The role of cognitive factors in adolescents' recovery from corrective surgery for idiopathic scoliosis

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Thank you all.

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Abstract

This study explores the experience of adolescents in hospital. The aim of the study was to explore the relationship between health cognitions and pre and post operative health status in young people having major surgery. A sample of adolescent patients with idiopathic scoliosis (a progressive deformity of the spine) having corrective surgery at an orthopaedic hospital was assessed pre and post operatively. Standardised self report questionnaires were used to assess perceived value of health, locus of control, acceptance, satisfaction with care, depression and anxiety. Pain, functioning and self image associated with the disorder were also assessed and biomedical data including deformity and duration of surgery were recorded. Using a semi-structured interview, a subset of the patients discharged from hospital was asked about their expectations of, preparation for and experience of hospitalisation. Analysis of variance was used to explore the interactions between health beliefs and health status in recovery. The deformity appeared to be portrayed as external to the youngsters and an external perceived control was associated with better health status preoperatively. At follow up, a more internal locus of perceived control was associated with better recovery.

Introduction

Hospitals are unusual places. They contain promises of renewed health, safety and care and threats of harm and separation in equal measure. Few people would voluntarily expose themselves to the experience of hospitalisation. In adolescence, young people may expect to be healthy and not to have to become part of the hospital world that perhaps they have experienced only through contact with adults. Occasionally, accidents or acute illness may precipitate hospitalisation and the youngster may have to adjust quickly, adopting new thought processes to help deal with the situation. In chronic illness, these processes are developed gradually and may be more stable. Hospitalisation may be necessary regularly or occasionally, for youngsters with chronic illness to restore function, repair damage, reduce pain and so on.

This study will investigate whether the cognitions and beliefs that adolescent patients bring with them to hospital help in the understanding of the short term outcome following surgery. The hospitalised group investigated in this study are adolescents having corrective spinal fusion surgery for idiopathic scoliosis. This represented a specific, usually singular hospitalisation for major surgery. Scoliosis is a spinal deformity that is not usually regarded as a chronic illness nor as an acute crisis, often has little pain and functioning disability and is not life threatening in itself. Yet many youngsters with this condition subject themselves to major surgery, the outcome of which is a medium term reduction in health.

Firstly, the transitional developmental period of adolescence is discussed followed by a review of the experience of hospitalisation for adolescents. Models of health beliefs are described and the theoretical processes by which cognitions affect health are outlined. The role of psychological variables in surgical outcome is reviewed, focusing primarily on perceived control as a predictor of outcome. The nature, management and psychological impact of scoliosis is then discussed, with specific emphasis on adolescent idiopathic scoliosis (AIS) and spinal fusion surgery. Specific research questions investigated are then detailed and the design of the study described. Data on a cohort of 28 AIS spinal fusion patients then follows, including a qualitative description of the preparation for the hospitalisation experience by a sub-sample of five.

Adolescence

It is not precisely clear what or when adolescence is. Furnham & Gunter (1989) suggest it could be from age 11 to 22, Coleman & Hendry (1990) says it could just be the teenage years, 13 - 19. Laufer & Laufer (1989) offer from "puberty" to 21. Lerner & Galambos offer a definition of adolescence as "...the period within the lifespan when most of a person's biological, cognitive, psychological and social characteristics are changing from what is typically considered child-like to what is considered adult-like." (Lerner & Galambos 1998, p 414). Chambers dictionary suggest that it is the time between childhood and maturity and does not try to be more specific. All of which adds to the sense of it being a relatively new concept to consider that time to be distinct. In general, it is seen as that period of transition from around age 12 with the onset of puberty, to around age 19/20 with the end of skeletal growth and physical maturity. Naturally, this varies enormously between individuals and between sexes. In considering psychosocial models of adolescence, Coleman & Hendry (1990) feel that there is a large gap between what they refers to as the classical views of adolescence and the empirical evidence. The classical view is informed by two models - the psychoanalytic and the sociological. In both, adolescence is seen as a period of great stress and difficulty.

As Coleman & Hendry (1990) describe it, the traditional psychoanalytic model developed by Freud and later by Peter Blos emphasises internal conflict, a renewed upsurge in psychosexual instincts and old conflicts, which in turn leads to a second individuation process involving regression and ambivalence. Eric Erikson revised this model by placing less emphasis on sexual instinct and more on psychosocial conflict and culture. In his general developmental model, he saw life as consisting of a series of developmental crises. In adolescence, he felt the crisis was between identity and role confusion. In resolving this crisis, the major characteristics are the consolidation of the previous developmental stages into a sense of self with peers as the main social group and a delay from adult responsibilities. In turn, the sociological perspective on adolescence is one in which changing social roles are emphasised and development is based on external societal forces. The many conflicting roles expected of adolescents are highlighted in this model (eg be a good son and stay at home with family vs be a good friend and stay out late with peers). Socialisation becomes a difficult transition, conflicting social pressures cause problems and success depends upon appropriate social role models.

As part of Rutter's seminal large scale study in the Isle of Wight, 200 14 and 15 year olds and their parents were interviewed (Rutter, Philip, Chadwick & Yule 1976). Although there were differences in the reported difficulties from parents and from the adolescents, with between a third and a half reporting occasional arguments with parents, overall there were few reports of serious difficulties between parents and their children (between 2 and 9%). About a fifth of the group reported feeling miserable and it appeared that rates of actual psychiatric disorder were moderately higher in the mid teens than at age 10 or in adults. Rutter concluded that emotional and relationship difficulties do exist in adolescence but that their psychiatric importance and the idea of turmoil had become overstated. While the inception of this study of a very specific population was around 30 years ago, Coleman argues that its findings are still replicated and valid. The view of Coleman & Hendry (1990) is that the traditional theories have much to offer in understanding the adolescent who is in difficulty or who has high levels of pathology. However, he feels that in concentrating on the study of abnormal or interrupted development, they have created a myth of all adolescents as being in turmoil. Much of the criticism of the psychoanalytic and sociological theories of adolescent development stem from a belief that both these perspectives emerged from non-normal samples. In can be argued that psychoanalytic theory was derived from the study of those individuals being presented or presenting themselves for treatment (eg Laufer & Laufer 1989). Sociological theory may similarly come from undue attention attracted by subgroups or individuals who are coping less well with societal demands or who are regarded as problematic. Most adolescents, he feels move through this period with relative success, with lower levels of pathology, better relations with adults and parents, successful role transitions and higher satisfaction with life than might be predicted.

In the review of Lerner & Galambos (1998), adolescence is similarly presented as a period of development characterised by a multilevel interaction and integration of changes within biological, social, cultural, interpersonal, institutional and psychological domains. However, the individual's development of self-definition and roles is not necessarily within a protracted period of stress and anxiety as it is generally portrayed. When stressors occur within smaller numbers of these domains, or where there is a supportive social/familial context attuned to developmental change, then most adolescents develop the resources to handle most situations adequately. When coping is not in accord with the stress, and where there is a coincidence of stress, then vulnerability is increased and health will be compromised.

Coleman & Hendry (1990) describe the development of a focal theory of adolescence within a lifespan developmental model. In this model, they argue that all development must be seen as a product of the overall psychosocial, economic, geographic and cultural environment; the reciprocal influence of family and individual is emphasised and the cumulative influence of the individual as agent is brought forward. As with Lerner & Galambos (1998), Coleman & Hendry (1990) feel that adolescents are active agents in forming their maturation and environment. From the overall model, Coleman's focal theory of normal development was developed from work in which he found that at different ages, different relationships and concerns about those relationships came into focus. Thus, young people are not faced with an immutable mass of role and relationship conflicts for their whole adolescence. Peers are likely to be facing similar foci and thus the amount of adaptation required at any one time is manageable.

Schmidt (1997) and Heaven (1996) argue that, by adolescence, we are capable of sophisticated and abstract thinking about health and illness. Kirscht (1988) has suggested that subjective health utility models like the Health Belief Model and Theory of Reasoned action and Planned Behaviour have little utility in exploring adolescent health. As with Coleman & Hendry (1990), Kirscht feels that models of self efficacy and perceived control need to be explored when considering how one individual copes and another does not. Similarly, Eiser & Kopel (1997) argue that in young people, development of health beliefs parallels that of cognitive development in general as outlined by Piaget. They suggest that in the Piagetian preoperational phase, before the age of seven, children may lack the ability to differentiate between cause and effect in illness and health. Up to age 11, during the concrete operational stage, children have some understanding of where illness comes from but it is not until the formal operational stage, after age 11, that a clearer understanding of health processes emerges. (These ages are, of course, only indicative and are individually determined.) Although understanding in this area is hindered by poorly defined terms and research protocols, and a lack of ethnic and cultural sensitivity in much of this research, this is still a useful framework. Chassin, Presson, Sherman & McConnell (1995) also believe that in adolescence, health beliefs that have long term consequences become activated and that the emerging evidence is that adolescents' thinking about health is increasingly sophisticated, not necessarily based on poor decision making, not based on rejections of adult roles and positions, and is still influenced by parents. Their more concrete ideas about health and self are beginning to give way to notions of feelings, thoughts about health and the influence of the peer group. However, physical appearance is still a major determinant of self esteem. By adolescence, then, youngsters have started to develop clear and measurable health beliefs that can be understood by health care providers and they go on to argue that children's health beliefs inform four specific areas of health care, namely providing developmentally appropriate health education, reducing treatment anxiety, including patients in health care decisions, and increasing compliance.

Donovan (1998) reports on two studies of adolescents' utilisation of health care that illustrate poor access to health care by teenagers, who increase their risk to health. Although most adolescents move through adolescence successfully, their vulnerability is increased by a lack of skill and understanding of the processes in accessing health care. Furnham & Gunter (1989) report on their mid-eighties survey of over 2000 young people across the age and socioeconomic band of adolescence. In a subset asked about health beliefs, there seemed to be a lack of overall confidence in the medical profession and medical treatment.

Chassin et al. (1995) also believe that, while adolescence is a period of high health, it is also a period of increased self-determined heath risk. During adolescence, they argue, youngsters find their health beliefs increasingly influenced and reinforced by peers and any restriction to their developing autonomy could lead to negative consequences, possibly leading to what they describe as psychological reactance - that is attempting to reestablish personal freedom by engaging in health risky behaviours. However, they also suggest that in chronic illness a regressive process, with an individual adolescent regressing to a lower level of developmental maturity might actually be protective.

Hospitalisation leads to major changes in routine with less privacy and independence which, in adolescence, is only just beginning to develop. Consequently, Eiser (1998) argues for a more biopsychosocial approach to health care in adolescence, feeling that many interventions target physical symptoms without addressing more psychosocial issues. Approaches to research that attempt to understand the child's perspective and how they make sense of illness are necessary and urgently needed. It also appears that much of the current research still focuses on the progress, adjustment to and outcome of chronic illness and less on specific interventions for illness. Much of the work of helping young patients cope with hospitalisation and stressful medical procedures, and on the outcome of these procedures, has centred on younger children. However, Lansdown (1996) argues that there is a need for tailored provision and consideration of the needs of adolescents as distinct from younger children or adults. Often they report not being asked what they know or what they would like. He emphasizes the need for communication in the care of adolescents and an understanding of their needs as distinct from children or adults.

Lansdown (1996) argues that the key issue in considering adolescents' health care is that nurses are trained in adult or paediatric health and the adolescent group are in a vacuum. He feels that while many adolescents may be content in child or adult wards, in general adolescents seem to prefer separate provision of care. Lansdown goes on to argue that although there has been a shift in attitude to caring for adolescents in hospital, including providing specific adolescent units or distinct sections of child wards set aside for adolescents, there remain several issues that are beyond a consideration of accommodation. A great deal more negotiation is required between staff and youngsters in considering independence, self care (including medical care), peer support & social needs, issues of consent and preparation for interventions and discharge. To achieve this, appropriate communication is essential. Chassin et al (1995) suggest that one of the main barriers to successful communication between adolescent patients and health care givers in hospital is the abrupt reversal of the autonomy and development of self that is a central feature of adolescence. Young people are becoming used to less parental monitoring and supervision and may thus have more difficulty in asking for or accepting help from staff.

Thus, there is a need to explore further the health beliefs of adolescents and to consider how these beliefs impact on the experience of being in hospital and of the experience of associated interventions.

Coping and resilience in adolescents

Using semi structured interviews, Stevens investigated the anticipated and actual coping strategies of 59 adolescents having surgery (Stevens 1989). Just over half of the sample were having orthopaedic surgery. Youngsters were interviewed one day preoperatively and two weeks post discharge. The interviews were designed to elicit data on the likely stressors and how they might cope. From analysis of the transcribed interviews, six coping styles in two categories were identified. In the emotion-focussed category were distancing, inaction, self control and seeking social support. In the problem focussed category were active coping and situational control. Although no relationship existed between the anticipated and the actual coping, the most consistently reported strategy was seeking emotional support, particularly from mothers. Field & Prinz (1997) reviewed the literature on coping in adolescence and in addition to the problem focussed/emotion focussed framework found, they used an avoidant/approach framework. They felt that Stevens' findings and those of others suggested that adolescents in hospital do not rely on avoidant strategies as younger children seem to and an approach strategy was more likely to be associated with better outcome.

In considering coping and resilience in adolescents in the context of physical disability, deformity and hospitalisation, Tyc (1992) considered psychosocial outcomes for young people with limb deficiencies - predominantly amputations or congenital limb loss. She found that children and adolescents were reported as adjusting well to the disability and to be resilient to maladjustment, while some specific patterns were identified, for example, poor long term work record and some mild psychological symptoms. Family and social support were always seen as important in adjustment and as a group they were not significantly depressed. Age, sex and socio-economic status were not indicated in risk. The degree of impairment due to the limb deficiency was not a predictor of poor adjustment, consistent with the general paediatric disability literature on, for example, spina bifida and juvenile arthritis. A fluctuating course in any illness was found to lead to a negative impact. The general level of stress in the child and family seemed to be related to social support and the interactive process between degree of disability and stress/family/social variables is emphasised. The studies are presented as somewhat flawed, with a lack of prospective studies and of control groups, and comparisons between studies are difficult. Limb deficiencies require time-limited intensive surgical treatment and it may be that these youngsters get more social support than other illness groups. Tyc (1992) considers that disfigurement rather than disability may predict psycho-social impairment. The overall conclusion, however, is that this group is very resilient but still need to be considered as vulnerable.

Is it possible, then, to identify youngsters who may be more vulnerable than others or who may respond differently to the same interventions, through an understanding of their beliefs about their health? If health beliefs are useful in understanding health, at what point in the interaction might this be useful? Below, the literature on how thoughts and feelings can influence health is reviewed. This is followed by an exploration of the role of pre-intervention and psychosocial intervention and its utility in surgery and hospitalisation.

How can thoughts and feelings influence health?

An individual's health is affected by many interrelating variables. Their heredity, levels of stress, personality and numerous other factors will have a bearing on their continuing health and approach to illness. One major influence is the individual's health beliefs or cognitions. Health cognitions are the relatively abstract activities of thinking, conceiving and reasoning about "health" and its related concepts. This includes health, health behaviour, representations of illness and recovery from illness; for example "I am in control of my health." Marteau (1995) states that, while psychologists agree that health cognitions play an important role in predicting and explaining health behaviours, processes and outcomes, there is a dispute about which cognitions are relevant and which cognitive models most apply. Various models have been proposed to explain the interaction between cognitions and health. In expectancy-value models, the individual aims to maximise gains and minimise losses. Examples of these are the Health Belief Model and the Theory of Reasoned Action which are both intended to predict behaviour. Models of Perceived Control, which grew out of social learning theory, are examined in more depth. Perceived control is described by Wallston (1992) as "...the belief that one can determine one's own internal state and behaviour, influence one's environment or bring about desired outcomes" and was developed through social learning theory as an expectancy model for the future as opposed to attribution theory, with its concerns for understanding past events. Although both attribution theory and social learning theory contain elements of perceived control, the distinction is between ‘cause’ and ‘course’. Social learning theory states that individuals will gain attitudes, knowledge and behaviours from others around them, through several cognitive processes including modelling and instrumental conditioning.

One of the earliest attempts to formalise locus of control as a stable personality characteristic or trait was by Phares in the 1950s (Phares 1973), but perhaps the most widely considered measure of perceived control is Rotter’s Locus of Control (LoC) scale from 1966 (described in Lefcourt 1991) which measured control along an internal-external dimension. LoC is the generalised expectancy as to where the person perceives that reinforcements lie. Individuals with internal LoC believe that reinforcements are controlled by themselves through ability and effort, amongst others. Those with an external LoC tend to believe that reinforcements are controlled by external factors over which they have no influence. Skinner (1995) records that models of perceived control have been used in studies of school performance, peer relationships, political beliefs, and parenting amongst many others and that it has important implications in understanding mood, esteem and adjustment following major life events. The interest for Health Psychologists in perceived control is its utility as a prediction of future health status.

