headache experienced more depressive symptoms and lower levels of self-esteem compared to children without headache. With regard to coping responses, children with headache became more anxious in response to their pain than children without headache. Younger children with headache used more avoidant coping strategies and were less effective when using negative coping strategies. They used less active strategies and were less effective when using these strategies compared to children without headache. Older children with headache used more avoidant and negative coping strategies than children without headache.

Insert Table 2 about here

Group Differences in QoL

In order to test the hypothesis that children with headache would have a poorer QoL than children without headache, a MANOVA was calculated. Table 3 shows that the difference between groups on the CQOL was highly significant. Children with headache self-reported a poorer overall QoL compared to peers who do not experience headache. Children with headache felt they performed less well across 15 life domains overall and were more upset and less satisfied about their performance overall.

Insert Table 3 about here

In order to reveal where the group differences in QoL actually lay, Mann-Whitney U analyses were then conducted for combined functioning, upset and satisfaction scores. Given the number of analyses conducted, Bonferroni's correction was used and an acceptable alpha of .003 was employed (.05/15). Tables 4, 5 and 6 summarise these findings. Children with headache reported that they performed less well at school, had more bodily discomfort, worried more and slept more poorly than did children without headache. They were also more upset about their performance in these four areas than were children without headache. Children with headache were also less satisfied with their eyesight, their levels of bodily discomfort, their levels of anxiety and their poor sleep than were children without headache.

Insert Table 4 about here

Insert Table 5 about here

Insert Table 6 about here

Ratings of pain intensity, severity and duration *(headache group only).*

The mean VAS scores for the headache group were as follows. The mean pain intensity was 68.5 (SD = 18.1, range 26.0 - 100.0), the mean severity was 63.8 (SD = 16.81, range = 16.0 - 89.0) and the mean duration was 67.8 (SD = 22.72, range = 15.0 - 100.0). These scores are comparable to those of paediatric headache patients reported elsewhere (e.g., Kashikar-Zuck, Goldschneider, Powers, Vaught, & Hershey, 2001).

Association between Pain Parameters and QoL

Correlational analyses (Pearson's r) were used to determine the level of association between pain parameters and QoL in children with headache. A significant association was found between headache intensity and CQOL overall ($r(30) = .50$, $p < .01$), combined functioning ($r(30) = .52$, $p < .01$), upset ($r(30) = .50$, $p < .01$) and satisfaction ($r(30) = .44$, $p < .05$). This indicates that the greater the intensity of head pain, the worse the child perceived their QoL to be. A significant association was found between headache severity and combined functioning ($r(30) = .46$, $p < .01$) and satisfaction ($r(30) = .41$, $p < .05$), but not with CQOL overall ($r(30) = .32$, $p = ns$) or combined upset ($r(30) = .33$, $p = ns$). This indicates that children with more severe head pain felt they did less well across the 15 areas and were less satisfied with this performance overall. In contrast, headache duration was not correlated with CQOL overall, combined functioning, upset or satisfaction, $rs(30) = -.02, .12, .06$ and $.16$ respectively, $ps = ns$. In summary, variation in the quality of headache was related to variation in QoL, but there were insufficient sample numbers for further mediational analyses.

Association of QoL with Depression, Global Self-Esteem and Coping

Correlational analyses (Pearson's r) were used to determine the level of association of the hypothesised mediating variables with the dependent variable (QoL). Table 7 illustrates these correlations. Depression and global self-esteem were associated with all four QoL scores. Feeling sad and generally distressed in response to pain was associated with level of functioning and upset, whilst feeling anxious was only correlated with level of upset. The use and efficacy of coping strategies in younger subjects was not associated with QoL. For older subjects, only the use of negative coping was found to be associated with QoL.

Insert Table 7 about here

Depression, Global Self-Esteem and Coping as Mediators of the Headache-QoL Link

Table 8 shows the results of the multiple regression analyses (enter method) used to test a model hypothesising that depression, global self-esteem and coping could act as mediators in the relationship between the presence of headache in children (group) and self-reported QoL. In addition to group having a direct effect, depression mediated the relationship between group and all four QoL variables. This same mediating role was found for self-esteem.

With regards to coping, distress in response to pain did not play a mediating role between group and the four QoL variables, although a direct effect of group was found for each. In addition to a direct effect of group, older children's use of negative coping mediated the relationship between group and combined upset. However, only a direct

effect of group was found for overall QoL, combined functioning and combined satisfaction.

Insert Table 8 about here

In order to test which of these variables were the best predictors of QoL, forced entry multiple regression analyses were then performed. Table 9 shows the results of these analyses. In the first step, group was found to have an independent effect on overall QoL, combined functioning, upset and satisfaction, $\underline{F}s_{(1, 58)} = 17.16, 38.91, 33.94, 35.37$, $\underline{p}s = < .001$. In a second step, depression, self-esteem and coping variables previously shown to play a mediating role were then entered into the analysis. Depression was shown to have the largest additional effect as a predictor of QoL.

Insert Table 9 about here

As depression was itself 1 of the 15 CQOL domains, these results were re-run (using combined functioning as the dependent variable) excluding this domain from the analysis. Similar results were obtained ($\underline{\beta} = .40$, $\underline{p} = .002$) which indicates that this finding is not an artefact of the scoring.

Associations between Child CQOL and Parent CQOL

Table 10 shows a comparison between the child and parent versions of the CQOL on overall QoL and overall levels of functioning, upset and satisfaction. Parents of children

with headache rated their children's overall QoL as worse than their children did. However, parents felt that their children performed better overall and were less upset and more satisfied about their children's performances. Low correlations were found between child and parent scores.

Insert Table 10 about here

Additional Investigations

Due to the representation of children of different ages, genders and referral patterns in the sample, two further sets of analyses were conducted.

Relationship between age and gender and QoL.

In order to examine whether the QoL of children with headache varied according to age and gender, MANOVAs were computed. No difference between the QoL of girls or boys was found for overall QoL, combined functioning, upset or satisfaction, $\underline{F}s_{(1, 56)}$ = .00, .14, .02 and .00 respectively, $\underline{p}s = \underline{ns}$.

Meanwhile, children of 12 years and above were found to have a poorer QoL compared to those under 12 in terms of overall QoL ($\underline{F}_{(1, 56)} = 5.18$, $\underline{p} < .05$), combined functioning ($\underline{F}_{(1, 56)} = 5.94$, $\underline{p} < .05$), upset ($\underline{F}_{(1, 56)} = 5.68$, $\underline{p} < .05$) and satisfaction ($\underline{F}_{(1,56)} = 14.37$, $\underline{p} < .001$). This finding applied regardless of group, $\underline{F}s_{(1, 56)} = 1.35, .25, .01$ and 1.06 respectively, $\underline{p}s = \underline{ns}$.

Comparison of QoL and depression according to psychology referral pattern.

Table 11 shows that the QoL and mood of the 21 children with headache referred on to clinical psychology did not differ from the 9 children not subsequently referred on. This

indicates that children with headache who were not referred on had just as much depression and impairment in QoL as the referred children.

Insert Table 11 about here

Discussion

This study aimed to further our knowledge of the impact of chronic recurrent headache on children's QoL and the ways in which this effect occurs. The results support the first hypothesis by confirming that a clinical group of children with chronic recurrent headache report significantly poorer QoL compared to age- and gender-matched peers who do not experience headache. Further analyses identify that children with headache report the most impairment in the areas of school, anxiety, sleep, bodily discomfort and eyesight. Meanwhile, it is important to note that due to the correlational nature of the data, no firm conclusions about the direction of results can be made.

Perceived impairment within the school arena is consistent with previous research, which has documented lowered attendance (Carlsson et al., 1996), increased unhappiness (Cunningham et al., 1987) and stressful experiences at school (Langeveld et al. 1999). From the questionnaire used in this study, it is not clear what aspect of the school experience may be most impaired. With regards to the academic aspect, headache is not known to adversely affect cognitive and intellectual functioning (Billie, 1962; Andrasik et al., 1988). However, problems with concentration when learning and working on the computer are more likely to be described by adolescents with headache compared to those with other chronic pains (Hunfeld et al., 2002). Meanwhile, the social aspect of school may also be troublesome for children with headache. This is suggested

by previous findings of social withdrawal, poor social skills and bullying (Beiter et al., 1991; Cunningham et al., 1987). The reported impairment in school-related QoL could therefore be reflective of academic and/or social difficulties.

Perceived impairment in terms of increased anxiety levels is consistent with existing studies which document maladaptive psychological functioning in children with headache (Andrasik & Passchier, 1993; Engström, 1992). Impairment in terms of sleep-related QoL is also compatible with existing reports of increased tiredness (Aromaa et al., 2000; Carlsson et al., 1996; Larsson, 1988) and sleep disturbance in children with headache (Bruni et al., 1997). One option is that head pain directly disrupts the child's sleep. In this way, the child may be woken by the pain or use sleep as a coping strategy. Alternatively, a more indirect route is possible as highlighted by the link between stressful life events especially school-related stressors and sleep problems, and the role of anxiety in maintaining these problems (Carr, 1999). This may help to explain why poor sleep quality has been reported even on pain-free days (Palermo, 2000).

Reports of increased bodily discomfort may be expected in a comparison of children who experience head pain and those who do not. However, this domain is defined so as to include a variety of symptoms rather than headache alone. Therefore potential impairment from a variety of ailments reflects the recognition by other authors that children with headache report poorer physical health, more somatic concerns, and evaluate their health as less satisfactory compared to no-headache controls (Carlsson et al., 1996; Martin-Herz et al., 1999; van den Bree, Passchier, & Emmen, 1990).

The isolated finding that children with headache are less satisfied with their eyesight, even though they do not report poorer levels of functioning or upset in terms of their sight, may also reflect a greater somatic focus noted in this population (Carlsson et al., 1996). Several sources of this internal focus have been put forward. From a

cognitive-perceptual perspective, attending to one's internal states serves to enhance the perceived intensity of physical symptoms, so that individuals tend to experience even normal physiological sensations as disturbing and respond with hypervigilance (see Siegel, 1998). It has also been proposed that this heightened concern with health status may be either a reaction to, or a means of coping with ongoing stress (Carlsson et al., 1996; Mikail & von Baeyer, 1990).

The second set of hypotheses received partial support. The presence of headache in children has a consistent, direct effect on QoL. This is consistent with previous findings in non-clinical populations (e.g., Langeveld et al., 1996; 1999). Moreover, the current study is compatible with a model where depression (and self-esteem to a lesser extent) plays a key role in mediating the headache-QoL relationships. This finding is compatible with recent work which found that depression accounted for nearly 50% of the variance in functional disability in children with chronic pain (Kashikar-Zuck et al., 2001). The important influence of depressive symptoms in lowering QoL may act through several routes such as reduced participation in peer activities and sleep disturbance (Palermo, 2000).

Coping plays a more restricted mediating role. In this way, older children's use of negative strategies mediates the link between headache and overall level of upset. The detrimental effects of these strategies in terms of increased pain, lowered functioning and mood are well-recognised (e.g., Beck, 1967; Gil, Williams, Thompson, & Kinney, 1991). Indeed, children with headache in Holden et al.'s (1998) study reported negative strategies to be the least helpful compared to active or avoidant approaches.

Partial support was also found for the third hypothesis regarding child and parent ratings of QoL. There is poor agreement between their viewpoints, which echoes the general finding that children and parents do not necessarily share similar views about the

impact of illness (Eiser & Kopel, 1997). Compared to the views of their children, parents of children with headache feel that their children perform better over the 15 domains and are less upset and more satisfied with their children's performances. This pattern is congruous with existing comparisons of child and parent ratings of children's QoL (Theunissen et al., 1998). The current findings may partly reflect the use of denial or minimisation by parents as to the impact of headache on their children's lives. Support for this idea can be found in the family systems literature whereby the families of children with somatising conditions have been observed to avoid conflict, lack emotional language and to present a façade of 'supernormalcy' (Lask, 1986; Minuchin, Baker, Liebman, Milman, & Todd, 1975).