Wallston and colleagues developed this model to consider health specific cognitions in Wallston, Wallston, Kaplan, & Maides (1976), whilst still considering control to be uni-dimensional. They found this to be less than adequate to predict health status and further developed their multidimensional health of control scale in Wallston, Wallston, & DeVellis (1978). This considered perceived control to be measurable along three semi-independent orthogonal dimensions - an internal LoC; control by powerful others (other people's involvement as a stronger influence than the individuals); and chance (a fatalistic approach). The constructs are not mutually exclusive but are held to greatly differing degrees, one usually dominating the cognitive process. Although Wallston (1992) no longer supports the use of using the two-dimensional version of their control scale, he feels that Internality in the sense of self mastery is the only factor or dimension that may be related to health status. He suggested that the general consensus about locus of control and health was that positive health outcomes were more often predicted in people with a higher internal locus.

Lefcourt (1991) believes that Locus of Control can help explain why some people may succumb to a range of negative emotions whilst others are resilient to difficult circumstances. Internal control leads to outcomes that are contingent upon the self, whilst External controls consider that outcomes are not determined by the self. Externalisers are more depressed, anxious and show poorer coping; Internals are more potent, assertive and effective, he suggests. However, Skinner (1995) considered Perceived Control not to be a personality trait but a set of related beliefs based on prior experience in specific contexts. They are portable and flexible but not loose or easily changed. Similarly, Reid (1984) believed that perceived control was a developmental construct developed out of considerable experience of relationships and experience and that it is a single construct but needs to be measured by context specific, developmentally sensitive measures.

How do control cognitions impact on health?

Control cognitions may affect health via different routes. Primarily, locus of control models have been used to predict behaviour. Health behaviour can be divided into behavioural pathogens or behavioural immunogens (Mattarazzo and Leckliter 1988). Pathogenic behaviour is more risky or potentially associated with risk to health whereas immunogenic behaviour is more likely to lead to health gains or health preservation. Another proposed path is through physiological routes, some times referred to as psychoneuroimmunology (PNI), in which it is suggested that perceived control, stress and other psychological constructs are related to and impact on immunity functioning (eg Wallston, Wallston, Smith & Dobbins 1989, Cohen & Herbert 1996). As an emergent field, the links between psychosocial variables, physiological & immune functioning and health are still being refined and not fully understood. However, research protocols are being developed and are seen as promising much.

A third pathway for control cognitions and heath beliefs to affect health is through individuals' representation of their health (eg Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller, & Robitaille 1997, Parkes 1984). Individuals develop a representation of their illness, including where it came from and what outcomes may exist; they develop actions plans; and then they reevaluate or appraise their situation and thus re-represent their illness. Components of the individual representation include their prior experience of illness and their perceived control. Levanthal et al (1997) go on to suggest that individuals can have different types of illness representation for chronic, acute or cyclic illness. Representations of one condition may shift over time from one type to another and medical procedures are linked to these representations, leading to specific outcome expectations. Similarly, Watson & Pennbaker (1989) suggest a symptom perception hypothesis in which individuals vary their attention to and perception of sensation, impacting upon their subjective health. Similarly, Mathews & Ridgeway in 1981 had proposed a three-model underlying mechanism to understand how personality influenced recovery from surgery: i.e. subjectivity, behaviour and physiological effects. In their model, subjectivity includes the differential attention individuals will pay to cues for instance, high anxiety or high vigilance patients may be more attenuated to pain cues and report different experiences to low anxiety or avoidant patients in a model similar to the illness representation theory. It has been suggested that patients can alter their representations or experience of symptoms to be more in accord with the experience of treatment and that this can actually produce physiological change (Richardson 1997).

Locus of control as a concept has always promised much. Indeed, when Phares wrote a general introduction to the construct, his paper reads as if he believed an understanding of perceived control could lead to an understanding of all the worlds woes (Phares 1973). There are, however, many criticisms of these cognitive approaches, despite their apparent success in predicting health behaviours. Kirscht (1983), warned that for all of the models, much of the work has been done on college students. Steptoe & Wardle (1992) justify this approach in their work by saying that students are a homogeneous, easily identified group, but even the authors recognise that caution must be used when drawing conclusions. Kirscht (1983), also offers the caveat that many studies are retrospective, requiring similar caution. Taylor (1991) points out that since many studies use different questionnaires to measure apparently similar constructs, the comparisons across studies may not be entirely valid.

However, these criticisms should be seen as calls for refinement and further investigation rather than as demands for the models to be abandoned. To reiterate Schneider (1991), social cognitions are possibly the most heavily researched area in social psychology but it should be borne in mind that, although not in its infancy, social cognition has yet to come of age. By combining models it may be possible to increase their validity and predictive power. Although unrefined, these models clearly show that health cognitions play an integral role in health and it would be unwise to belittle their importance.

Utility of perceived control in understanding health outcomes

How useful has Perceived Control been in considering outcome from treatment, in particular surgery and treatment for back problems? Härkäpää and colleagues (Härkäpää, Järvikoski, Mellin, Hurri

& Luoma 1991) studied 459 adults with a history of low back pain and outcome from three treatment conditions were considered. They used Wallston's original unidimensional HLoC scale, psychological stress via GHQ, compliance with exercise and treatment and level of disability as measures. They found that stronger internals gained more from the treatment protocols and showed better compliance with treatment, but they also noted that those with higher internal LoC might show poorer response to treatment regimens that are dictated by health care professionals.

Returning to locus of control and back pain, Härkäpää, Järvikoski & Vakkari (1996) tested the relationship between different locus of control measures - general, health and illness specific - and further investigated the relationship between control cognitions and coping, noting that from their previous research high internals showed more adaptive coping. Their sample was 76 clinic patients with a history of low back pain. Measures used were Levenson's three sub scale General Locus of Control Scale, Wallston's Multidimensional Health Locus of Control Scale and a Back Pain specific LoC scale, along with GHQ-12 and measures of behavioural and cognitive coping. Overall, associations were found between the relevant subscales on each LoC measure, which suggested that the patients' general identity may have become highly related to their back condition, i.e. their back pain may have been so chronic as to make it difficult to look beyond their backs when considering their health in general. As expected, those with higher internal beliefs used more cognitive coping strategies. However, behavioural coping was associated with a higher external locus which may reflect behaviour being an external activity and cognition being an internal activity.

In considering outcome from oral surgery, George, Scott, Turner & Gregg (1980) found that those with a higher internal locus of control might benefit most from preoperative psychological support to facilitate better outcome. George et al. (1980) set out to explore the role of expectations in 38 patients, aged 17 - 32, who were having wisdom teeth extracted. The participants completed self report measures of anxiety, coping health locus of control, expectations about recovery and anxieties about recovery. All but the HLoC (they used the unidimensional HLoC scale) were measures devised for the study. The trauma of the procedures was assessed with a single measure derived from the degree of impaction, difficulty of surgery, and duration of surgery. Outcome was also by self report measures of pain, functional interference, swelling and by surgeons rating of healing at two weeks postoperatively. As expected, those with higher anxieties about recovery and higher expectations that surgery would cause suffering reported more pain and disability. They were also noted to have slower observer-rated healing. Higher treatment anxiety was associated with higher pain, disability and swelling; vigilant coping was associated with higher pain and disability and slower healing. For locus of control, higher internal LoC. was associated with higher disability and slower healing. George et al. (1980) speculated that situational anxiety and expectations about the surgery could be addressed preoperatively and that while higher locus of control, coping style and treatment anxiety may be personality variables, an awareness by staff of these factors may assist in identifying those more in need. Patients with a higher internal locus may find the surgery more difficult to deal with as the loss of control is more in congruent with their general beliefs. It was not stated whether the surgeons rated healing blind to other patient reported variables, although this was probably so. Details of the specific measures devised for the study used were not available.

Kugler, Tenderich, Stahlhut, Posival, Korner, Korfer & Kruskemper (1994) investigated whether perceived control was related to adjustment after heart transplant surgery. With 20 patients assessed for perceived control (using Levenson's tridimensional measure), depression (using a developed measure), and trait & state anxiety (from the STAI) pre and 20 days post intervention, they found that a belief in powerful others and chance was associated with increased preoperative anxiety and depression scores. Post operatively, higher belief in powerful others was associated with higher post operative anxiety. They also found no relationship between pre and post operative anxiety and depression scores and conclude that these measures must be situationally determined. Preoperatively, patients scored higher than reference scores provided in manuals, whereas the scores returned to normal levels post operatively. Their belief was that any preoperative intervention should aim to maximise patients internal beliefs and minimise external beliefs. Heron, Turner & Weiner (1988) on the other hand found that, in 91 patients with lumbar disk herniation, those with poorer treatment outcome had low powerful others scores as measured on the Health Attribution Test, i.e. a higher belief in health professionals (Powerful others), indicated good outcome. However, in accord with Kugler et al (1994), higher chance scores were also associated with poorer outcome.

Abbott & Abbott (1995) note that in general, higher preoperative anxiety has been associated with greater post operative pain, greater use of analgesics and longer stay in hospital and there is a general acceptance that post operative outcome is influenced by psychological factors. In their study, they specifically investigated cardiovascular and anaesthesia variables in association with General Health Questionnaire, Health Locus of Control, Perceived Stress and devised measures of worry about the procedure in a sample of 102 women having simple gynaecological procedures. The most consistent finding was that worry and locus of control were the most predictive psychological variables, with higher worry predicting poorer post operative self reported outcome (pain, headaches, nausea & vomiting). Higher internal locus of control was associated with greater amounts of anaesthesia being required and it was thought that the loss of mastery was associated with greater cardiovascular activity both before anaesthesia and during the procedure.

Matthews & Ridgeway (1981) report on two surgical outcome studies that found that locus of control appeared to interact with other variables (eg birth order or anxiety) rather than be a useful predictor in its own right. In a study of 116 workers considered for lumbar surgery, Doxey, Dzioba, Mitson & Lacroix (1988) attempted to devise a battery of psychological and medical tests that might predict prognosis, including Locus of Control and MMPI scores. Of the psychological constructs investigated, MMPI hypochondriasis and pain drawings were useful - LoC was found to have no association with outcome. Further, Kincey (1995) believes that in general any correlations between surgical outcome and perceived control are due to interactions between control and other pre and peri- operative variables and cannot be accounted for by locus of control alone.

Partridge & Johnston (1989) acknowledged that much of the ambiguity in outcome studies using LoC measures may come from the lack of use of situation-specific measures and so devised a specific Recovery Locus of Control Scale for use in studies of recovery from physical disability. The scale was limited in that it contained only a unitary score, indicating higher or lower internality. With two patient groups, stroke and wrist fracture, they found that indices of disability suggested better recovery for patients with higher internal recovery locus of control.

From the above, it is clear that there is no easily measured relationship between health outcomes and locus of control. However, more of the studies find associations suggesting that higher internal locus of control is associated with better outcome and higher chance or powerful others locus is associated with less desirable outcomes. Most of the studies above have attempted to measure other factors in addition to locus of control and clearly perceived control cannot account for all the variance in outcome. Many others factors have been investigated and it is worth considering studies that have had specific focus on factors not related to perceived control in order to assess the relative importance of the multitude of hypothesised factors. Below, studies are presented that have focused more on general health beliefs, personality variables and anxiety.

Other factors in recovery from surgery

It was Janis in 1958 who originally proposed a curvilinear relationship between preoperative anxiety and post operative recovery (Janis 1958). He found that the best postoperative adjustment was related to moderate levels of preoperative anxiety. He proposed that those with low anxiety had a lack of preparatory cognitive rehearsal necessary for dealing with surgery and recovery; those showing high anxiety, he considered to experience intense fear postoperatively. However, there is little replicated evidence for this curvilinear "work of worrying" hypothesis. In a study of 73 patients having minor gynaecological surgery, Johnson & Carpenter (1980) found limited evidence for any relationship between pre and postoperative anxiety and for the predictive power of preoperative anxiety on overall postoperative outcome. They found some support for Janis's curvilinear model, in that there was a trend for low preoperative anxiety to be associated with less successful recovery, but in general they found no *significant* relationship between preoperative anxiety and outcome. In considering their definition of recovery, they addressed many of the general criticisms of this type of research by collecting a range of subjective psychological and physical outcome measures but then combined many of these measures into small recovery coefficient variables and thus may have lost some of the specificity of the outcome.

Boeke and colleagues report twice on a study involving length of stay in elective cholecystectomy (removal of the gall bladder) (Boeke, Stronks, Verhage, & Zwaveling (1991), Boeke, Jelicic & Bonke (1992)). Boeke et al (1991) investigated personality and anxiety variables in 58 patients. It was found that only three-day-post operative anxiety had any additional length-of-stay predictive value over the biomedical data, with a hypothesis that increased stress and anxiety preoperatively led to suppression of the immune system, making the patient vulnerable to complications. However, in their analysis of the enlarged data set of 81 patients (Boeke et al 1992), the effect of any pre or post operative psychological variable disappears, with only age, health status and wound infection remaining. In short, they found no psychological variable of value in considering length of stay in hospital. Due to length of stay's dependence on confounding variables like pressure for beds, home-life, etc., only the broadest bio medical measures such as wound infection may be useful.

In related work by de Groot and colleagues (de Groot et al 1996, 1997a, 1997b), a cohort of 126 lumbar surgery patients are reported on. De Groot also investigated the role of anxiety in post operative recovery assessed at three days and three months post-operatively. At three days, higher preoperative anxieties were associated with higher leg and back pain and poorer general recovery as observed by the surgeon. At three months, there appeared to be an increase in this association. Overall, coping variables, measured along the dimensions of blunting and monitoring had no predictive power, although it was again noted that vigilance has been associated with poorer outcome in other studies.

In a study designed to investigate long term outcome from surgery for ulcerative colitis (a chronic inflammation of the colon and rectum), Weinryb, Gustavsson & Barber (1997) took a psychodynamic perspective on preoperative personality variables. Fifty three patients aged 17 - 62 were assessed by interview before their operation. Follow-up was at a median of 23 months after their initial assessment. The results suggested a curvilinear relationship between alexythymia and general psychosocial functioning, with moderate levels of alexythymia having beneficial effect. The authors liken alexythymia to a general defence strategy and is thus like avoidant coping, which they argue has been seen as beneficial compared to vigilant coping. In addition, a capacity to cope with frustration seemed to indicate a better outcome.

Oostdam & Duivenvoorden (1983) investigated the predictability of outcome for low back pain patients undergoing surgery. The cohort consisted of 162 patients with a mean age of 40, the majority of whom had herniated disks. Oostadam found that patients with a satisfactory outcome could be differentiated from those with poorer outcome on preoperative psychological measures. They generally showed fewer somatic complaints and preoccupations and were less likely to use physical symptoms to avoid psychological difficulties and stress. They do not, however, discuss the clinical utility of this preoperative differential. This was identified by using extensive personality tests which may have to be administered by a psychologist rather than by self report.

The relationship between preoperative anxiety, pain and subsequent complications is also investigated by Nelson, Zimmerman, Barnason, Nieveen & Schmaderer (1998). Outcome from cardiac artery bypass surgery has proved difficult to predict and often results in complications. Using the three dimensions of the McGill Pain Questionnaire and STAI, 96 patients were assessed at two and three days post operatively. Significant correlations were found on all three dimension and both time points between pain and anxiety but no significant correlations were found with trait anxiety. From analysis of variance for pain scores from day two to day three, Nelson et al felt that there were significant differences between the perception of pain on the two days and that this was related to level of anxiety, with those patients showing higher levels of anxiety reporting higher levels of pain intensity.

Hogg, Goldstein & Leigh (1994) investigated the psychological impact of Motor Neurone Disease (MND). 52 MND patients completed self report questionnaires on physical symptomatology, impact of the illness on everyday life, anxiety, depression, coping, self esteem, locus of control and acceptance of the illness. Higher scores on the internal scale of the locus of control were associated with more independent motor control and less motor impairment. In other words, the patients who had more control perceived themselves to have more control, which is as expected. Additionally, the patients with more physical symptoms appeared to have a lower acceptance of their illness and hence less acceptance of the sick role.

Acceptance of, or adjustment to, chronic illness has also been investigated in relation to other biomedical and psychological factors. In an investigation of patients' beliefs about coping with illness (de Ridder, Depla, Severens & Malsch 1997), 172 users of health care were involved in a study which encouraged them to express their beliefs about coping with illness and coping with the health care system. Statements of belief were then categorised using a method of concept mapping, which allows for stated concepts to be re-evaluated in terms of "content" and "priority." Two themes emerged as dominant - autonomy (see also Woodgate 1998 and Thompson 1998, below) and acceptance of illness. The health care consumers interviewed considered that one of the most preferable ways of coping with illness was to accept it and to work in partnership with health care providers whilst maintaining autonomy. This belief by consumers in the importance of acceptance seems supported by a study by Jensen (1986) in which women with diabetes were interviewed about their health and functioning. In a six-year follow-up, 50 women were assessed about factors relating to their diabetes and their sexual functioning. Women rated as having higher acceptance of their condition had lower risk of developing sexual dysfunction during the follow up period.

General critique of outcome research

As can be seen from the studies above, numerous research designs and measures, both predictive and outcome, have been used in the field, with no clear or consistent constructs or measures successful. There is clearly a complex relationship between variables that appear to be involved in successful outcome from surgical interventions. It needs to be noted, however, that health outcome itself is a difficult construct to measure. These difficulties in measuring outcome from surgery were highlighted by Hunt and colleagues in a study including 41 minor surgical patients and age/sex matched controls. Hunt, McEwen, McKenna, Backett & Pope (1984) used the Nottingham Health Profile, a well-standardised measure of health to investigate whether surgery improved the health of patients and whether their health improved more than matched controls. The Health Profile uses 38 statements about physical mobility, energy, sleep, pain, social isolation and emotion requiring a yes/no response. In addition, statements about the specific effect of health on occupation, home, personal relationships, social life, sex, hobbies and holidays are also presented for a yes/no response. In this way a health profile can be assembled for individuals and groups. In this study, the 41 surgical patients and their controls completed the profile preoperatively (they had a variety of minor surgical procedures) and eight weeks post operatively. Overall, no difference in health profile was found between or within the experimental or control groups, although Hunt et al. (1984) acknowledge that the time frame may have been too short for specific health gains to become apparent or that the purpose of the surgery may have been to intervene in a progressive illness at a time when health losses were not large but the trajectory was apparent. Thus, health outcomes are clearly not easily measurable. None-the-less, the studies below have relied upon some outcome measures in order to quantify the role of health beliefs.

Kincey (1995) argues that it is currently not possible to use any model or measure with any degree of certainty when attempting to investigate psychosocial and other outcomes post operatively. Young (1996) feels that there is a lack of standardised, reliable batteries of measures that attempt to independently measure pain, functioning, etc. and criticises the overreliance on the MMPI and similar measures of personality in outcome studies. The MMPI, he argues, is lengthy, clumsy, difficult to understand and may lead patients to make pejorative inferences about the surgeon's view of their condition. Young also found that sex and age (except in those over 40) were not reliable predictors of outcome after lumbar surgery.

Mathews & Ridgeway (1981) also criticise the use of ill defined and idiosyncratic measures of personality, mood and outcome. Mathews & Ridgeway (1981) and Young (1996) suggest that studies often use small, heterogeneous populations with little attempt to describe inclusion criteria, characteristics of the cohort, or the specific procedures of the surgery. Kincey has attempted to deal with the large variation in surgical procedures and tried to provide a taxonomy of interventions (Kincey 1995), although there is no evidence so far of this being useful. Prospective studies and repeated measures appear rare and follow up periods of just a few days are too short - Young suggests up to two years may be more meaningful. Constructs that Young (1996) suggests need further investigation include mood variables (anxiety and depression), coping, somatization and locus of control.

Many of the studies above have concluded that some aspect of the individual patient can be assessed and be useful in understanding how they may respond to illness or major medical interventions. Some also conclude that such an understanding of the patient's beliefs can be utilised in preoperative preparation sessions tailored to specific beliefs or requirements. As these measures have been inconclusive or situationally specific, most studies on psychological preparation for surgery have taken a more general approach and an overview of these is presented below.

Preparation for surgery

In an interesting early study attempting to understand why patients seem to recall little of what they are told in preparation for surgery, Stern, Baoz & Leiser (1982) tape recorded preoperative meetings between surgeons and patients and then reinterviewed them post operatively, using students not surgeons as the interviewers. Analysis of transcripts of the interviews showed a mismatch in the styles of the patient and surgeon. Surgeons seemed concerned with sharing information about the specifics of the intervention whilst initially, patients agendas were more emotional, looking for personal meaning in the information they were hearing. However, patients soon fell in with the surgeon's style and seemed to drop their own agendas. Pitts (1998) describes several studies that have shown that preparation for surgery can have a beneficial effect on outcome. This preparation may include describing different aspects of the intervention to the patient, including the actual procedure, the setting, the sensations they may experience or the postoperative behaviour and routines they should follow to aid recovery. However, many investigations into recovery from interventions have made assumptions about the beliefs of the patients. She reports studies suggesting that hospital staff will often overestimate patients' concerns about their symptoms whereas patients themselves report concerns about the world beyond the hospital and about outcome of interventions. This mismatch in concerns is suggested to cause stress comparable to that of the actual intervention. Clearly, the role of individual differences needs to be investigated further.

Harbeck-Weber & McKee (1995) review the literature on preparation programmes in young patients.

Most of the studies concern younger children, but some include older children and teenagers in their samples. Preoperative sessions were generally found to reduce anxiety, increase knowledge and potentially have longer term, post discharge consequences on fears and health behaviours. They concluded that, not surprisingly, developmental level, previous experience in hospital and presence of parents can all impact on the success of preparation interventions. In addition, the timing of a meeting can be important. Preparation for future events rather than imminent hospitalisation can help produce basic coping strategies. Further, preparation on the day before surgery showed some evidence of greater effectiveness in reducing anxiety and increasing receptivity to anaesthesia than preparation on the day of surgery. In aiming to reduce anxiety and increase knowledge and understanding of imminent hospital procedures, then, there is considerable evidence for an individually tailored, patient-centred preparation session. In these sessions, parents should be involved but with the opportunity for the youngster to address personal concerns; preparation in advance of admission may engage coping strategies and preparation should not be carried out on the day of surgery.

The role of parents in the hospitalization of children tends to be represented in the literature by the role of the mother and this tends to be concentrated on her role in care for younger children. None the less, Schmidt (1997) suggests that the mother's role is discussed in most studies of hospitalization in children and although quantitatively they do not always seem to represent an additional benefit to their child in hospital, qualitatively their role is seen as paramount. From Barnes & Sadowski's discussion of child health and family influence (Barnes & Sadowski 1998), this could be explained by the influence of parental anxiety on child coping and anxiety, which has been described as the emotion contagion hypothesis. Anxiety reducing and coping-enhancing preparation (as mentioned above) needs to include considerations of the parent's emotional state, perhaps outlining specific practical roles parents could take, thus engaging them in the care of the child and reducing their own anxieties.

As suggested from each of the sections above, the majority of work carried out in the field of psychological factors in preparation for surgery and recovery from surgery has been with adults or younger children. Adolescents, it seems, are somewhat neglected, with fewer studies investigating health beliefs in specific adolescent cohorts.

The story so far...

Thus far, this introduction has discussed psycho-social models of adolescence, the adolescents' experience of health care and the role of cognitions and emotional factors in health with particular emphasis on perceived control and its role in recovery from surgery. What appears to stand out is that a greater sense of personal control, responsibility over health and an acceptance of illness are generally more likely to be associated with better recovery but outcome studies have been mixed. Preparation for surgery that is more patient-focussed, involves the family and attempts to be sensitive to the emotional state and beliefs of the patient is recommended. Studies in this field were noted to concentrate more on adults and younger children. Studies involving adolescent patients are less often reported. Often, studies representing themselves as including adolescents in their sample only have teenagers in the tails of their distributions. It was suggested here that one reason for this may be the perceived ambiguity about what constitutes adolescence and a still extant suggestion that adolescents are fragile and/or tumultuous. Evidence has shown that this is clearly not the case. In order to investigate further the role of cognitions in adolescents having surgery, it was necessary to identify a suitable population. Corrective spinal fusion for idiopathic scoliosis is not a rare procedure but is uncommon enough generally only to be provided by specialist units. A cohort of adolescents having spinal fusion surgery would represent a suitable group in that they would be relatively homogenous facing extremely invasive elective surgery and it is reasonable to assume that the youngsters would have a broad range of beliefs and emotional responses to their health and their surgery. Below, then, a description of adolescent idiopathic scoliosis (AIS) and its treatment is presented along with a discussion about whether AIS has long term severe emotional consequences.

Scoliosis

Description and management of scoliosis

Idiopathic scoliosis is well defined by numerous authoritative texts. (eg Moe & Byrd 1987, Leatherman & Dickson 1988). Essentially, scoliosis is a spinal deformity in which the spine deviates from its normal vertical by least 10 degrees (although a perfectly straight spine is rare) and most commonly affects the thoracic or lumbar regions. The three dimensional deformity will often appear to have an S-shape and the deviation is not a simple two-dimensional bend. Scoliosis can be associated with many different conditions but in idiopathic scoliosis, the deformity appears to develop in the absence of any other congenital spinal deformity or musculoskeletal condition.

Idiopathic scoliosis can be infantile (appearing before age one), juvenile (age 1 - 10) or adolescent (age 10 plus). Adolescent idiopathic scoliosis (AIS) is the most common form of the disorder. As the name idiopathic suggests, the aetiology of AIS is unclear but it may be associated with an inherited structural abnormality that manifests during the growth spurt and hormonal changes in puberty. The prevalence of this significant curve has been difficult to judge but Strasburger & Brown (1996) suggest it may be between 1 and 3% of the general population.

However, only around 0.1% will have a condition that requires treatment. Treatment for scoliosis can be benign neglect, bracing or surgery and the decisions to treat and the type of treatment is based on consideration of the magnitude of the deformity, its pattern and its progression, as well as the age and sex of the patient. Strasburger & Brown (1996) go on to explain that the general measure of the curve is the Cobb angle, which is the angle of interception between lines drawn parallel to the articular surface of the highest and lowest vertebrae involved in the curve. The spine may have more than one curve and the general spinal deformity also causes rib deformity, differential leg length, pelvic imbalance and reduced height. Unchecked, progressive deformity leads to considerable reduction in heart and lung function.

Accounts of treatment criteria differ but generally benign neglect, involving monitoring, outpatients appointments, X-rays, etc. at periodic intervals is the general approach for curves of less than 20 degrees. If the curve progresses past 20 degrees then bracing might be considered. If the magnitude of the curve is more than 30 degrees or if the curve is progressing rapidly, then surgical treatment is used. In bracing and surgery, the long term aims are to reduce and minimise the physiological, pulmonary and osteoarthritic degenerative changes and the psychological impact of the deformity. In bracing, the patient is fitted for a waist-coat-like firm brace that is worn under the clothes around the torso for most hours of the day for up to several years, until progression is checked. In surgery, the spine is exposed and the vertebrae involved in the curve are fused together with bone grafts often utilising material taken from the ribs. To support the spine whilst the fusion takes hold, metal rods are attached to the spine by screws and hooks. This metal work is not visible from the outside and is redundant within 6 - 12 months. The fused spine becomes stronger than the metal work but as a minimum number of vertebrae are involved in fusion, the spine retains most of it flexibility and movement is generally not impaired. During the initial six months post operatively, the patient must wear a newly constructed brace for most of the day but for decreasing periods. Although the metal work is redundant, it is generally not removed unless necessary, for instance if a rod breaks or screw works loose.

Psychological impact of Scoliosis

Bengtsson, Fällström, Jansson & Nachemson (1974) assessed 26 women, aged 23 - 63 from a disability clinic, with untreated scoliosis and an average deformity of 105° (the high angle emphasises that the deformity is often S-shaped and not an indication that they are bent nearly double) and describe a profound emotional disturbance. Each was assessed by psychiatric interview in which personality traits, social adjustment and psychiatric symptoms were evaluated informally. Formal projective (eg Rorschach) and intelligence tests were also used. A high degree of synthesis was then applied to reduce the data to a small number of manageable scales. Benstonn and colleagues suggested that the women generally showed good superficial psychosocial adjustment but also demonstrated “mental insufficiency”, hypersensitivity and insecurity, with those with juvenile onset showing the least good adjustment. However, from this study, it seems difficult to conclude that the cohort had the profound disturbance the authors suggest. The poorer outcomes are reported as more significant than the encouraging finding of good superficial adjustment, the authors fail to address the lack of standardisation, definition of terms, selection procedure or control group and do not address the potential biases or investment in the outcome of the psychiatric assessors.

Fällström returned to the psychological assessment in adolescent idiopathic scoliosis (Fällström, Cochran & Nachemson (1986) starting with the premise that every adolescent experiences an identity crisis. In a nine year follow up of 157 treated patients (92 surgical, 65 brace), a semi structured interview was used to assess reaction to the diagnosis and treatment, attitudes to staff and body image. The minimum age at follow up was 22, although the mean is not given. Post treatment, the brace group had a mean curvature of 33° and the surgical group, 36° On diagnosis, around half of each group recalled denial and half of the brace group recalled panic as did one third of the surgery group. Nearly half reported feeling isolated following diagnosis. Although a third of the surgery group were satisfied with their treatment and only about one sixth had any complaints about staff, only one eighth of the brace group were satisfied and almost half complained about the staff. Half the brace group and a third of the surgery group reported a disturbed body image. The authors note the contrast here with the response given to the orthopaedic surgeon at follow up, where almost all in both groups reported satisfaction with the outcome. Fällström argued that, although surgery is more demanding and aggressive and physical outcome is similar, bracing has greater psychological impact. This may be due to the greater improvement in the surgical group and the shorter time required to wear a brace. Again this study is greatly weakened by a lack of definition in the measure and time scales used and poor reporting of the data but the overall suggestion is that two thirds of surgically treated scoliosis patients will be dissatisfied with their treatment and one third will have a disturbed body image at long term follow up.

Forstenzer & Roye (1988) reported preliminary findings from their longitudinal study investigating the psychosocial sequelae to treatment for scoliosis in adolescent girls. In their report, based on anecdotal evidence, they suggest that the diagnosis itself has a major impact on the individual, with potential damage to self image, loss of the fantasy "perfect adult" that the youngster may believe they would have become and loss of the "perfect child" for the parents, who have to deal with their own fear of inability to cope. They speculate that the three treatment options of benign neglect, bracing and surgery all have a psychological impact but that this impact is not taken into consideration when treatment options are considered. Benign neglect involves acute anxiety prior to hospital visits during which progression is monitored. Bracing is a pervasive treatment that impacts on appearance and functioning and also carries that acute anxiety of monitoring. Surgery, they feel, will include a fear of pain, death and separation with a renewal of dependence in the adolescent who is beginning to develop autonomy. Additionally, surgery is followed by a relatively shorter period of bracing with the associated anxieties of that. They remain unclear about which treatment modality represents the greatest threat to the adolescent and urge more investigation but fail to describe their longitudinal study, which does not seem to have produced any subsequent publications.

In a more rigorous population-based case control study, 34000 12 - 18 year old children sampled from state schools in the USA completed a self report Adolescent Health Survey (Payne, Ogilvie, Resnick, Kane, Transfeldt & Blum 1997), AIS was reported by 1.97% of the sample and was found to be a significant risk factor for increased suicidal thought, alcohol consumption and worries about physical development. AIS youngsters were also more concerned about peer relationships. The authors acknowledge that the instrument may have lacked sensitivity to specific health issues and the degree of magnitude of any condition, but considerable gender differences were reported, with male AIS youngsters appearing more vulnerable than female.

However, these studies contrast with others in which treated scoliosis-patients appear to do well in the long term. Moskowitz, Moe, Winter & Binner (1980) report on a 20-30 year follow up of 61 patients who had spinal fusion surgery between 1947 and 1957. Physically, the fusions were stable with little or no deterioration. Levels of back pain reported were no greater than the normal population and no significant psychosocial difficulties were reported. Similarly, in a seven year follow up of 95 female scoliosis patients (Noonan, Dolan, Jacobson & Weinstein 1997), 30 of whom had had surgery, any psychological impact seemed to be contained within the treatment period, although the surgical group still had a moderately lower body image compared to the non surgical and control groups. There was no difference in follow-up measures of depression or in the health locus of control of surgical, braced or control groups. The surgical group were more likely to be slightly dissatisfied with the specific appearance of their back, shoulders and hips than the brace and control groups, but satisfaction with overall appearance was no different. Both the surgical and brace group showed some greater recall of perceived discrimination during their teens than the control group but this perception was not recalled post treatment.

Heckman-Schatzinger, Nash, Drotar & Hall (1977) attempted to assess pre-treatment performance and personality variables as predictors of adjustment during treatment of 31 adolescents with idiopathic scoliosis. 13 had surgery (mean age 14.6); the remaining 18 had bracing alone (mean age 13.5). Pretreatment measures included a self-report measure of personal problems (in the domains of health, school, family and social activities, amongst others) a self esteem inventory, a parental report of the child's problem behaviour, a projective test of self image; and academic records and intelligence tests. Adjustment to treatment was assessed from a review of case notes and classified into: no difficulties; transient disruptions such as withdrawal from others in hospital or difficulties eating and sleeping but which were resolved prior to discharge; more severe reactions requiring some intervention by a psychologist but which resolved prior to discharge; and disruptions of longer duration, continuing after discharge, for example poor compliance with treatment, suicidal gestures and disruptive behaviour. On pretreatment scores, no differences were found between bracing and surgery groups nor with normative scores for the measures. Post treatment, around one third of patients showed some difficulties with treatment that required additional intervention. Only on one measure, that of self reported problems, was there a significant predictor of difficulties. Youngsters who reported a high number of problems in all areas of their life seemed to have more difficulties in adjusting to the additional imposition of their treatment. The authors acknowledge the need to assess whether this result is specific to scoliosis patients but it would seem fair to suggest that a checklist measure of perceived problems may be a useful screening instrument when trying to predict post treatment outcomes.