Paradoxically, parents of children with headache rate their children's overall QoL as worse than their children do. This may relate to differences in the overall appraisal of QoL between parent and child. Concepts such as preference, compensation, resilience and coping may be relevant here (Harding, 2001). For instance, children with headache may be better able to compensate for areas of difficulty by considering areas of strength or preference, in a similar manner to how self-worth can remain positive despite mixed competence judgements (Harter, 1982).

It must also be acknowledged that in general, agreement amongst raters differs as a result of factors such as child gender, age and condition (Verhulst & Van der Ende, 1992), as well as according to the type of measure used and age of respondent (Harding, 2001). Proxies may be influenced by the development of other children they know, their expectations and hopes for the child, additional life stresses and their own mental health (Eiser & Morse, 2001). Indeed, parents of children with headache are recognised as having an increased risk for psychological maladjustment (Fearon & Hotopf, 2001) which may have influenced their ratings.

Although not outlined in the initial hypotheses, the sample characteristics subsequently allowed for the relationship between QoL and gender, age and referral patterns to be investigated. Firstly, as indicated by the MANOVA on page 22, the QoL of boys and girls appears to be affected in the same manner. This is an interesting result as gender has previously been shown to be an influential factor in determining the psychological, social and physical functioning of children with headache (Egger et al., 1998; 1999; Martin-Herz et al., 1999; Sillanpää & Aro, 2000). It may therefore be beneficial to repeat this investigation in future studies.

Meanwhile, older children experience a poorer QoL compared to younger children. This may be due in part to the greater disruptive effects of pain for an older age-group in terms of social and academic developmental tasks (Andrasik et al., 1988). This is compatible with documented increases in anxiety and depression from childhood to adolescence in those with headache (Andrasik et al., 1988; Martin & Smith, 1995). Older children with headache and their parents also report significantly more interference with school (White, Alday, & Spirito, 2001). This effect was found for both children with and without headache and so may reflect the increase in social and academic pressures that are placed upon adolescents in general within our culture.

Finally, the finding that children with headache who are not referred on to clinical psychology have just as much depression and impairment in QoL as children who are referred on, raises an important clinical issue. In this way, the nine children not referred on for psychological input may yet have had just as much reason for such a referral to be made. It is however important to note that doctor's reasons for making or not making a referral were not explored in this study, and it is possible that some families may have refused such an offer or that a referral will be made following a

subsequent clinic visit. The small numbers in the group not referred on also means that some degree of caution is necessary in drawing firm conclusions from these results.

Several other important clinical implications ensue from this study. Overall, the relevance of applying the concept of QoL to children with headache in a clinical setting is confirmed. Particular attention should be paid to assessing and treating problems relating to school, anxiety and sleep as these areas seem to be the most detrimentally affected. In working to improve the QoL of children with headache, clinicians might also usefully address depressive symptoms and low self-esteem, and aim to reduce the tendency for older children to employ self- and other-blame. These treatment plans are supported by others in the field (e.g., Langeveld et al., 1999; Kashikar-Zuck et al., 2001). From this study's comparison of parent and child report, it is also important to note that relying on a single source may led the clinician to underestimate the distress and impairment being experienced. Support for seeking multiple informant data is therefore upheld.

Meanwhile, the following limitations are noted. Firstly, this study is correlational in nature from which no conclusions about directional causality can be firmly drawn. It is therefore possible that lowered QoL may lead to children experiencing headaches or depression as well as vice versa. Secondly, International Headache Society diagnostic criteria (1988) were not employed here, however this was partly because a continuum approach was taken on the basis of a previous lack of differentiation in QoL across headache types (Langeveld et al., 1999). Thirdly, the control group was a general population sample selected for the absence of headache, whilst headache occurrence would tend to be prevalent in unselected samples (Passchier & Orlebeke, 1985).

Fourthly, in this study the Kidcope questionnaire was specifically directed at assessing coping responses in relation to a painful episode. Although the questionnaire

was adequately flexible to accommodate for this purpose, it is recognised that it did not explicitly cover specific pain management strategies such as relaxation exercises or use of medication. Indeed, Holden et al. (1998) found that these additional strategies were used at a more frequent rate than the active, avoidant or negative strategies included in Kidcope. Measures such as the Pain Coping Questionnaire (Reid et al., 1998) and Pain Response Inventory (Walker, Smith, Garber, & Van Slyke, 1997) designed specifically to assess children's coping with recurrent and chronic pain may have been more extensive alternatives. Finally, the potential for shared method variance to partly account for the strength of relationship between QoL and the other variables is acknowledged.

Notwithstanding these limitations, this study has increased our knowledge of the QoL of children with headache in a number of novel ways. It has begun the investigation into the QoL of a group of children who are seen regularly within our clinics, both medical and psychological. Unique steps have been taken by employing a generic QoL instrument allowing for a comparison with a no-pain control group. Parent ratings have been reported for the first time, as have age and gender effects. Modifiable psychological factors that play a mediating role have also been identified which can help to guide treatment planning.

Meanwhile, continued research is needed in this young field. The preliminary results of this study would benefit from further validation and extension. For instance, the effects of gender on QoL could be explored in more depth with a larger sample. Qualitative methods might be used to explore the reported impairment in specific areas such as school and sleep in more detail. Although the models proposed here accounted for 50 to 70% of the variance between headache and QoL, examining the role of additional mediators or moderators of this link could further our understanding. For example, somatic focus and negative automatic thoughts might mediate the relationship

between headache, depression and QoL, whilst cognitive appraisal may mediate the relationship between headache, coping and QoL (see Bandell-Hoekstra et al., 2000). More systemic factors such as parental coping have not been discussed here yet may be relevant.