In reviewing predictors of subjective satisfaction with the outcome of fusion surgery, Haher, Merola, Zipnick, Gorup, Mannor, & Orchowski (1995) conducted a meta analysis of 76 studies involving 10,989 patients with corrective surgery for AIS. They looked at the different perceptions of well being and functioning as reported by patients, for example pain, self image and activity. Surgeons' measures of technical success were not reviewed. Most patients were satisfied with the outcome of the surgery and their perception of the post operative success of the operation was found to be best predicted by the degree of correction of the spinal deformity. Haher et al acknowledge the limitations of the Cobb angle as a two dimensional measure of deformity in a single structure when scoliosis is represented by three dimensional deformity in several structures.

Overall, there is very mixed evidence regarding the psychological impact of scoliosis. Reviews by Eliason & Richman (1984) and Kewman, Warschausky & Engel (1992) have criticised the overreliance on projective tests, non standardised instruments and a psychodynamic perspective in many studies. As mentioned, there are few studies reporting control group statistics or prospective designs and none reporting randomisation (although randomisation may be ethically difficult in a rapidly progressing deformity). Kewman et al (1992) argue that the body of evidence suggests that there is only a minimal impact of scoliosis and that where treatment variables have been considered, factors may not be specific to scoliosis.

In summary, scoliosis is not without impact. Some individuals seem to cope better than others; untreated, it probably has more impact; different treatment conditions may have differential effects; psychological variables may be useful in predicting outcome from treatment. In spite of a large degree of physical deformity requiring psychosocially and physically invasive and aggressive treatment, adolescents with idiopathic scoliosis seem to be a very resilient group. It remains unclear whether these psychological factors are unique to or specific to scoliosis or whether any treatment effects can be differentiated beyond the biomedical characteristics of the patient that dictate initial treatment decisions.

Qualitative methods

There has been much debate in the literature about the merits and demerits of qualitative research compared to quantitative research (for example the prolific correspondence in the letters page of the Psychologist over the last couple of years). Qualitative methodology is open to much more scrutiny, to much more scepticism, and there is less previous research of this kind in the field of adolescent health. It has been said that qualitative research lacks rigour, is unrepresentative, is not good science, is not replicable in accordance with Popper's scientific method and is presumably not the remit of the scientist-practitioner clinical psychologist (Logan 1997). Quantitative methods, on the other hand, are able to produce significant results out of data without any relationship to meaning and that ultimate model of quantitative science, the meta analysis is the most prone to “Garbage In - Garbage Out” (Sharpe 1997) whilst still emphasising p-values and significance. Just as the debate between psychodynamic and cognitive-behavioural theorists enriches clinical practice, so the debate between qualitative and quantitative research enriches research practice by requiring researchers to examine their own practice in detail, compare it to that of others and reach informed and constructively critical conclusions. Both clinical and research practice would be poorer and more limited if one side were to emerge victorious. In recent papers, Abraham, Fife-Schaaw, Ingham, Scott & Sheeran (1993) and Orford (1995) have tried to highlight the differences between quantitative and qualitative research without being critical of either.

Here, then is not the place to argue the case for qualitative science but it is necessary to outline the basic tenets of the approach and to illustrate its utility in adolescent health care. The basic tenet of the qualitative method is to establish and record discourse, which can be analysed thematically and understood in terms of the relationship between the discussants and between subject and environment. That is not to say that positivist methods discount the unmeasured environment. More that the qualitative method thrives on the unmeasured. Smith (1995) suggests that current models of qualitative analysis began with an alternative phenomenological paradigm formalised in the 1930's with the emergence of symbolic interactionism and the attempt to study discourse and relationships by interpreting the meanings individuals ascribe to events and situations. Rather than assuming that responses to standard questions reflect cognitions, discourse reflects relationships. Several models of qualitative methods have become well established in psychological research - discourse analysis, grounded theory, ethnography, for instance. Another model that has begun to emerge over the last few years is Interpretative Phenomenological Analysis (IPA) and is based on Smith's own work in Sheffield. Smith reminds us that the qualitative method may produce a more rich account of an individual's experience whilst the quantitative method provides a macro analysis and that these two can sit together.

Two specific instances of qualitative research will be reviewed here. The first concerns the view of adolescents with chronic illness about their care (Woodgate 1998) and the second investigates the views of young people who had contact with a Child and Family Consultation Service (Thompson 1998).

Using a sample of 23 13-16 year olds with chronic illness (diabetes, asthma, arthritis, Crohn's disease and ulcerative colitis) recruited from an outpatient clinic, Woodgate (1998) investigated their experience and perspectives of the health professionals involved in their care. Using an open-ended interview and grounded theory-type method of constant comparative analysis, Woodgate found eight emergent themes. The youngsters wanted to be treated as individuals and not just as the focus of a disease. A lack of sincerity and individuality would lead to resentment. They wanted professionals to try to understand them but show empathy, not sympathy. Although they wanted the uniqueness of their experience to be acknowledged, they wanted to be regarded as still a normal teenager. The youngsters wanted the professionals to be encouraging, to foster hope and to give them positive feedback. Although they did not want painful truths to be covered up, they hoped for sensitive honesty. Patience and gentle persuasion were appreciated and those professionals who were seen as pressuring aroused anger in the youngsters. Related to this was the appreciation of active involvement in the decision-making process about treatment programmes and being given choices. Finally, cheerful, sociable staff with a sense of humour were preferred and those who showed that they were knowledgeable, informed and willing to share information helped the relationship between staff and adolescent. Overall, Woodgate felt that the youngsters were advocating a process of collaborative, careful manoeuvring and were showing very definite thoughts and preferences for specific types of interaction.

A more service-specific piece of work is reported by Thompson (1998), who investigated the views of ex-clients to a Child and Family Consultation Service. Six teenagers, aged 12 - 16 were interviewed. Rating of the semi-structured interviews was by a thematic analysis in which transcripts were reviewed and annotated and categories of responses were grouped into themes. Confidentiality emerged as a major theme and all the youngsters discussed the importance of being heard, offered choice and being involved in decision making as being important. The adolescents also appreciated a therapeutic style that was collaborative, warm and non-judgemental. Perceived stigma of attending the service was another emergent theme and this related to anxieties about what to expect from the service. Overall, the youngsters regarded attending the service as part of an active response to resolving difficulties, although there was mixed response to whether or not contact had actually been beneficial.

From this, there are clear parallels with Woodgate's findings - individuality, choice, being heard, attributes of the professional involved. Both studies also recognised limitations in terms of representativeness. From Thompson's study, specific recommendations were drawn about future practice which seemed resonant within the organisation and were reported as representing major shifts in thinking for some professionals. Woodgate and Thompson both acknowledge that their work has been exploratory and that data exist within the information collected that may be amenable to statistical analysis. Further work on these or similar cohorts could make use of the emergent themes to inform specific research questions that may be addressed through more quantitative methods.

Here, then, the qualitative method has been presented as a valid and complementary method to quantitative research. Although protocols need not be restricted to one method of analysis, data need handling distinctly and recruitment may be more problematic, results do appear to be valid and to have service implications.

Summary

This introduction has outlined the developmental stage of adolescence and discussed how adolescents may view their health and make sense of being in hospital. Perceived control, as an example of a model of health cognition was described in detail although it was clear that no singular or even multiple model of health cognition could offer clear understanding in health outcome studies. Great ambiguity remains about the role of health beliefs in recovery from surgery. However, perceived control had demonstrated utility and is considered to be an important and under researched construct in understanding health. Acceptance has also had less focus in investigations than its apparent utility may suggest. It was decided, therefore to utilise a model predominantly informed by perceived control and using an additional acceptance of illness perspective in an exploratory study of adolescents in hospital. As studying "hospitalisation" was too broad an area for enquiry, this study focuses on recovery from surgery and the specific field of spinal fusion for adolescent idiopathic scoliosis (AIS) was selected as a convenience sample. There has been some research in the psychological impact of AIS but this now presented an opportunity to study the specific medium term impact of the surgical correction.

Hypotheses and research questions

The overall framework of this thesis has been to consider how to explore the experience of adolescents in hospital. By examining the thoughts and feelings youngsters have about themselves and their condition, it was hypothesised that a clearer understanding of the process of hospitalisation and recovery from surgery could be gained for a cohort of adolescents having corrective spinal fusion surgery for adolescent idiopathic scoliosis. To test this, the following research questions were devised:

1. What is the subjective health status of a cohort of adolescents about to undergo corrective spinal fusion surgery for Adolescent Idiopathic Scoliosis?

2. Is there a relationship between the Cobb angle of deformity and subjective health status?

3. What beliefs do the youngsters have about their health and condition pre-operatively?

4. Is there a relationship between the youngsters' health beliefs and their health status?

5. Does pre-operative preparation impact on pre-operative anxiety, depression and satisfaction with the care received?

6. What is the medium term impact of the surgery on the health status of the youngsters?

7. Is there an association between pre-operative health beliefs and recovery, as measured by change in health status?

Method

Design

This exploratory, longitudinal prospective study used standardised self report instruments to collect measures of health beliefs and health status pre-operatively from adolescents having spinal fusion surgery. Repeated measures were collected for health status at 10 weeks postoperative follow up. Associations between health belief variables (health value, locus of control and acceptance) and health status variables (general health, pain, functioning, activity, self image, anxiety and depression) both preoperatively and post operatively were explored. It was anticipated that the biomedical variables of: sex, age, previous surgery, deformity and severity of surgery would confound this prediction and they were controlled for. In addition, a semi-structured interview was used to elicit qualitative data on the youngsters' experience of preparation for surgery.

Setting

The study was carried out in the Adolescent unit of an NHS national orthopaedic hospital. The ward contains 28 beds in a traditional nightingale style design, i.e. a long ward with beds arranged down each side facing into the centre. The nurses' station is half way down the ward, with younger patients bedded at one end and older patients at the other. The hospital has accommodation on site for parents or carers and all youngster have the opportunity for one carer to remain on site for some of their stay. Once patients have been assessed by the orthopaedic surgeon as requiring surgery, they are placed on a waiting list of several months and then offered a "To Come In" (TCI) date. On this day, usually Friday, patients arrive on the ward to be admitted. This process involves being allocated a bed and key nurses and then further x-rays, blood tests and physical examinations are carried out over a few hours. Most patients then return home and come back to the ward on Sunday or Monday evening for surgery on Monday or Tuesday morning. Surgery is followed by 24/48 hours in the intensive care unit and a return to the Adolescent Unit for a stay of up to two weeks.

Participants

This study involved patients aged 12 to 19 with adolescent idiopathic scoliosis who were having spinal fusion surgery during the six-month research period from September 1998 to March 1999. A preliminary list of possible participants was compiled by the scoliosis admission coordinator at the hospital. This list was reexamined at monthly intervals to include patients newly offered TCI dates. Overall, 60 potential participants were identified in this way. Of this initial list of 60, 13 were excluded as they did not fit the inclusion criteria, which were: a diagnosis of adolescent idiopathic scoliosis, the absence of other congenital spine deformities, associated musculo-skeletal conditions or learning disability and the ability to communicate in English. A further nine were missed as their admission date was changed at the last minute.

38 patients were invited to take part in the study and only one declined. Three sets of questionnaires (one preadmission, one preoperative, one follow up) were sent to each of the remaining 37 patients. Five did not return any questionnaires and so a total of six (15.8%) were classified as having decided not to participate. 32 (84.2%) returned some questionnaire data. Of these, four (10.8%) returned only one questionnaire (two preadmission, two follow up) and these data could not be used. In total, 28 (75.7%) returned usable data. Five (13.5%) returned two questionnaires and 23 (62.2%) returned all three. The mean age of these 28 participants was 16.23 years (sd 2.26, range 12.08 - 19.11) and 23 (79.3%) were female. 26 classified their ethnic background as white and two classified themselves as Indian. The predominance of female participants is representative of the general AIS population. As with Woodgate's and Thompson's studies above, the lack of cultural diversity in the sample is disappointing but represents the hospital population at the time of the study. Eyeballing the demographic details of the patients who did not complete questionnaires suggests that the age and ethnic diversity of the sample would not have been different if more invited participants had taken part.

Measures

(All measures are presented in Appendix 7, 8 & 10)

Demographics

Age, sex and ethnic background data were asked for. Other factors such as socioeconomic status and siblings' experience in hospital may have been interesting in larger samples but would have provided too many variables to be of use here.

Impact of the condition

Scoliosis Patient Questionnaire (SPQ) Haher, Gorup, Shin, Homel, Merola, Grogan, Pugh, Lowe & Murry (1999). This is a 24-item questionnaire designed specifically for patients undergoing treatment for scoliosis to standardise the reporting of patient measures and outcome. The first 15 items only are administered to pre-treatment patients, with all 24 items administered to post treatment patients. The questionnaire measures seven domains consisting of both physical and psychological aspects of life. Four are repeated measures pre and post intervention: pain, general self image, general function and overall level of activity. Three additional domains are assessed post intervention: perceived change in self image, perceived change in functioning and satisfaction with the outcome of the intervention. Items are scored by either choosing a point on a ten-point Likert scale, selecting response items from a three or five item response list or yes/no answers. Overall scores are calculated by converting responses into a five-point scale for each item. This requires scoring on some items to be reversed so that for all items higher scores indicate better outcome. In evaluating the measure, Haher et al administered it to 244 adolescent patients with idiopathic scoliosis. High test - retest validity and fairly high internal consistency were found. Validity was established using a sample of non-symptomatic adolescents and it was found to distinguish well between the two groups. Haher reports sample scores for the scoliosis cohort on the four domains of pain, general self image, functioning and activity. Standard deviations are not reported.

Patient's experience of pain:

Example:	On a scale of 0 to 10, with 0 meaning "no pain" and 10 meaning "severe pain", indicate the degree of pain you experience regularly.
Range:	6 (high pain) - 30 (low pain) (direction of scale reversed)
Pilot sample:	Mean - 13.23, alpha - 0.80, test-retest - 1.00

Function in terms of level of activity:

Example:	What is your current level of activity?
Range:	3 (low activity) - 15 (high activity)
Pilot sample:	Mean - 12.16, alpha - 0.78, test-retest - 1.00

General ability to function as a result of back condition

Example:	What is your current level of school/work activity?
Range:	3 (low function) - 15 (high function)
Pilot sample:	Mean - 11.75, alpha - 0.59, test-retest - 0.68

General evaluation of self image

Example:	How do you look in clothes?
Range:	3 (low self esteem) - 15 (high self esteem)
Pilot sample:	Mean - 12.19, alpha - 0.69, test-retest - 0.98

Self image after surgery

Example:	Has your treatment changed the way others view you?
Range:	3 (low) - 15 (high)
Pilot sample	alpha - 0.69

Function after surgery

Example:	Has your back treatment changed your ability to enjoy sports/hobbies?
Range:	2 (low) - 10 (high)
Pilot sample:	alpha - 0.71

Satisfaction with surgery

Example:	Would you have the same treatment again if you had the same condition?
Range:	3 (low) - 15 (high)
Pilot sample:	alpha - 0.75

Current health

An additional *Perceived Health Status (PHS)* single item scale was added to the Health Value measure. This PHS measure consisted of a single 10-cm line visual analogue scale (VAS), with "poor" and "excellent" as the two anchors. Respondents were asked to mark on the line where they perceived their current health to be on that scale. McCormack, de le Horne & Sheather (1988) and Johnson et al. (1995) have reviewed the use of VAS in a variety of health and mental health contexts and have found VAS to be a simple, valid and reliable measure.

Perceived control over health

Multidimensional Health Locus of Control Scale - Adolescent Version (MHLoC - A) Stanton, Nada & Langley (1995). This scale is a reworking of the multidimensional scale developed by Wallston, Wallston & DeVellis (1978), with some items changed slightly to make them easier to understand. The MHLoC is a widely used measure of perceived control on three subscales - internality, chance and powerful others. Respondents indicate their level of agreement from strongly disagree to strongly agree with 18 statements about health control. Each dimension is scored separately and the maximum total is 36. Wallston et al. (1978) found that internality and powerful others were independent. Internality and chance were negatively correlated and chance and powerful others were positively correlated. Subscale internal reliabilities are reported as high. Furnham and Steele (1993) report that in generally healthy samples, outcome is better predicted by internality and chance than by powerful others, whereas in less healthy populations, belief in powerful others is more predictive. Johnston, Wright & Weinman (1995) report mean scores for the original MHLoC scale for 749 college students of IHLoC - 26.68, CHLoC - 16.72 and PHLoC - 17.87. Standard deviations are not reported. In the adolescent version of the scale (Stanton et al 1995), some evidence was found for the emergence of a three-factor structure by age 15 but there were higher correlations and lower internal consistency in the three scales than might be expected from adult samples. Stanton et al. (1995) suggest combining scales in samples where independent dimensions are not represented by the three scales. In their sample, taken from the large scale longitudinal Dunedin study in New Zealand of 1139 children born in 1972/73, means for 837 15 year olds were equivalent to 25.8 (sd 2.6), 19.8 (sd 3.2) & 22.2 (sd 3.0).

Internal locus of control

Example: If I get sick, how soon I get well again depends upon what I do.
Range: 6 (low internal) - 36 (high internal)
15 year old sample: 25.8 (sd 2.6). Alpha range - 0.56 - 0.61.

Chance locus of control

Example: No matter what I do, if I am going to get sick, I will get sick.
Range: 6 (low chance) - 36 (high chance)
15 year old sample: 19.8 (sd 3.2). Alpha range - 0.56 - 0.61.

Powerful others locus of control

Example: Going to the doctor regularly is the best way for me to avoid getting sick.
Range: 6 (low powerful others) - 36 (high powerful others)
15 year old sample: 22.2 (sd 3.0). Alpha range - 0.56 - 0.61.

Health value

Health Value Scale (HVS) Lau, Hartman & Ware, (1986) This is a four-item measure using a five-point Likert scale designed to measure the value individuals place on their health. Scores on the four items are meaned with a maximum total score of five, higher scores indicating a higher value placed by the individual on health. Lau reports good reliability and validity scores and Johnson, Wright & Weinmann (1995) report norm scores from a sample of 97 11-16 year old girls and they also report that the predictive power of other health beliefs such as locus of control can be improved by the addition of a health value scale.

Health value:

Example: There is nothing more important than good health
Range: 1 (low health value) - 5 (high health value)
11 - 16 yr old sample scores: Mean - 4.73, sd 1.34, alpha - 0.66

Acceptance and adjustment to condition

Acceptance of Illness Scale Felton, Revenson & Hinrichsen (1984). This is an eight-item scale designed to measure the extent to which individuals accept their condition without experiencing negative feelings. The items are scored on a 5-point Likert scale from strongly agree to strongly disagree and a maximum score of 40 would indicate extremely high acceptance or adjustment and a minimum score of eight would indicate extremely low acceptance or adjustment. The measure was designed using 151 patients with one of four chronic illnesses: rheumatoid arthritis, cancer, hypertension and diabetes. The scale had high internal consistency and reasonably high test retest reliability. In their sample, the mean total score was equivalent to 28 (sd 5.6).

Acceptance and adjustment

Example:	I have had a hard time adjusting to the limitations of my condition. My condition makes me feel useless at times.
Range:	8 (low acceptance/adjustment) - 40 (high acceptance/adjustment)

Chronic illness sample: 28, sd - 5.6, alpha - 0.81 - 0.83, test-retest - 0.69

Perceived control over recovery

This was assessed using the *Recovery Locus of Control Scale (RLoC)* Partridge & Johnston (1989). The measure was designed with physical disability populations in mind and the pilot study investigated two distinct populations, one with a transient disability (wrist fracture) and one with a longer term disability (stroke). The scale has nine items scored using a five point Likert scale with responses from strongly agree to strongly disagree and is scored to reflect higher internal beliefs, with a maximum score of 45. Significant internal consistency was found and the scale had predictive validity, with higher internality predicting faster recovery in the two groups of patients. For stroke patients the mean RLOC score was 33 (sd 6.1) and for wrist fracture patients the mean was 30.8 (sd 5.6) The mean age for these two groups was considerably higher than the population of this study (stroke - 70, wrist fracture - 69) but its specific use in populations with both short term and long term physical disability suggests it appropriateness for this population.

Recovery control

Example: It's up to me to make sure that I make the best recovery possible under the circumstances.
My own contribution to my recovery doesn't amount to much.

Range: 9 (strong external locus) - 45 (strong internal locus)

Wrist Fracture sample: Mean - 30.8, sd - 5.6

Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) Zigmond & Snaith (1983) is a 14-item measure designed to screen for symptoms of depression and anxiety over the previous seven days amongst medical populations, with seven items for each domain. Respondents indicate one of four responses, which are then coded from 0 - 3 and the total score for each domain is 21. Higher scores indicate higher levels of symptomatology. Zigmond & Snaith have suggested a score of eight or above as indicating possible disorder. Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss (1991) found that the two subscales have acceptable internal consistency and Hermann (1997) reports high test-retest reliability. Hermann (1997) discusses its use in over 200 studies and reports that HADS has been useful in predicting psychosocial and physical outcome in several populations. Although Berard & Ahmed (1995) found that, while the HADS was a less useful screening instrument amongst depressed adolescents when compared to the Beck Depression Inventory, its ease of use encouraged compliance. The original pilot study for the HADS included adolescents in the population, as did Berard & Ahmed (1995), Moorey et al (1991) and studies reported by Hermann (1997). Gillies, Smith & Parry-Jones (1999) report that the use of the HADS in adolescent populations has been well validated and argues that it is an appropriate instrument for use with surgical adolescent patients. In their study of post operative pain in adolescents, around 10% of the cohort were orthopaedic patients.

Anxiety

Example:	I feel tense or 'wound up' Worrying thoughts go through my mind
Range:	0 (no anxiety) - 21 (high anxiety), alpha - 0.93.
Cut off:	7/8 for possible disorder.

Depression

Example:	I still enjoy the things I used to enjoy I feel as if I am slowed down
Range:	0 (no depression) - 21 (high depression), alpha - 0.90
Cut off:	7/8 for possible disorder.

Satisfaction with care

This was measured using the *Medical Interview Satisfaction Scale (MISS)* Wolf, Putnam, James & Stiles (1978). The MISS contains 26 items covering behavioural, affective and cognitive aspects of the encounter with medical staff. Items are scored on a Likert scale ranging from 1 - extremely low satisfaction to five extremely high satisfaction. The summed scores are divided by the number of questions answered to give a MISS total score. The highest total score is therefore five. Although limited psychometric evaluation has been published, the scale has been shown to have satisfactory internal consistency (Kinnersly, Stott, Peter, Harvey & Hackett 1996, Wolf et al. 1978) and to compare well to other measures of satisfaction (Kinnersly et al. 1996). Although the items are intended to reflect three aspects of the encounter and these three subscales show good internal reliability, Kinnersly et al. (1996) found high correlations between the total score and subscale scores and argues that they may not be measuring distinct dimensions and that the total score may be preferred. The measure was originally intended to evaluate satisfaction with a specific medical encounter and the instructions for the measure were altered to direct the respondents to consider their satisfaction with encounters with staff for the whole of their admission up to the pre-operative period (usually 12 - 24 hours). One item was accidentally omitted in the version used in this study but the method used to calculate total scores as described above can accommodate this error. In his pilot study of 50 adults attending a screening clinic, Wolf et al. (1978) found a mean total satisfaction score of 4.01 (sd 0.55). Kinnersly (1996) found a mean total score of 3.84 (sd 0.57) in a sample of 198 primary care attenders.

Satisfaction with medical encounter

Example: After talking with the staff, I have a good idea of what changes to expect in my health over the next few weeks and months.
I felt that the staff didn't take my problems very seriously.

Range: 1 (low satisfaction) - 5 (high satisfaction)

Sample scores: Mean - 4.01, sd - 0.55, alpha - 0.93

Biomedical data

In order to investigate the contribution of psychological variables in surgical outcome, the following biomedical factors have previously been controlled for: length of hospitalisation (Boeke et al. 1991, Johnston & Carpenter 1980), blood loss (Boeke et al. 1991, Boeke et al. 1992), duration of surgery (de Groot et al. 1997), severity of disorder (de Groot et al. 1997) and previous experience of hospitalisation (Faust & Melamed 1984). For the cohort reported here, eight biomedical factors were recorded for each participant in addition to the demographic and subjective self report measures detailed above.

Deformity

The degree of deformity most often reported in the scoliosis literature is the Cobb angle. This is a measure of the curvature of the spine as seen on a standing posteroanterior radiograph (Strasburger & Brown 1996). Moe & Byrd (1987) highlight the limitations of the Cobb angle as a unitary measure of the severity of scoliosis, noting that the pattern of deformity, rate of progression, skeletal maturity and measures of other musculoskeletal manifestations (eg rib hump, pelvic tilt, leg length) must all be considered in treatment decisions. However, in a meta-analysis of 33 papers reporting on a total of 2926 patients, Haher and colleagues (Haher, Merola, Zipnick, Gorup, Mannor & Orchowski 1995) found that degree of correction was a good predictor of patient satisfaction. This degree of correction was taken as the difference between the Cobb angle pre and post operatively. In the present study, post operative Cobb angles were not available and so pre-operative deformity was used alone.

Number of fusions

Spinal fusion patients may have one or two operations, several days apart, to effect optimum correction and the number of operations was recorded.

Estimated length of procedure

Time, recorded in minutes in the medical notes, from knife-to-skin to closure.

Estimated blood loss

Blood loss during surgery recorded in mls in the medical notes.

Length of stay

Number of days in hospital post operatively.

Previous experience of hospitalisation

Previous experience as described by the participant, then categorised as none or minor surgery and major surgery.

Preadmission preparation

During the waiting period, some patients would be referred to the Clinical Nurse Specialist (CNS) responsible for preadmission visits and preparation. The Clinical Nurse Specialist would then contact the families and invite them for a visit to the ward, although not all would accept. This service was also mentioned to potential participants in the initial contact letter for the study (see Appendix). Being referred to and then taking up this service depended on sets of complex and apparently arbitrary variables differently applied by the different consultants involved. It was felt that this process equated to a quasi-random selection. About 50% of the patients received this level of preadmission information and preparation. Preparation would involve a 90 minute to two hour visit, during which individual patients and their families would see the ward and meet some of the nursing staff. The CNS would use various materials to explain what would be involved in the operation and to answer the patient's questions. These materials included x-rays and photographs of previous patients and, if available, the patient's own X rays, along with illustrations and examples of the instrumentation (rods, screws, etc.) The patient was also told what to expect during the two weeks' post operative stay and how they might expect their lives to be affected in the 6 - 12 months following the operation. The timing of this meeting varied and could take place several months or just a few days before the planned admission date.

Surgeon

Five consultant surgeons were involved in this cohort but as there were only 28 participants, a Surgeon variable could not be used in the analysis.

Expectations & experience of hospitalisation

A semi-structured interview (Appendix 11) was devised, in accordance with the model described by Smith (1995), to elicit qualitative data on specific aspects of the preparation that the youngsters found most helpful, whether any issues and anxieties remained, what they found less helpful and to explore further the adolescents' experience of hospitalisation. When around half the expected sample for the main study had completed the MISS, the responses were examined for specific issues which seemed to elicit high or low satisfaction. Pilot interviews were conducted with three postoperative adolescent orthopaedic patients (two with spinal fusion, one with leg lengthening) who were not included in the main study. This semi-structured interview was devised from these pilot interviews and from the preliminary analysis of the Medical Interview Satisfaction Scale. The main topics covered were: thoughts and feelings about their health and general health beliefs; initial beliefs about the experience of going to hospital; knowledge, information and experience; coping and support; discharge & endings. The interview, which lasted around 40 minutes, was tape-recorded and transcripts were made. The next five patients from the main study who were discharged after the semi structured interview was devised were invited to be interviewed. One refused and so the next patient from the discharge list was approached. The interview took place at the patients' homes.

This group of five was slightly but not significantly older than the cohort as a whole (mean age 16.49 years, sd 2.04, range 14.23 - 19.04) and all were female. The interview group also represented the range of previous experience in hospital, severity of deformity and of intervention of the cohort.

Only one part of this interview, the impact of the specific pre-operative preparation, will be reported on here. It is anticipated that the full data from these interviews will be analysed and presented elsewhere.

Procedure

Local research ethical committee permission was applied for and suggested changes to the procedure were incorporated (Appendix 1 & 2). The non-scoliosis specific questionnaires were piloted on three youngsters (aged 11, 14 and 19), who were then interviewed about the clarity, comprehensibility and emotive content of the questionnaires. From this, clearer emphasis was placed on confidentiality in the introduction but no other changes were felt necessary.

As mentioned above, potential participants for the study were identified from the hospital waiting lists. Once inclusion criteria had been checked, the patients (or their parents, if under 16) were contacted by letter around two weeks prior to their planned admission date. The letter briefly explained the study and invited the youngster to take part. At the request of the Hospital Research Ethics Committee (Appendix 1), this initial contact letter was written by the Clinical Nurse Specialist and contained a further invitation to contact her for advice on the hospitalisation (Appendix 3). This letter was followed up by a phone call from the researcher, in which the study was further described, initial consent obtained and directions on the appropriate completion of the measures given. A questionnaire pack was then posted to the participants. This contained a covering letter repeating the instructions for the completion of the measures (Appendix 4), an information sheet (Appendix 5), consent form (Appendix 6), Preadmission and Preoperative questionnaires (Appendix 7 & 8) and stamped addressed envelopes for their return. It was possible to meet most patients on the day of their arrival at the hospital and the directions were explained again.

Pre-operative Data

At the request of the nursing team and the ethics committee, the preoperative measures were split in two. The hospital team felt that a large battery of measures presented to the patients the night before their operation may be too anxiety-provoking. Accordingly, the main body of questionnaires - those intended to measure the more stable health constructs for the participants - were completed at approximately five days preoperatively.

Preadmission Questionnaire

This set of questionnaires contained the Health Values Scale, Scoliosis Patient Questionnaire, Multidimensional Health Locus of Control, Acceptance of Illness Scale and Recovery Locus of Control Scale.

Preoperative Questionnaire

The more situationally dependent measures were filled out the evening before their operation. This collection contained the Hospital Anxiety and Depression Scale and the Medical Interview Satisfaction Scale.

Post operative Follow Up Data

Participants received the follow up questionnaires through the post in the second month post discharge. Mean follow up time was 49 days from discharge (SD 19 days), 69 days from first operation (SD - 20 days). This battery consisted of the repeated Hospital Anxiety and Depression Scale and the post intervention version of the Scoliosis-specific Scale. Participants selected for post-discharge interview were also recruited at this time.

Analysis

Quantitative analysis

All variables were examined for skewness and were found to be satisfactory (between -.93 and +.79). The analysis of the results therefore used parametric tests of significance. Pearsons product moment correlation coefficients was used to measure the strength of linear relationships between variables; analysis of variance was used to test for differences in means for multiple variables between subjects and repeated measures analysis of variance was used to test differences in means on multiple variables within subjects between preoperative and post operative assessments. The probability of Type I errors, in which the null hypothesis (ie that any differences or associations were found by chance) is rejected when it is true, was controlled for by setting a 0.05 level of significance. In addition, where multiple comparisons are made and with consideration for the relatively small cohort size, Type I errors were adjusted for using Bonferroni correction. SPSS v8.0 for Windows was used for statistical analysis. Regression models were not used in the analyses as this would have required the calculation of specific "change" variables that may have introduced or compounded existing measurement error.

Combining some variables derived from the same measure was considered. On the scoliosis patient questionnaire, the distinction between "function" and "activity" as described by Haher et al. (1999) is not strictly clear and correlations between the scores were high (see below). However, it was decided not to combine the scores as it was considered that they might produce distinct results post operatively. On the Health Locus of Control Scale, it was felt that Wallston et al.'s (1978) consideration that the three dimensions should always be analysed separately, regardless of any emergent significant relationships between them, would be adhered to. Stanton et al (1995) had suggested that if there were emergent correlations, combining scales would be appropriate. Although some authors have suggested combining anxiety and depression scores on the HADS (see above) and these scores were highly correlated in this sample (see below) they were not combined as

Zigmond & Snaith (1983) consider this inappropriate and anxiety was of specific interest. The Medical Interview Satisfaction Scale has three subscales as described above - behavioural, affective and cognitive. Correlations between the subscales and the total score were all highly significant (all $p<.001$) and it was decided that no additional insight would be gained from examining the three subscales separately.

Qualitative description of semi structured interview.

The analysis of the semi-structured interview data followed the outlines presented by Barker, Pistrang & Elliott (1994) and Smith (1995). Firstly, verbatim transcripts were prepared for each interview. Then the transcript data was cleaned by removing interruptions, errors, repeats or other irrelevant material, and a version with double spacing, wide margins and line numbers added was printed. Identifying details were removed and the names were changed. The five respondents became known as Anna, Becky, Catherine, Debbie and Elizabeth. As mentioned above, only the part of the interview relevant to the rest of the study presented here will be discussed. This will consist of a presentation of a broad narrative of thoughts and feelings. These themes appear to be consistent through the five transcripts.