Further exploration of parent-child concordance might help to place the current results in a more comprehensive framework and dissolve some of the present inconsistencies. Moreover, the QoL of parents and families with children with headache would be of systemic interest in itself. Clinician's ratings of the QoL of children with headache might also be a useful avenue, particularly if related to referral reasons and pathways. This could potentially inform referral decisions and ensure appropriate treatment delivery.

Using QoL assessment tools as outcome measures seems pertinent. Palermo (2000) has observed that there has been very little treatment research on paediatric chronic pain specifically focused on functional QoL improvements. Yet she points out that psychological interventions such as cognitive-behaviour therapy need to be used to enhance children's functioning as the primary goal, with reductions in pain as a secondary goal. In this manner, the use of QoL in treatment effect studies may result in a more detailed evaluation of the effects of headache and psychological intervention on these specific domains (Langeveld & Passchier, 2001). From a methodological point of view, treatment and longitudinal studies would also assist in clarifying causality.

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Table 1

Demographic Details of the Headache and Non-Headache Group

	Headache group M (SD; range)	Non-headache group M (SD; range)
Age of child (years)		
Boys (n = 14)	12.14 (1.65; 9.8 - 16.0)	12.14 (1.87; 9.0 - 16.6)
Girls (n = 16)	12.84 (2.42; 8.0 - 16.4)	12.89 (2.49; 8.8 - 16.5)
All	12.51 (2.09; 8.0 - 16.4)	12.54 (2.22; 8.8 - 16.6)
Age at which parents completed full-time education (years)		
Mothers	18.37 (3.82; 15.0 - 30.0)	16.8 (1.99; 15.0 - 21.0)
Fathers	18.2 (4.25; 15.0 - 30.0)	16.93 (2.0; 15.0 - 23.0)

Table 2

Comparison of Mean Scores for Depression, Global Self-Esteem and Coping for Children with and without Headache

	Headache group		Non-headache group		
	M	SD	M	SD	p
Depression	9.90	5.75	5.27	3.77	.001
Global self-esteem	18.4	3.08	20.63	2.58	.004
Coping					
Overall distress	4.20	2.52	3.00	2.39	ns
Anxious	1.60	1.13	1.00	.98	.032
Sad	1.60	1.33	1.37	1.00	ns
Angry	1.00	1.11	.63	1.16	ns
Younger children					
Avoidant coping					
Use	2.47	.51	1.91	.83	.025
Efficacy	2.47	1.12	3.00	1.50	ns
Negative coping					
Use	.18	.39	.29	.47	ns
Efficacy	.00	.00	.35	.61	.029
Active coping					
Use	2.41	.62	2.94	.86	.048
Efficacy	3.88	1.27	5.53	2.24	.013

Older children					
Avoidant coping					
Use	6.54	2.54	4.46	2.44	.044
Efficacy	2.85	1.63	3.69	2.84	ns
Negative coping					
Use	.54	.66	.077	.28	.034
Efficacy	.00	.00	.23	.83	ns
Active coping					
Use	4.27	2.24	4.00	2.09	ns
Efficacy	5.23	3.63	4.92	3.28	ns

Table 3

Comparison of CQOL Overall, Combined Functioning, Upset and Satisfaction scores for Children with and without Headache

	Headache group		Non-headache group		
	M	SD	M	SD	p[a]
CQOL overall	3.30	1.24	2.10	.99	< .001
Combined functioning	46.60	9.17	31.83	9.16	< .001
Combined upset	39.47	11.79	24.63	7.45	< .001
Combined satisfaction	43.27	12.14	26.90	8.94	< .001

[a]$F_{s\ (1, 58)}$ = 17.16, 38.91, 33.94, 35.37 respectively.

Table 4

Comparison of Mean CQOL Domain Scores for Children with and without Headache for Combined Functioning Scores

	Combined functioning			
CQOL domains	Headache group M (SD)	Non-headache group M (SD)	U	p[a]
Mobility	2.90 (1.09)	2.37 (.85)	325.50	ns
Self-care	2.03 (1.07)	1.90 (.76)	446.00	ns
Continence	1.83 (1.26)	1.37 (.67)	364.50	ns
School	3.40 (1.57)	2.23 (1.14)	252.00	.003
Activities	2.53 (1.31)	2.00 (1.05)	344.00	ns
Friends	2.80 (1.42)	1.87 (1.01)	269.50	ns
Family	2.83 (1.72)	2.10 (1.09)	354.00	ns
Discomfort	5.40 (1.43)	2.10 (.92)	36.00	< .001
Worry	3.80 (1.52)	2.50 (1.33)	235.50	.001
Depression	3.37 (1.85)	2.30 (1.09)	301.00	ns
Sight	2.93 (1.44)	1.93 (1.14)	267.50	ns
Communication	2.67 (1.40)	2.10 (1.16)	351.50	ns
Eating	2.60 (1.61)	2.40 (1.33)	441.00	ns
Sleep	4.03 (1.61)	2.17 (1.37)	176.00	< .001
Appearance	3.30 (1.34)	2.47 (1.14)	285.00	ns

[a]Bonferroni correction = .003

Table 5

Comparison of Mean CQOL Domain Scores for Children with and without Headache for Combined Upset Scores

	Combined upset			
CQOL domains	Headache group M (SD)	Non-headache group M (SD)	U	p[a]
Mobility	2.23 (1.30)	1.43 (.86)	273.00	ns
Self-care	1.60 (1.25)	1.13 (.43)	356.50	ns
Continence	1.53 (1.07)	1.03 (.18)	343.00	ns
School	3.23 (1.48)	1.97 (1.19)	229.00	.001
Activities	2.43 (1.68)	1.67 (.96)	326.00	ns
Friends	2.63 (1.50)	1.73 (1.01)	285.00	ns
Family	2.73 (1.80)	1.73 (.94)	300.00	ns
Discomfort	4.53 (1.80)	1.63 (.93)	75.00	< .001
Worry	3.57 (1.50)	2.10 (1.13)	205.00	< .001
Depression	3.00 (1.88)	1.97 (1.33)	309.00	ns
Sight	2.13 (1.72)	1.33 (.71)	353.50	ns
Communication	2.37 (1.38)	1.57 (1.01)	291.50	ns
Eating	2.03 (1.50)	1.77 (1.25)	404.00	ns
Sleep	3.13 (1.89)	1.53 (.94)	227.50	< .001
Appearance	2.50 (1.57)	2.00 (1.23)	370.50	ns

[a]Bonferroni correction = .003

Table 6

Comparison of Mean CQOL Domain Scores for Children with and without Headache for Combined Satisfaction Scores

	Combined satisfaction			
CQOL domains	Headache group M (SD)	Non-headache group M (SD)	U	p[a]
Mobility	2.53 (1.48)	1.60 (.81)	287.50	ns
Self-care	1.80 (1.10)	1.70 (.95)	432.50	ns
Continence	1.57 (1.01)	1.17 (.53)	358.50	ns
School	3.23 (1.76)	2.20 (1.37)	286.00	ns
Activities	2.67 (1.67)	1.77 (.90)	304.50	ns
Friends	2.63 (1.56)	1.70 (.92)	289.00	ns
Family	2.43 (1.55)	1.93 (.94)	388.00	ns
Discomfort	5.63 (1.50)	1.80 (1.03)	28.50	< .001
Worry	3.57 (1.33)	1.93 (1.05)	160.50	< .001
Depression	3.33 (1.92)	2.10 (1.21)	279.50	ns
Sight	2.60 (1.69)	1.53 (1.11)	249.00	.001
Communication	2.47 (1.43)	1.70 (.99)	314.50	ns
Eating	2.20 (1.49)	1.83 (1.09)	405.00	ns
Sleep	3.63 (1.63)	1.70 (1.21)	147.50	< .001
Appearance	2.90 (1.58)	2.13 (1.14)	326.00	ns

[a]Bonferroni correction = .003

Table 7

Correlations between QoL and Depression, Global Self-Esteem and Coping

	CQOL score			
	CQOL overall	Combined functioning	Combined upset	Combined satisfaction
Depression	.65**	.70**	.78**	.78**
Global self-esteem	-.66**	-.56**	-.56**	-.65**
Coping				
Overall distress	.18	.28*	.37**	.20
Anxious	.04	.25	.33*	.16
Sad	.23	.27*	.35**	.17
Angry	.11	.09	.15	.12
Younger children				
Avoidant coping				
Use	.10	.21	.29	.29
Efficacy	-.18	-.17	-.16	-.14
Negative coping				
Use	.20	.12	.06	.12
Efficacy	.00	-.04	-.17	-.04
Active coping				
Use	-.02	-.27	-.29	-.29
Efficacy	-.09	-.31	-.30	-.31

Older children				
Avoidant coping				
Use	.27	.26	.15	.15
Efficacy	-.09	.07	.14	.06
Negative coping				
Use	.42*	.57**	.55**	.55**
Efficacy	-.14	.10	.03	.07
Active coping				
Use	.11	.00	.30	.02
Efficacy	.26	.05	.34	.04

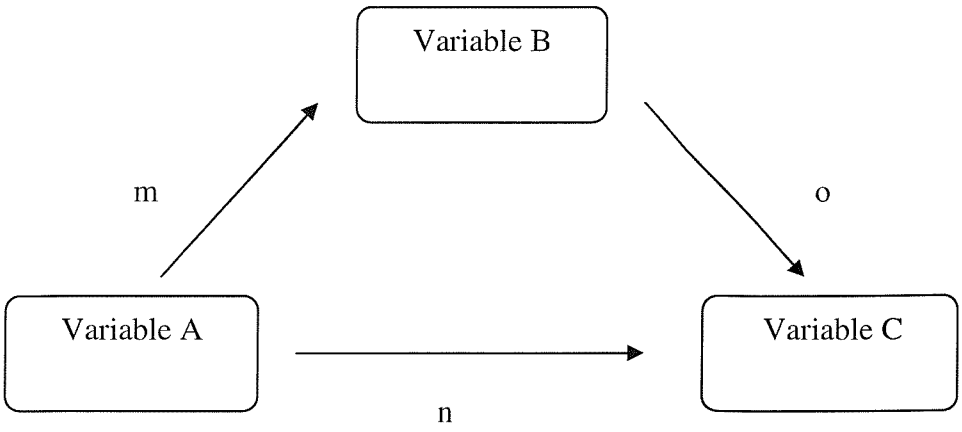
*$p < .05$. **$p < .01$.

Table 8

Multiple Regression Analyses using Overall QoL, Combined Functioning, Upset and Satisfaction as the Dependent Variable

Variable A	Variable B[a]	Variable C	m	n	o
Group	Depression	Overall QoL	-.44**	-.24*	.55**
		C. Functioning	-.44**	-.40**	.53**
		C. Upset	-.44**	-.33**	.63**
		C. Satisfaction	-.44**	-.34**	.63**
	Global self-esteem	Overall QoL	.37**	-.27*	-.56**
		C. Functioning	.37**	-.49**	-.38**
		C. Upset	.37**	-.46**	-.39**
		C. Satisfaction	.37**	-.44**	-.49**
	Distressed in response to pain	C. Functioning	-.24	-.60**	.13
		C. Upset	-.24	-.55**	.24*
	Anxious in response to pain	C. Upset	-.28*	-.56**	.17
	Sad in response to pain	C. Functioning	-.10	-.61**	.21*
		C. Upset	-.10	-.58**	.29**
	Older children's use of negative coping	Overall QoL	-.28*	-.42**	.19
		C. Functioning	-.28*	-.58**	.19
		C. Upset	-.28*	-.54**	.23*
		C. Satisfaction	-.28*	-.56**	.21

Note. Group = presence/absence of headache. C. Functioning = combined functioning; C. Upset = combined upset; C. Satisfaction = combined satisfaction.



[a]Only significant covariates are shown.