Results

Descriptive statistics derived from the measures are presented first. Demographic characteristics of the cohort are followed by descriptions of the seven preoperative health status scores (pain, functioning, activity, self image, health, anxiety and depression) and correlations between these scores. The relationship between the Cobb measure of deformity and preoperative health status variables and with satisfaction with outcome of the surgery is then described. The six independent health belief scores (health value, internal, external & powerful other health locus of control, acceptance of condition and recovery locus of control) are presented and their correlations are examined. The correlations between all preoperative variables are investigated. The impact of pre-operative preparation on anxiety, depression and satisfaction scores is considered. Post operative change in the health status scores are illustrated. The process of dichotomising the health belief scores is described, including the peri-operative and post operative variables of number of operations, time and blood loss during surgery and length of admission. The dichotomised scores are used in Repeated Measures ANOVAs to investigate interactions between health beliefs and health status.

Demographics

Demographic and preadmission characteristics of the cohort are shown in Table One. Twenty three are female, 27 are white. Just over half of the cohort had no previous experience of surgery, 25% had previous minor surgery before (for example tooth extraction or tonsillectomy) whilst 21.4% had previous major surgery (for example, previous orthopaedic surgery). Half of the 28 had a specific preadmission preparation meeting. The mean age on admission was 16 years 3 months; the youngest was 12 years and the eldest was 19. There was no significant difference between the ages of the girls and boys. The mean Cobb angle of deformity of the cohort was 53.71°; the smallest angle was 34° and the largest was 80°.

Table One: Demographic and Preadmission characteristics of the cohort (n = 28)

		N	%
Sex	Female	23	82.1%
	Male	5	17.9%
Ethnic origin	White	26	92.9%
	Asian	2	7.1%
Previous surgery	None	15	53.6%
	Minor	7	25.0%
	Major	6	21.4%
Preadmission preparation meeting	Yes	14	50%
	No	14	50%

	Mean	SD	Range
Age	16.23	2.26	12.08 - 19.11
	male - 16.70, female - 16.10, t = 0.506, p = .617		
Deformity (Cobb angle)	53.71°	10.69°	34.0° - 80.0°

Question 1. What is the subjective health status of a cohort of adolescents about to undergo corrective spinal fusion surgery for Adolescent Idiopathic Scoliosis?

Scoliosis Patient Questionnaire and Current Health

On the scoliosis-specific measure (Table Two), the mean rating of pain was 19.89. Haher et al (1999) report data from a scale-development cohort of 244 (the "index cohort") and non-scoliosis controls. In the index cohort, mean pain score was 13.23. The present cohort are reporting higher scores (*i.e. less pain*) than the index cohort. General functioning was rated as 11.00. The index cohort mean was 11.75, so in this respect the present cohort are similar. Similarly, with the activity scores, the mean score was 11.61 (index mean 12.16). Self image had a mean rating of 10.84, (lower than the index cohort score of 12.19). Overall, the scores for the present cohort indicate an impaired group compared to Haher's index *controls* (Haher et al. 1999). Functioning, activity and self image are slightly lower compared to Haher's index *cohort* (Haher et al. 1999) but they report a lower level of pain associated with their back condition. On the single item VAS for health, the mean score for current health was 58.89 (SD 23.1). This is just over the half way position between poor and excellent, although no comparison scores exist for this single item VAS.

Table Two: Scoliosis Patient Questionnaire and Current Health Scores (n = 28)

	Mean	SD	Minimum	Maximum
Pain	19.89	5.18	10	28
General function	11.00	2.33	5	13
Activity	11.61	3.86	4	15
Self image	10.84	2.01	6	13
Current health	58.89	23.1	23	100

Mood

On the night before surgery, 23 participants rated their anxiety and depression (Table Three). For HADS anxiety and depression, the suggested cut off when considering possible disorder is 7/8

(Zigmond & Snaith 1983). Mean anxiety score was 7.4 (SD 3.84). 14 (60.9%) fell below the cut off and 9 (39.1%) were above. For depression scores, the mean was 3.30 (SD 2.96). 21 (91.3%) were below the cut off, with only 2 above. This suggests that as a group, the cohort were experiencing an elevated level of anxiety but their mood was normal.

Table Three: HADS Scores (n = 23)

	Mean	Std. Deviation	Minimum	Maximum
Anxiety	7.74	3.84	1	18
Depression	3.30	2.96	0	10

	Below HADS cut off (7 or below)	Above HADS cut off (8 or above)
Anxiety	14 (60.9%)	9 (39.1%)
Depression	21 (91.3%)	2 (8.7%)

Relationship between health status variables

Table Four shows the relationship between the health status variables. The degree of association between the health status variables was examined using Pearson correlation coefficients. Current health is associated with all but the anxiety scores. Higher current health was associated with less pain, more functioning, more activity, better self image and lower depression. Self image remained an independent factor on the Scoliosis Patient Questionnaire, with activity being highly correlated with pain (ie more pain was associated with less activity) and function. This further blurred the distinction between activity and functioning and it was considered that combining the two scales would be valid. However, outcome data (see below) suggests that keeping the scales separate would be more useful. Anxiety and depression scores were highly associated.

Table Four: Pearson correlation coefficients between the Health Status variables (with significant p value in brackets) (n = 28 except for HADS where n = 23)

	Current Health	Pain	General Function	Activity	Self Image	HADS Anxiety
Pain	.441 (.019)					
General Function	.387 (.042)	.676 (.000)				
Activity	.440 (.019)	.596 (.001)	.701 (.000)			
Self Image	.521 (.005)	.299	.159	.269		
HADS Anxiety	-.152	-.167	-.171	-.071	.063	
HADS Depression	-.415 (.049)	-.208	-.236	-.134	-.132	.531 (.009)

Question 2. Is there a relationship between the Cobb angle of deformity and subjective health status?

There was no relationship, measured by Pearsons correlation coefficient, between preoperative deformity (as measured by the Cobb angle) and current health, function, activity, anxiety or depression. Nor was self image related to the deformity (Table Five). However, preoperative deformity was related to the patients' satisfaction with the outcome of surgery. Deformity was also related to preoperative pain, with larger deformity associated with less pain.

Table Five: Pearsons correlation coefficients between Cobb angle of deformity and preoperative heath status variables and outcome of surgery.

	Current health n = 28	Pain n = 28	General function n = 28	Activity n = 28	Self image n = 28	Anxiety n = 23	Depression n = 23	Outcome satisfaction n = 28
Cobb	.270	.412	.301	.156	.197	-.267	-.221	.409
p		.030						.031

Question 3. What beliefs do the youngsters have about their health and condition pre-operatively?

Health Belief Scores

Table Six shows the mean, SD and minimum & maximum scores reported for the seven health belief variables. For Health Locus of Control values, scores obtained were broadly similar to those described in the literature above, with mean Internal HLoC of 24.11 (SD 4.62), Chance HLoC 18.68 (SD 4.23) and Powerful others HLoC 20.14 (SD 5.49). This is also true of the mean Acceptance score of 29.96 (SD 7.39) and mean Recovery LoC score of 34.82 (SD 3.43). With a lower mean score and less broad SD, the Value of Health score for this cohort of 3.51 (SD 0.72)) appears slightly lower than that reported above.

Table Six: Health Belief Scores (n = 28)

Scale	Mean	SD	Minimum	Maximum
Value of Health	3.51	0.72	2	5
Internal Health Locus of Control	24.11	4.62	13	32
Chance Locus of Control	18.68	4.23	11	26
Powerful Others Locus of Control	20.14	5.49	9	35
Recovery Locus of Control	34.82	3.43	30	42
Acceptance of Illness	29.96	7.39	11	40

Relationship between Health Belief Variables

The only health belief scores that had any statistical association, examined using Pearson correlation coefficients, were Internal HLoC and Chance HLoC, which were negatively correlated (Table Seven).

Table Seven: Pearsons correlation coefficients between the Health Belief variables (n = 28) (with significant p value in brackets)

	Health Value	Internal LoC	Chance LoC	Powerful Others LoC	Acceptance of Condition
Internal LoC	-.079				
Chance LoC	-.125	-.387 (.042)			
Powerful Others LoC	.261	-.147	-.023		
Acceptance of Condition	.294	-.234	.281	-.117	
Recovery LoC	.089	.134	-.043	-.093	.000

Question 4. Is there a relationship between the youngsters' health beliefs and their health status?

The relationship between preoperative health status variables and health beliefs was examined using Pearson correlation coefficients (Table Eight). Significant associations were found between pain and several health beliefs and between acceptance of condition and several health status variables. The relationship between pain and chance locus of control suggests that lower experience of pain (represented by *higher pain scores*) was related to a higher chance locus of control. Similarly, lower experience of pain was associated with a more external recovery locus of control. Lower pain was also associated with a higher acceptance of the condition. In addition to the relationship with pain, higher acceptance of condition was also associated with higher current health, higher general function, higher activity and with higher self image. Health value and anxiety were also related suggesting that a higher value on health was associated with higher preoperative anxiety. Interesting trends that were approaching significance were for higher chance locus of control to be associated with higher self image and lower anxiety and for higher experience of pain to be associated with a higher internal health locus of control.

Table Eight: Pearson correlation coefficients between Health Belief and Health Status variables (with significant p values in brackets) and {non-significant but interesting p value in curly brackets}

	Current health n = 28	Pain n = 28	General Function n = 28	Activity n = 28	Self image n = 28	HADS anxiety n = 23	HADS depression n = 23
Health Value	.138	.228	.239	.239	.206	.419 (.047)	.272
Internal LoC	.063	-.363 {.058}	.110	.179	-.184	-.015	.010
Chance LoC	.269	.442 (.019)	.215	.226	.521 (.005)	-.363 {.089}	-.147
Powerful others LoC	.165	.110	-.151	.071	.218	.029	.268
Acceptance of Condition	.425 (.024)	.664 (.000)	.642 (.000)	.628 (.000)	.287	-.109	-.389
Recovery LoC	-.051	-.488 (.008)	-.153	-.045	.015	.139	-.074

Question 5. Does pre-operative preparation impact on pre-operative anxiety, depression and satisfaction with the care received?

The effect of the preoperative preparation session on preoperative measures was examined statistically using multivariate tests and also through the semi-structured interview. Having a preoperative meeting did not have a significant statistical effect on preoperative anxiety, depression or satisfaction with care (Wilks' lambda = .96, F (3, 19) = .24, p = .87). Table Nine shows mean and SD scores for anxiety, depression and satisfaction with care for the group that had a specific preoperative preparation meeting and the group that did not.

Table Nine: Means and SD for anxiety, depression ans satisfaction with care scores for those who did not (n = 11) and those who did (n = 12) have a preoperative preparation session

	Pre admission preparation session	Mean	SD
HADS anxiety	No (n = 11)	8.27	3.13
	Yes (n = 12)	7.25	4.47
HADS depression	No (n = 11)	3.18	3.28
	Yes (n = 12)	3.42	2.78
Satisfaction with care	No (n = 11)	4.16	.579
	Yes (n = 12)	4.18	.440

The impact of the preparation was also assessed through the semi structured interview. Four of the five youngsters interviewed had had a specific session and all five discussed their perception of the importance of these meetings. From this data, gathered at around two months post operatively, there was a clear impact of the meeting. Before coming into hospital, the youngsters had ideas about hospitals and what happened there although they had limited direct experience. Their ideas made them nervous but having a preadmission preparation meeting made them feel better. The idea of not knowing was uncomfortable.

Extracts from the interviews are presented below. The participants have been identified only as Anna, Becky, Catherine, Debbie and Elizabeth.

> The only thing I'd been told was about the bad food you could get in hospitals. (Becky)

> I was paranoid that I'd get paralysed or something. I know that's probably stupid because you probably couldn't; well, you probably could, because it's spinal, but...I don't know....I couldn't bear to lose my legs; that was my worst fear. (Catherine)

> I was talking to the bloke next to me in hospital. He said, what have you had done, and I said I haven't a clue, because then I really didn't have a clue. It's like; how can you let yourself go under the knife without knowing about that. And I thought about that and I thought well, that's quite silly really isn't it; letting myself go under. (Catherine - the only one of the five who did not have a preadmission meeting)

> [In the meeting, we] went over everything about the operation, about the first one and the second one and everything, and she drew pictures and everything. She just talked about it and that made me feel better. She calmed me down a bit cos I knew what to expect. [Before, I was] a bit nervous, bit scared. (Elizabeth)

> I didn't think I would wake up....I'd just go off and never wake up. So I am glad I went [to a preadmission meeting] cos I liked to know what was going to go on. ... Everything she said was right. [People who didn't have a pread meeting] didn't know what was going to happen. They used to say - oh, look, one foot's hot and one foot's cold. And they used to go and ask the nurse what's happened. And they said - I'm numb on this side and that they didn't know why. But I was glad I knew. (Debbie)

> There was a girl next to me, she didn't know anything that was happening to her and the day

> before the operation she was just in tears and she had her Mum spend the night with her and she was crying all the time. I think that's what I'd have been like cos you know if I hadn't known anything I'd have been scared and the first time in hospital. I don't know. I'd probably just break down myself. As I did know, I was more confident of what was gonna happen to me. (Anna)

Question 6. What is the medium term impact of the surgery on the health status of the youngsters?

The overall effect of the surgery on health status effect was calculated using repeated measures analysis of variance, with the seven health status variables in a single factor nominally called "recovery." Wilks' lambda, a multivariate test of significance in which values close to zero indicate that group means are different, is used and its value and equivalent F statistic is quoted. Multiple comparisons were adjusted for using Bonferroni correction. From this analysis, a significant decrease in health status was found (Wilks' lambda = .20, exact F (7,16) = 9.16, $p<.001$). This analysis suggests a significant negative impact of the surgery at follow-up. Table Ten shows mean scores for the pre and post-operative health status variables. The negative impact appears to consist of a decrease in functioning and activity and an increase in depression.

Table Ten: Mean preoperative and follow up scores on Health Status variables

	Time	Mean	SD
Pain (n = 28)	Preop	19.89	5.18
	Follow up	20.80	4.81
Function (n = 28)	Preop	11.00	2.33
	Follow up	8.68	1.81
Activity (n = 28)	Preop	11.61	3.86
	Follow up	6.82	2.02
Self Image (n = 28)	Preop	10.04	2.01
	Follow up	9.50	2.74
Anxiety (n = 23)	Preop	7.74	3.84
	Follow up	6.26	4.01
Depression (n = 23)	Preop	3.30	2.96
	Follow up	5.00	3.81
Health (n = 28)	Preop	58.89	23.10
	Follow up	61.86	19.30

Question 7. Is there an association between pre-operative health beliefs and recovery, as measured by change in health status?

In order to further examine the effect of health beliefs on the outcome of surgery, it was necessary to categorise each of the health beliefs into "high" and "low" scorers and to consider the severity of the surgery.

Severity

Fifteen youngsters (53.5%) had one operation only and 13 (46.5%) had two. Table Eleven shows the details of the blood loss and time in surgery for the two operations. There were wide variations in the amount of blood lost during surgery and the amount of time spent in surgery. The shortest total time in surgery was just over one hour and the longest was around six and a half hours. As expected, blood loss and time in surgery were highly correlated. For further analysis, it was necessary to dichotomise the impact of the actual surgery into High and Low severity. It was felt that just to split the participants by the number of operations they had would be to ignore the fact that some youngsters had very lengthy and high blood-loss single operations. Those youngsters who had two operations were automatically placed in the high category. Of the youngsters with just one operation, those with blood loss below the mean total blood loss were placed in the low category and those with blood loss above the mean were placed in the high category. This provided a useful High/Low split of 15/14.

Table Eleven: Blood Loss in mls and Time in Surgery in minutes

	Mean	SD	Minimum	Maximum
First Operation (n = 28)				
Blood loss in mls	825.93	669.87	150	2700
Time in surgery in minutes	132.41	48.03	65	255
Pearson's correlation for blood loss & time	.605 (p<.001)			
Second Operation (n = 13)				
Blood loss in mls	1215.38	696.24	300	2800
Time in surgery in minutes	157.31	60.26	75	260
Pearson's correlation for blood loss & time	.825 (p<.001)			
Total Blood loss	1362.07	808.95	250	3100
Total time in surgery	198.28	85.51	70	390
Pearson's correlation for blood loss & time	.761 (p<.001)			

The mean length of stay from the day of the first operation to discharge was 19 days (SD 4 days). The shortest stay was 12 days and the longest was 31 days. Not surprisingly, the single operation group had a significantly shorter stay (17 days) than the double operation group (22 days) (t = -3.94, df = 27, p<.001). The high severity/low severity split provided a similar but less significant result, with the low severity group staying for a mean of 18 days and high severity staying for 21 days (t = -2.15, df 27, p = .040). Length of stay was also highly correlated with total blood loss (Pearson correlation coefficient = .49, p = .007). Overall, this provides support for the High/Low split.

Categorising Health Beliefs Scores

This process involved calculating the central tendency of each health belief score and using that to split the group into two groups as equal as possible. The central tendency used was either the mean or the median, depending on which gave the more equal split for that health belief measure (Table Twelve).

Table Twelve: Central Tendency used to dichotomise Health Belief Variables

Measure	Central tendency	Resultant high:low ratio
Health Value	Mean - 3.53	10:19
Internal Health Locus of Control	Mean - 24.35	14:15
Chance Health Locus of Control	Median - 19	15:14
Powerful others Health Locus of Control	Mean - 20.21	14:15
Acceptance of condition	Median - 32	16:13
Recovery Locus of Control	Mean - 34.69	14:15

Interactions between health beliefs and recovery

The effect of health beliefs on post operative health status was then examined using repeated measures ANOVAs. With a potential for 49 ANOVA models (seven health status variables and seven health belief & preparation variables) it was necessary to consider which interactions were more pertinent. No statistical effect of preparation had been shown above and the marginal change in depression scores was still within the "normal" range and so it was decided not to use these variables in this analysis. From the significant preoperative relationships illustrated in Table Seven, and considering variables of specific interests, it was decided to examine the following ANOVAs:

Health Belief Variable	Health Status Variables
Health value	pain, anxiety
Internal LoC	pain, function, activity
Chance LoC	pain, function, activity, self image, anxiety
Acceptance	health, pain, function, activity
Recovery LoC	pain.

Thus, 15 ANOVA models were calculated. Overall effect was tested using repeated measures analysis of variance, with biomedical variables controlled for as covariates. These were: sex (male:female), age (12 - 14:15 - 17:18&19), previous surgery (none:minor:major), number of operations (1:2), deformity (<53°:>53°) and severity of procedure (high:low). Differences between high and low health belief groups at preoperative and follow up were tested using univariate tests based on pairwise comparisons of estimated marginal means. Differences within groups for pre and follow up were tested with multivariate statistics, also based on pairwise comparisons of estimated marginal means (a measure of expected means that are adjusted for the influence of the covariates and the influence of all the effects in the model) and Wilks' lambda is quoted as before. The significance of the pair-wise comparisons was adjusted for multiple comparisons using Bonferroni adjustment. Significant results are illustrated with charts.

Health Value

A significant interaction was found between health value and pain. No significant effect was found between health value and anxiety. Other health value interactions were calculated.

Health value and pain

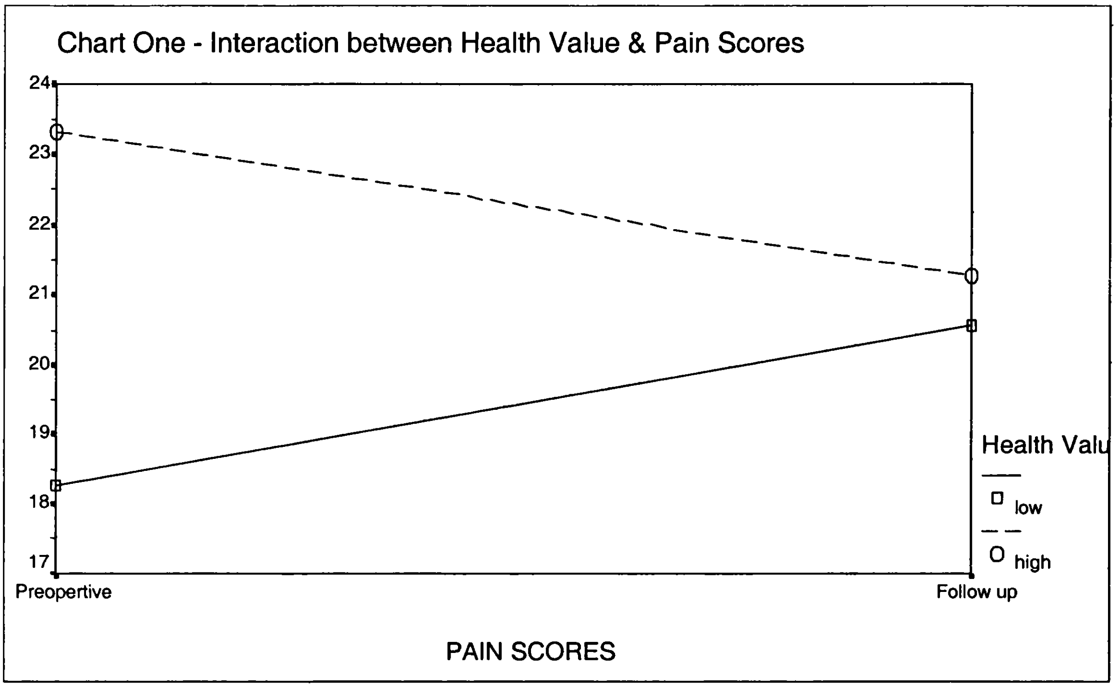
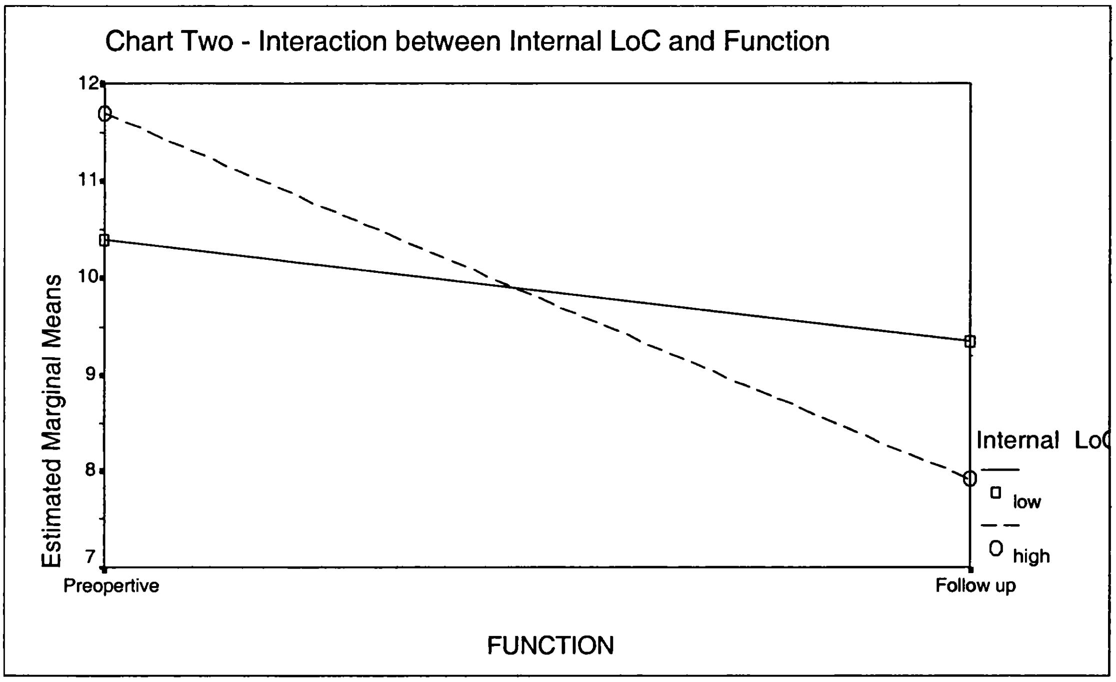


Chart One above illustrates the effects between health value and pain. From Table Ten, it has been shown that there was no significant change in pain scores from the preoperative questionnaire to follow up. However, there is an overall significant interaction between health value and pain - the extent of change in pain depended upon the individual's health value. Wilks' lambda = .79, exact F (1, 20) = 5.15, p = .034. Preoperatively, there is a significant difference between those with high health value reporting higher pain scores (*i.e. lower pain*) and low health value reporting lower pain scores (F (1, 20) = 6.65, p = .018) but this difference does not continue to follow up. There has been a significant increase in pain scores (decrease in pain) for the low health value group (Wilks' lambda = .81, F (1, 20) = 4.71, p = .042) but no significant change in pain scores for the high health value group.

Internal Health Locus of Control

There was no significant relationship between Internal HLoC and pain and activity. The interaction illustrating the extent to which change in function was dependent upon Internal HLoC is illustrated below.

Internal locus of control and function

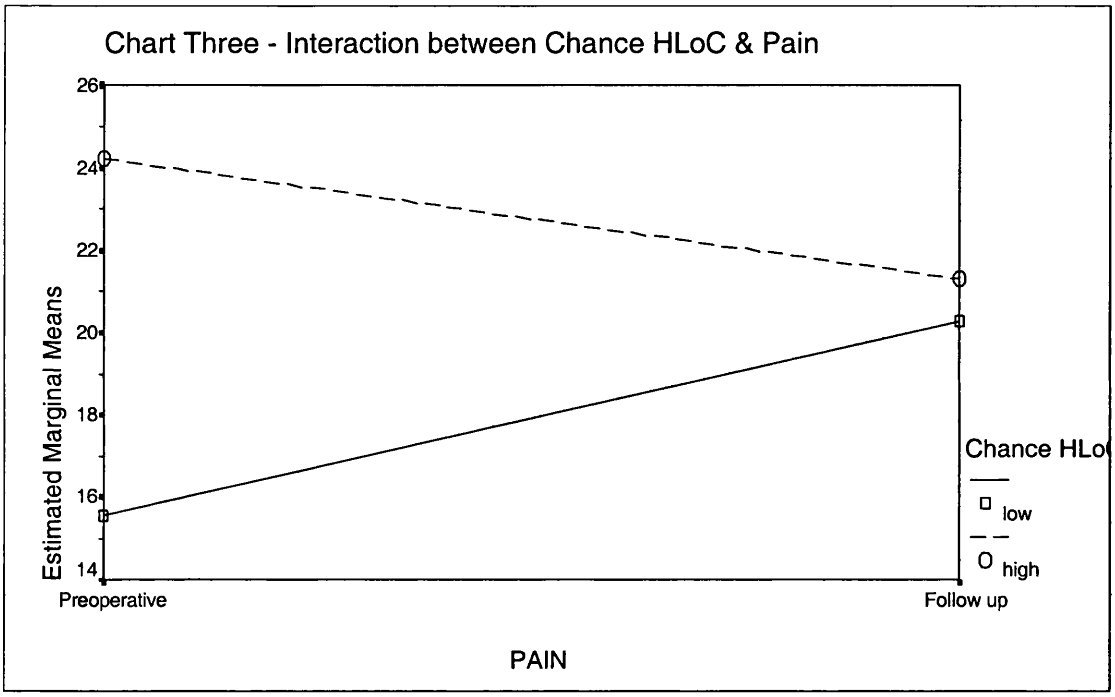


From Table Ten, it has been shown that there was a significant decrease in reported function from preoperative to follow up. There is also is a significant interaction between health value and pain (Wilks' lambda = .78, exact F(1, 20) = 5.80, p = .026) - Chart Two. Preoperatively, there was no significant difference between those with high internal HLoC and low internal HLoC value on function, nor at follow up. There is, however, a significant decrease in function scores for the high internal LoC group, (Wilks' lambda = .49, F (1, 20) =24.66, p < .001). The change in function for the low internal group is not significant.

Chance Locus of Control

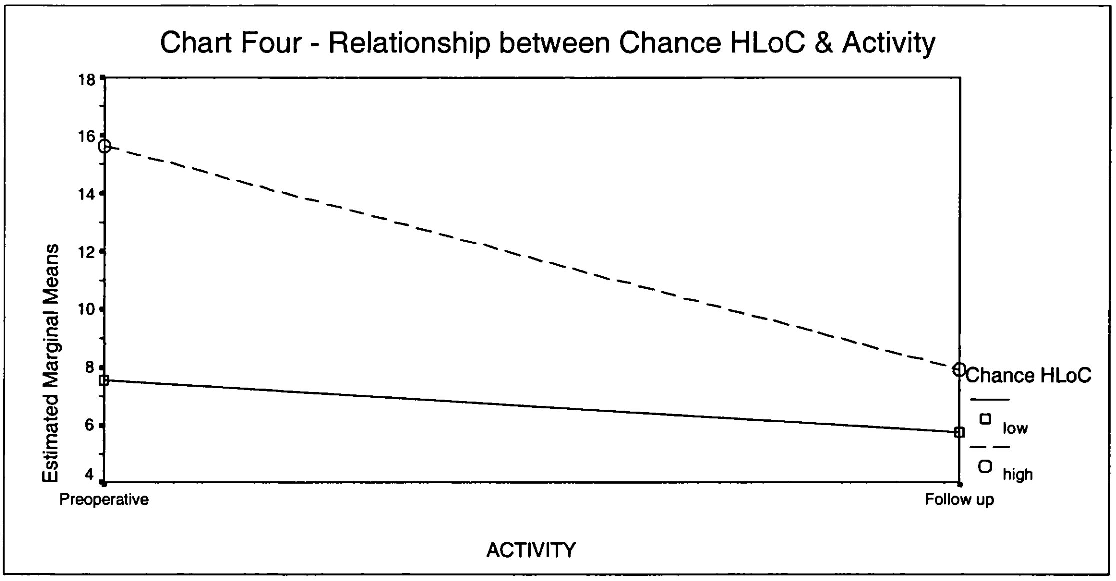
There was no significant relationship found between chance locus of control and self image or anxiety. Significant interactions were found between chance locus of control and pain and activity. These are illustrated below. Also illustrated is the marginally significant interaction between chance locus of control and function.

Chance locus of control and pain



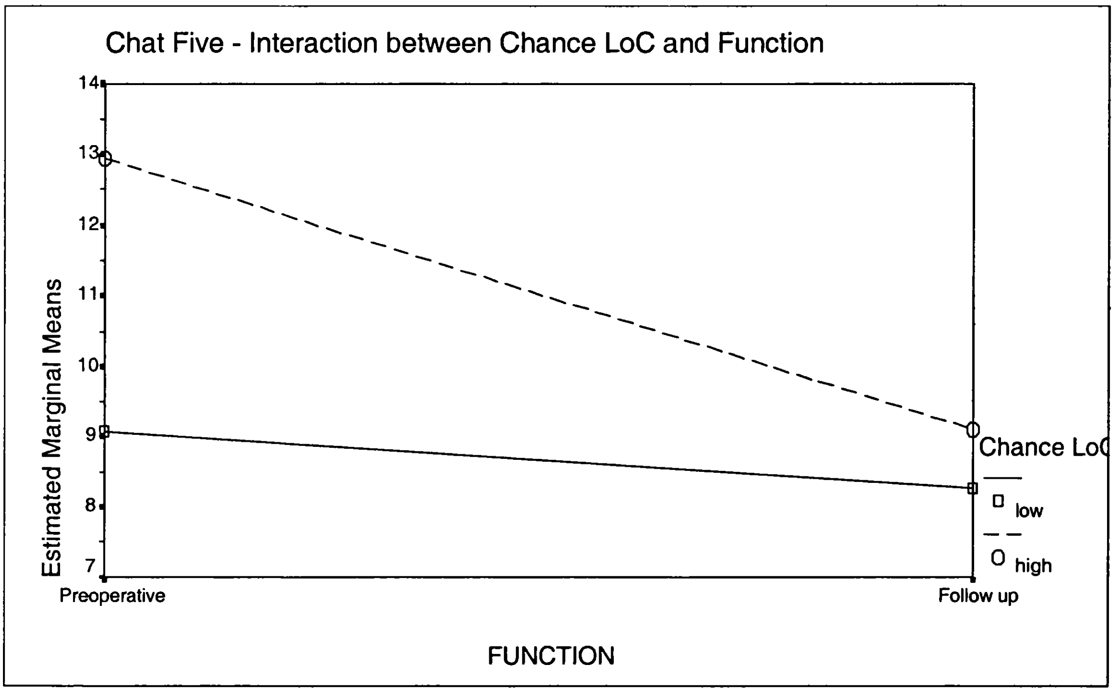
As already mentioned, there is no overall significant change in pain scores from preoperative assessment to follow up. There is a significant relationship (Chart Three above) between chance HLoC and pain (Wilks' lambda = .71, exact F(1, 20) = 8.34, p = .009). Preoperatively, there is a significant difference between those with high chance HLoC and low chance HLoC on pain, with the low chance group reporting higher pain. From preop to follow up, there is a significant decrease in pain for the low chance HLoC group, (Wilks' lambda = .68, F (1, 20) = 9.25, p = .006). The change in pain for the high chance group is not significant.

Chance locus of control and activity



As with function, there is an overall significant change in activity scores from preoperative assessment to follow up. Chart Four above shows that there is also a significant relationship between chance HLoC and activity (Wilks' lambda = .69, exact F(1, 20) = 9.16, p = .007). Preoperatively, there is a significant difference between those with high chance HLoC and low chance HLOC, with the high chance group reporting more activity (F (1,20) = 16.69, p = .001). From preop to follow up, there is a significant decrease in activity for the high chance HLoC group, (F (1, 20) = 45.57, p < .001). The change in activity for the low chance group is not significant.