*p < .05. **p < .01.

Table 9

Summary of Forced Entry Multiple Regression Analyses using Overall QoL, Combined Functioning, Upset and Satisfaction as the Dependent Variable

Dependent variable	Predictor variable entered[a]		B	SE B	β
Overall QoL[b]	Step 1	Group	-1.20	.29	-.48***
	Step 2	Group	-.52	.25	-.21*
		Depression	.072	.03	.31*
		Global self-esteem	-.16	.05	-.37**
C. Functioning[c]	Step 1	Group	-14.77	2.37	-.63***
	Step 2	Group	-9.24	2.12	-.40***
		Depression	1.02	.26	.47***
		Global self-esteem	-.35	.44	-.09
C. Upset[d]	Step 1	Group	-14.83	2.55	-.61***
	Step 2	Group	-7.81	2.04	-.32***
		Depression	1.43	.25	.62***
		Global self-esteem	.063	.42	.02
		Older children's use of negative coping	2.77	2.78	.08
C. Satisfaction[e]	Step 1	Group	-16.37	2.75	-.62***
	Step 2	Group	-8.69	2.13	-.33***
		Depression	1.29	.26	.52***
		Global self-esteem	-.76	.44	-.17

Note. Group = presence/absence of headache. C. Functioning = combined functioning; C. Upset = combined upset; C. Satisfaction = combined satisfaction.

[a]Only variables previously shown to play a mediating role are included (see Table 7).

[b]R^2 = .22 for Step 1; ΔR^2 = .52 for Step 2 (ps = < .001). [c]R^2 = .39 for Step 1; ΔR^2 = .61 for Step 2 (ps = < .001). [d]R^2 = .36 for Step 1; ΔR^2 = .68 for Step 2 (ps < .001). [e]R^2 = .37 for Step 1; ΔR^2 = .70 for Step 2 (ps < .001).

*p < .05. **p < .01. ***p < .001.

Table 10

Comparison of Results from the Child and Parent Versions of the CQOL

	M (SD)	p	Correlation
Child overall QoL	2.70 (1.27)		
		< .001	-.34**
Parent overall QoL	5.38 (2.82)		
Child combined functioning	46.60 (9.17)		
		.006	.28
Parent combined functioning	38.83 (13.75)		
Child combined upset	39.47 (11.79)		
		.013	.16
Parent combined upset	32.17 (11.64)		
Child combined satisfaction	43.27 (12.14)		
		.001	.08
Parent combined satisfaction	32.57 (11.99)		

**p < .01.

Table 11

Comparison of QoL and Depression in Children with Headache Subsequently Referred and Not Referred on to Clinical Psychology

	Referred (n = 21)		Not referred (n = 9)		
	M	SD	M	SD	p
Overall QoL	3.33	1.32	3.22	1.09	ns
Combined functioning	46.38	9.57	47.11	8.71	ns
Combined upset	38.67	12.49	41.33	10.40	ns
Combined satisfaction	42.33	11.95	45.44	13.01	ns
Depression	10.10	5.37	9.44	6.89	ns

List of Appendices

Appendix A

Regional and University ethical approval letters

SOUTHAMPTON & SOUTH WEST HANTS
LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Dr A Kermode

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Ref: CPW

3 July 2001

Miss C Dlckson
Trainee Clinical Psychologist
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Highfield
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Dear Miss Dickson

Submission No: 135/01 – The impact of paediatric headache on quality of life

The Ethics Committee considered your recent response in accordance with the decision to withhold approval for the above study at the meeting on 27 June and I am pleased to inform you that **approval is now granted**.

May I draw your attention to the enclosed conditions of approval which must be complied with. YOU SHOULD BE AWARE THAT A SUBSTANTIAL RANDOM PROPORTION OF RESEARCH PROJECTS ARE AUDITED ANNUALLY.

The data protection officer for the Trust/University is to be notified of the study.

This committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end, it undertakes to adhere as far as is consistent with its constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

The composition of the committee is enclosed for your files and confirms which members were present at the meeting. Most pharmaceutical companies request this information and we would be grateful if you could forward this to them if appropriate.

Should any unforeseen problem of either an ethical or procedural nature arise during the course of this research and you feel the Joint Ethics Committee may be of assistance, please do not hesitate to contact us.

Yours sincerely,

Cwright

Clair Wright
LREC Manager

Isle of Wight, Portsmouth and South East Hampshire
Health Authority

Finchdean House
Milton Road
Portsmouth PO3 6DP

Tel: 023 9283 8340
Fax: 023 9273 3292

Direct Line: 023 9283 5139
Fax: 023 9283 5073

Miss Clare Dickson
c/o Doctoral Programme in Clinical Psychology
University of Southampton
Building 44 (Shackleton)
Highfield
Southampton SO17 1BJ

14 February 2002

Dear Clare

REC Prop No: 01/02/1291
Title: **The impact of paediatric headache on quality of life**

This is to inform you that the Local Research Ethics Committee has approved the above study at its meeting on **8 February 2002**.

This study was given full approval, with the understanding that the control group will not be recruited in Isle of Wight, Portsmouth and Southeast Hants area.

Approval for the study is only granted until the end of **30 June 2002**. If your study continues after this date further Ethics Committee approval will be required.

The following documents were reviewed:

Patient/control consent forms	not dated
Patient/control information sheet	not dated
Assessment protocol	not dated
Life events checklist	not dated
CD inventory	not dated
Self-worth questionnaire	not dated
Kid cope - younger/older children	not dated
Children's headache assessment scale	not dated
Child/adult quality of life questionnaire	not dated

- The Ethics Committee will require a copy of the completed study for its records. You are therefore requested to submit a copy of the completed study to the address above.

- The Committee must be informed of any untoward or adverse events which occur during the course of the study.

- Please inform the Committee if the study is withdrawn, or does not take place.

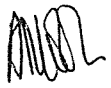
- The Ethics Committee must also be informed of, and approve, any proposed amendments to your initial application.

- Please note it is the policy of the Committee NOT to deal direct with sponsoring companies. All correspondence (including telephone enquiries) MUST be from the first named researcher. Enquiries from other sources will be refused.

- Ethics Committee approval means that the proposal is ethically sound. It does not mean approval of resources, access to data or any other requirement relating to the project. These must be agreed with the organisation where the research / project is to take place.

If you have any further questions please do not hesitate to contact me quoting the Research Ethics Committee Proposal Number given above.

Yours sincerely



Anna Noble
Administrator to the Research Ethics Committee

E-mail: anna.noble@portsha.swest.nhs.uk

NB: The Committee endorses the Royal College of Physicians Report on 'Fraud & Misconduct in Medical Research Practice 1991'. This states that all original data (eg questionnaires, lab books, hard copies of any computer data) are kept for a minimum of ten years in a retrievable form. If storage is to be outside either Portsmouth Hospitals or Portsmouth HealthCare NHS Trusts' premises, the Committee must be informed of the site of storage. It is a condition of any approval that such storage occurs.

From:	"AMANDA" <Amanda@psy.soton.ac.uk>
Organization:	Psychology - University of Soton
To:	dc4@soton.ac.uk
Date sent:	Wed, 23 May 2001 15:59:43 +0000
Subject:	Ethical
Send reply to:	A.Josling@soton.ac.uk
Priority:	normal

Hi Denise

Can you inform Clare Dickinson that she has ethical approval.

Thanks.

Amanda

Appendix B

Participant information sheet - clinical group

ON HEADED PAPER

INFORMATION SHEET

Study Title: *The Impact of Children's Headache on Quality of Life.*

You are being asked for your permission for you and your child to take part in study regarding the impact of children's pain on their quality of life.

What is the purpose of this study?

The aim of the study is to enable us to understand how headache affects children's lives and how we can best help them.

Why has my child been chosen?

We are studying children between the ages of 8 to 16, who experience recurrent headaches.

Do my child and I have to take part?

It is up to you to decide whether or not you and your child take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you and your child are still free to withdraw at any time and without giving a reason. This will not effect the standard of care you and your child receive.

What will my child and I have to do if we take part?

Your child will be asked to complete a short series of questionnaires with the help of a psychologist. This will include questions about how your child feels things are for them at the moment and what they do to cope with their pain. This will take up to 25 minutes in total. You will be asked to complete one or two short questionnaires about your child's pain. This will take you up to 15 minutes in total.

What are the possible benefits of taking part?

We hope that the information we get from this study may help us to treat future young patients with headache better.

Will information on my child be kept confidential?

All information which is collected on your child will be kept strictly confidential and will not be viewed by anyone other than the researchers and staff involved in this study.

What will happen to the results of the research?

If the results of the study are published, your child will not be identified in any way. A summary of the study can be supplied to you on request.

Who has reviewed the study?

This study has been reviewed by the Research Ethics Committees for Southampton and SW Hampshire and for the Isle of Wight, Portsmouth and SE Hampshire and also by the Department of Psychology at the University of Southampton.

Thank you for reading this information sheet.

Contact for further information:
Clare Dickson (Trainee Clinical Psychologist), C/O Doctoral Programme in Clinical Psychology, Building 44, University of Southampton, Highfield, SO17 1BJ.
Tel: (023) 8059 5321.

Appendix B

Participant information sheet and letter - control group

ON HEADED PAPER

INFORMATION SHEET

Study Title: *The Impact of Children's Headache on Quality of Life.*

You are being asked for your permission for your child to take part in study about children's quality of life.

What is the purpose of this study?

The aim of the study is to compare healthy children with children who attend the hospital due to frequent headaches. The results may enable us to understand how painful chronic conditions affect children's lives and how we can best help them.

Why has my child been chosen?

We are studying children between the ages of 8 to 16, who are generally healthy and **do not** experience frequent headaches (i.e. less than 1 per week).

Does my child have to take part?

It is up to you to decide whether or not to allow your child to take part. If you do decide for your child to take part, you will be need to sign both copies of the consent form and complete the question in the box. Keep one copy for yourself and return the other copy in the pre-paid envelope. If you decide for your child to take part, your child is still free to withdraw at any time and without giving a reason. This will not effect the standard of education your child receives.

What will my child have to do if they take part?

Your child will be asked to complete some questionnaires whilst in school, with the help of a psychologist. This will include questions about how your child feels things are for them at the moment and what they do to cope with being unwell. This will take up to 25 minutes in total.

What are the possible benefits of taking part?

We hope that the information we get from this study may help us to treat future children with painful conditions better.

Will information on my child be kept confidential?

All information which is collected on your child will be kept strictly confidential and will not be viewed by anyone other than the researchers involved in this study.

What will happen to the results of the research?

If the results of the study are published, your child will not be identified in any way. A summary of the study can be supplied to you on request.

Who has reviewed the study?

This study has been reviewed by the Research Ethics Committees for Southampton and SW Hampshire and for the Isle of Wight, Portsmouth and SE Hampshire and also by the Department of Psychology at the University of Southampton.

Thank you for reading this information sheet.

Contact for further information:
Clare Dickson (Trainee Clinical Psychologist), C/O Doctoral Programme in Clinical Psychology, Building 44, University of Southampton, Highfield, SO17 1BJ.
Tel: (023) 8059 5321.

ON HEADED PAPER

March 2002

Dear parents,

Re: A research study.

I am writing to you to ask for your permission for your child to take part in a study about children's quality of life.

The aim of the study is to compare healthy children with children who attend the hospital due to frequent headaches.

Your child can take part as long as they are generally healthy and have **less than 1 headache per week** on average. Your child will be asked to fill out some questionnaires with my help. This will take up to 25 minutes in total. It will include questions about how your child feels things are for them at the moment and what they do to cope with being unwell. This will be done in school, at a time that is convenient for your child and their teacher.

We hope that the information we get from this study may help us to treat future children with painful conditions better.

Please note that we will not be able to use all children who might wish to volunteer. This is because we require children of the same age and gender as those in the hospital group.

An information sheet is attached with further details.

If you are happy for your child to take part, you will need to:

1. **Sign both copies of the consent form and complete the question in the box.**
2. **Keep one copy.**
3. **Return the other copy to me in the envelope provided by Friday 5th April.**

Many thanks for your time and consideration.

Yours sincerely,

Clare Dickson
Trainee Clinical Psychologist
University of Southampton.

Appendix C

Participant consent form - clinical group

ON HEADED PAPER

CONSENT FORM

Title of Project: The Impact of Children's Headache on Quality of Life.

Name of Main Researcher: Clare Dickson.

Please initial box

1. I confirm that I have read and understand the information sheet dated.....for the above study and have had the opportunity to ask questions. ☐

2. I understand that my child's participation and my own participation is voluntary and that we are free to withdraw at any time, without giving any reason, without our medical care or legal rights being affected. ☐

3. I agree to take part in this study and for my child to take part in the study. ☐

Name of Parent/ Guardian	Date	Signature
Name of Child	Date	Signature
Name of Person taking consent *(if different from researcher)*	Date	Signature
Researcher	Date	Signature

Appendix C

Participant consent form - control group

ON HEADED PAPER

CONSENT FORM

Title of Project: The Impact of Children's Headache on Quality of Life.

Name of Main Researcher: Clare Dickson.

Please initial box

1. I confirm that I have read and understand the information sheet dated.....for the above study and have had the opportunity to contact the researcher to ask questions. ☐

4. I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, without their legal rights being affected. ☐

3. I agree for my child to take part in the above study. ☐

Name of Parent/ Guardian	Date	Signature
Name of Child	Date	Signature

How old were you when you finished full-time education?

Mother: ... . years old

Father: ... . years old

Appendix D

Instructions to authors

Instructions to Authors

The main emphasis of the journal is on original research Analytical reviews of research, brief scientific reports, scholarly case studies, and commentaries are also considered for publication The *JPP* website (http //www jpepsy oupjournals org) includes book reviews and letters to the editor, in addition to general information on the journal Submissions are welcomed from authors in psychology and other disciplines serving children and families

Manuscript preparation: Manuscripts (text, references, tables, figures, etc) should be prepared in detailed accord with the *Publication Manual of the American Psychological Association* (4th ed) There are two exceptions (a) The academic degrees of authors should be placed on the title page following their names, and (b) a structured abstract of ≤ 150 words should be included The abstract should include the following parts *Objective* (brief statement of the purpose of the study), *Methods* (summary of the participants, design, measures, procedure), *Results* (the primary findings of this work), and *Conclusions* (statement of implications of these data) *Key words* should be included, consistent with APA style Submissions should be double-spaced throughout with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12–15 characters per inch) Authors should remove all identifying information from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations E-mail addresses, whenever possible, should be included in the author note

Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter

Brief Scientific Reports should not exceed 12 pages, including a maximum of two tables and/or figures This format should be considered for papers with scientific merit, but utilizing small samples or introducing new methodologies It is also appropriate for reports of replication or application of an existing approach to a novel sample or problem

Scholarly reviews should not exceed 30 pages total

Case reports should not exceed 12 pages Case reports are appropriate to document the efficacy of new treatment applications, describe new clinical phenomena, to develop hypotheses, to illustrate methodological issues, difficult diagnoses, novel treatment approaches and to identify unmet clinical or research needs Guidelines for case study submissions can be found in Drotar, D , LaGreca, A , Lemanek, K , and Kazak, A (1995) Case Reports in Pediatric Psychology Uses and guidelines for Authors and Reviewers, *Journal of Pediatric Psychology, 20,* 549–565

Commentaries should not exceed 4 pages, including references Commentaries are invited on all topics of interest in pediatric psychology

Letters to the editor should not exceed 350 words Letters should be prepared in response to articles published in the journal and should be received by the editor within 30 days of the publication of the relevant article Letters will be posted on the website at the discretion of the editor A disk copy of the letter should accompany the submission Microsoft Word for IBM/PC is the preferred format Disks should be clearly labeled with the author's name, brief title of letter, the date and the hardware/software used

The clinical relevance of research should be incorporated into the manuscripts There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers

Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s) Authors will also be asked to sign a statement, provided by the Editor, that they have complied with the American Psychological Association Ethical Principles, with regard to the treatment of their sample

Terminology should be sensitive to the individual who has a disease or disability The Editors endorse the concept of "people first, not their disability" Terminology should reflect the "person with a disability" (e g , children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e g diabetic children HIV patients, cancer families) Nonsexist language should be used

Manuscripts that do not conform to these guidelines will be returned to the authors for revision prior to peer review

Four copies of the manuscript should be sent to Ronald T Brown Ph D , ABPP, Editor Elect, *Journal of Pediatric Psychology,* Medical University of South Carolina, College of Health Professions, 19 Hagood Avenue Suite 910, P O Box 250822, Charleston, SC 29425

Submission is a representation that the work has not been published previously and is not currently under consideration for publication elsewhere Authors should indicate in their cover letter that these conditions have been met The relationship of the submitted manuscript with other publications or submissions of the author(s), if any, should be explained The cover letter should also include a statement indicating that the paper has been seen and approved by all authors The full mailing address, telephone, fax and e-mail address should be included in the cover letter

The journal makes no page charges Authors will receive 25 reprints of their article Additional reprints may be ordered when page proofs are sent to authors

A statement transferring copyright to the Society of Pediatric Psychology will be required before the paper can be accepted for publication Such a written transfer of copyright is necessary under the U S Copyright Law in order for the journal to be disseminated widely and effectively At the time of final acceptance of manuscripts, the authors will be asked to provide a copy of the final accepted version of the paper on disk (Microsoft Word preferred) The author will be asked to confirm in writing that the disk copy is an exact match with the final version accepted by the Editors Discrepancies between the hard and soft copies will result in delays in publication