Chance locus of control and function

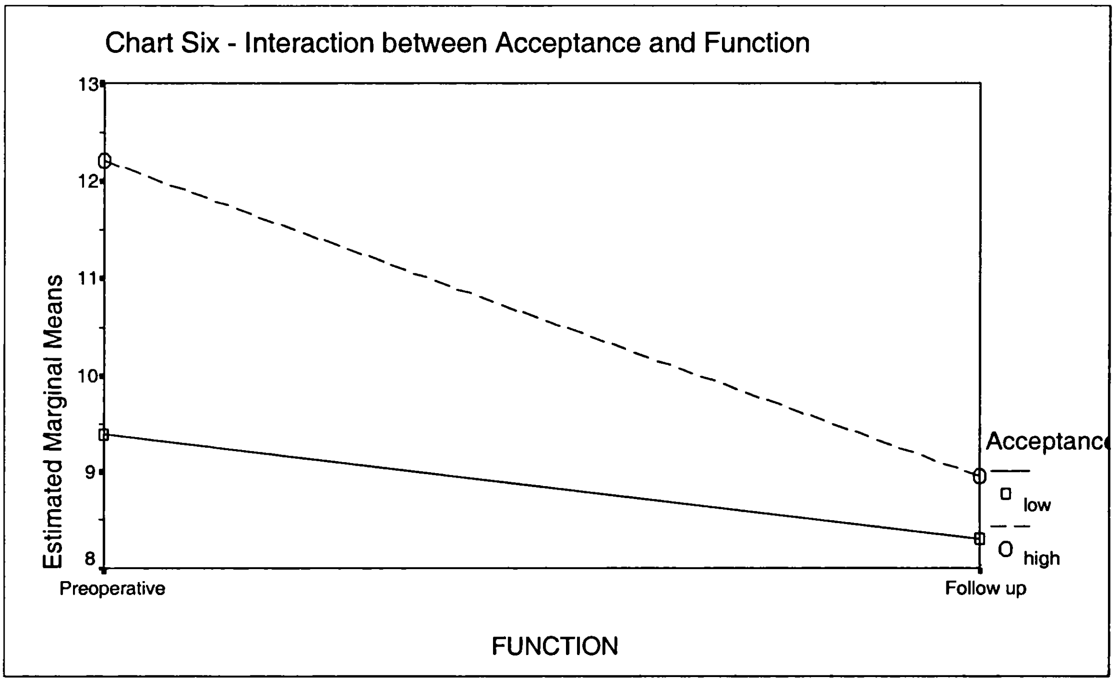


The relationship between chance locus of control and function was not significant (Wilks' lambda = .84, exact F (1, 20) = 3.80, p = .065) but the statistic was approaching significance and the chart and results were examined. There was a significant difference in function preoperatively, with youngsters with high chance HLoC reporting higher function (F (1, 20) = 9.07, p = .007). Again, the difference disappears at follow up but the change is due to a significant decrease in function for the high chance group (Wilks' lambda = .53, exact F (1, 20) = 17.65, p < .001).

Acceptance of Condition

There was no significant relationship between Acceptance of condition and health and pain. The interactions between acceptance of condition and functioning & activity are illustrated below.

Acceptance and function



Again, function decreases significantly from preop to follow up, as already mentioned. Chart six shows the significant relationship between Acceptance of Condition and function (Wilks' lambda = .82, exact F(1, 20) = 4.55, p = .046). Preoperatively, there is a significant difference between high and low acceptance, with the high acceptance group reporting higher function (F (1,20) = 11.88, p = .003). From preop to follow up, there is a significant decrease in function for the high acceptance group, (Wilks' lambda = .44, F (1, 20) = 25.6, p < .001). The change in function for the low acceptance group is not significant.

Acceptance and activity

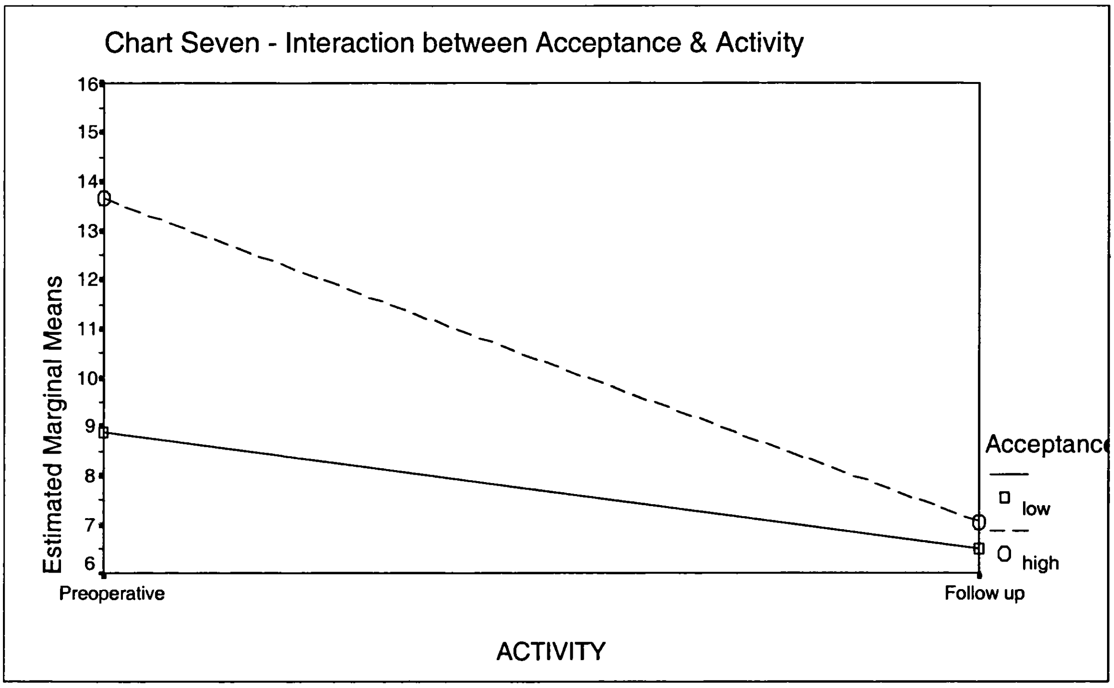


Chart Seven - Interaction between Acceptance & Activity

Activity is very similar to function. As seen, activity decreases significantly from preop to follow up. Chart Six shows the significant relationship between Acceptance of Condition and activity (Wilks' lambda = .64, exact F(1, 20) = 11.11, p = .003). Preoperatively, there is a significant difference between high and low acceptance, with the high acceptance group reporting higher activity (F (1,20) = 10.67, p = .003). From preop to follow up, there is a significant decrease in function for the high acceptance group, (Wilks' lambda = .23, F (1, 20) = 68.84, p < .001). The change in activity for the low acceptance group is also significant (Wilks' lambda = .75, F (1, 20) = 6.72, p = .017).

Recovery Locus of Control

There was no significant interaction between recovery locus of control and pain.

Results summary

Cohort

- Predominantly white female
- Mean age - 16 years 3 months
- Mean Cobb measure of deformity - 53.7°

Question 1. What is the subjective health status of a cohort of adolescents about to undergo corrective spinal fusion surgery for Adolescent Idiopathic Scoliosis?

- Experienced pain associated with impaired function, activity and self image.
- Subjective global health not high
- Low levels of depression
- Moderate level of anxiety
- High level of satisfaction with care
- Associations between function, activity, pain, health, self image and depression.
- Anxiety independent of all other health measures except depression

Question 2. Is there a relationship between the Cobb angle of deformity and subjective health status?

- Cobb measure of deformity not related to health, function, activity, self image, anxiety or depression. Higher Cobb measure associated with lower experience of pain.
- Higher preoperative Cobb measure of deformity associated with higher satisfaction with outcome of surgery at follow up.

Question 3. What beliefs do the youngsters have about their health and condition pre-operatively?

- Internal health locus of control predominant
- Generally internal recovery locus of control
- Internality and chance health locus negatively correlated
- Value of health only moderate
- Good acceptance of condition; higher acceptance in those with better health status (higher current health, function and activity; lower experience of pain)

Question 4. Is there a relationship between the youngsters' health beliefs and their health status?

- Low experience of pain associated with high chance beliefs, high acceptance, external recovery locus; marginal association with low internal health locus.
- Self esteem associated with high chance locus
- Lower anxiety associated with lower health value and marginally with high chance locus
- Higher external beliefs appear to be associated with better health status

Question 5. Does pre-operative preparation impact on pre-operative anxiety, depression and satisfaction with the care received?

- Quantitative analysis of data gathered preoperatively suggests preparation has no impact.
- Qualitative description of meeting suggests high positive impact.

Question 6. What is the medium term impact of the surgery on the health status of the youngsters?

- Decrease in overall health status, function & activity; marginal increase in depression (although still within normal range).

Question 7. Is there an association between pre-operative health beliefs and recovery, as measured by change in health status?

- Health value & pain

  Lower health value group report higher experience of pain preoperatively

  Lower health value group report decreased experience of pain at follow up

- Internal health locus and function

  High internal group report decreased function at follow up.

- Chance health locus and pain

  Low chance group report higher experience of pain preoperatively

  Low chance group report decreased experience of pain at follow up

- Chance health locus and activity

  High chance group report more activity preoperatively

  High chance group report decreased activity at follow up

- Chance health locus and function

  High chance group report higher function preoperatively

  High chance group report decreased function at follow up

- Acceptance and function

  High acceptance group report higher function preoperatively

  High acceptance group report decrease in function at follow up

- Acceptance and activity

  High acceptance group report higher activity

  High acceptance group report decrease in activity at follow up

  Low acceptance group report less decrease in activity at follow up.

Discussion

Preoperative beliefs and health

This study aimed to investigate the relationships between health beliefs, health status and recovery from surgery for a group of adolescents with idiopathic scoliosis. From their preoperative health beliefs and health status, this cohort of 28 youngsters is very similar to their peers. In terms of the impact of their condition, they show similar functioning and activity to clinic sample norms although with less pain and lower self image. Their general health rating was not good and comparison values for this would be very useful. On measures of anxiety and depression on the night before their surgery, most of the group fell into the normal range, although mean anxiety just entered the range of possible pathology, and they were very satisfied with the care they received. Satisfaction is difficult to quantify and in general is reported as high (Johnson et al. 1995) and this group's reported satisfaction falls within expected values.

When the association between the heath status variables was investigated, it appeared that the youngsters' global evaluation of their general health was associated with a large number of the other measures of health status. Higher health was associated with less pain, more functioning, more activity, higher self esteem and lower depression. Health was not associated with anxiety although anxiety and depression were highly associated. This independence of anxiety from the other health status measures adds further to the notion that the anxiety score was very situation specific whereas the other scores represent more long term and interrelated aspects of the individual and their health.

Function, activity and pain were all highly associated, with those who reported least pain also reporting more function and activity. As mentioned, merging the activity and function subscales was considered. The distinction between the two was not clear and this high association suggested that they were not measuring distinct dimensions of the scoliosis condition. However, it was decided to keep them separate in order to see how they altered at follow up. While self image was associated with current health, it had no significant association with pain, function or activity. It was also shown that self-image was independent of the degree of deformity for the cohort. It was interesting to note that a higher degree of deformity was associated with a lower experience of pain. As mentioned, the youngsters' self image was not good compared to the index cohort of scoliosis patients but still had a mean value above the nominal half way point.

When considering the health belief scores, it is worth noting that some of the measures used had been standardised on clinic samples (Recovery LoC and Acceptance) whilst other had been standardised on population samples (MHLoC, Health Value). Reviewing the values obtained and the sample scores presented, this cohort reported health beliefs that were clearly in accord with the populations the measures were devised for. As expected, internality was the domain of health locus of control that was dominant. Powerful others had the largest range and least focus, perhaps suggesting some ambivalence about the importance of powerful others in light of the trust the youngsters were about to put into the hands of their surgeons. Recovery locus of control was predominantly internal. In fact, no youngster scored less than 30, when a score of less than 27 would be needed on the scale to pass the midpoint between internality and externality. Similarly, with acceptance, the predominant report was of a high adjustment to the condition, although in this case, the lower range of acceptance scores were represented. The cohort reported a slightly lower value of health than expected from norms. The value of health is one of the scales standardised on a normal population and this lower score may represent an adjustment made by the youngsters who, when faced with disability and deformity, may find it adaptive to place a lower value on being healthy. When the relationship between the health beliefs was investigated, only internal and chance health locus were associated, as Stanton et al. (1995) had suggested might be the case in adolescent samples. Higher internality was related to lower externality. They went on to suggest that such a correlation may be an indication that subscales should be combined. With no clear construct of powerful others emerging, the sample seemed to have locus of control beliefs that were along the single dimension of internal-external. There was no relationship between general health locus and recovery locus, adding to Partridge & Johnson's (1989) idea that there are quite separate beliefs at play in general health and in recovery.

Having considered the health status and health beliefs separately, associations between the two dimensions of health were investigated. A pattern emerged in which pain was associated with several health beliefs, chance locus of control appeared to have the strongest pattern of association of the locus of control dimensions and acceptance was associated with several health status variables.

Low reported pain was associated with higher externality both in general and recovery health beliefs, suggesting that those with a more fatalistic or chance attitude reported less pain and those who felt more individually responsible experienced more pain. Higher chance locus was also associated with a better self image and marginal association with lower anxiety. For acceptance, those with a higher acceptance of their condition reported better health, less pain, more functioning and more activity. The trend of the non-significant correlations with self image, anxiety and depression all add to the notion of individuals with better health being more accepting of their condition and those with poorer health having generally poorer adjustment. Also associated with anxiety was health value. Those who had a higher value on their health experienced more anxiety in the immediate preoperative period, perhaps recognising or perceiving the operation as more threatening to their health in general.

There began to emerge, then, a model of understanding the health of these youngsters as one in which externalisation of the problem and the responsibility for change was adaptive. In general, externalisers seemed to report better health status.

The impact of the preadmission preparation meeting on the preoperative measures was tested and surprisingly no significant difference in anxiety, depression of satisfaction scores was found between those who had a meeting and those who did not. However, the importance of this meeting to the individuals who had it (and their perception of the effect of not having it) was striking from the interview data. All the youngsters mentioned the anxiety of "not knowing." Two saw others who had not been informed about what would happen and they interpreted the others' reactions as extreme distress. The quantitative measure of anxiety was possibly used at a time (the night before their operation) when anxiety would have been high but when difference in experience had not become apparent. A number of days post operatively, the difference in knowledge of the two groups probably becomes more important and then the statistical results may have been different. The shortcomings of the anxiety measure will be discussed later.

Changes at follow up

At follow up, there is an overall decrease in health status which consisted of decreases in function and activity and increase in depression (of which more later) and no significant change in pain, self image, anxiety or overall health. It may have been useful to have evaluated the nature of the pain in more detail as the source of pain could reasonably be expected to be very different. Preoperatively, pain was due to some aspect of the deformity. At follow up the pain is more likely to be due to surgical trauma. Of course it is expected that following such major surgery, activity and function should be impaired. Of note would be the patients' attributions of the source of that impairment.

Whether the change in depression scores should be rejected as significant raises the question of statistical vs clinical significance. Should the criteria of $p = 0.05$ as a gold standard be rigidly adhered to such that the null hypothesis is true at 0.051 and rejected at 0.049? Secondly, are changes from one clinically normal score (3) to another (5) clinically significant regardless of their statistical significance? In the case of these depression scores, it is difficult to accept the result as significant over consideration of measurement error and both scores are below the suggested cut off for possible pathology. Where these depression scores are useful is in indicating that depression has not been a clinical issue for this cohort and so the HADS depression scale has been useful. In general, the cohort displayed the general resilience discussed previously in the introduction and while clinicians need to be aware of individual differences in vulnerability, the overall results were encouraging. This argument around significance will be more pertinent when considering the results of the interaction analyses, in which one set of findings has $p = 0.065$ but is in accord with others that are $p = 0.006$ and $p < 0.001$.

Health belief and health status interactions

Of the health belief/health status interactions investigated, seven were presented in detail in the results. Health value, control cognitions and acceptance were useful in differentiating groups of patients preoperatively and how one or more of their health status scores would change at follow up. There is a distinct pattern in all but one of the interactions (that between internal LoC and function). In the other interactions, there is a significant difference in preoperative health status that disappears at follow up and this change is due to a significant change in one of the groups. A short-hand convention will be adopted to describe interactions; for example, the interaction between health value and pain will become merely health value*pain.

Health value was associated with pain and the higher health value group experienced less pain. As mentioned, it may be possible for this group to invest more in a belief about how important it is to be healthy whereas those with more pain may be avoiding any dissonance by placing less importance upon being healthy. At follow up, those youngsters who have a low investment in their health may be better placed to have a positive interpretation of the change in pain and so now experience pain as reduced. The higher health value group do not report a significant change in their experience of pain. In this case, a more detached, lower investment may have been more adaptive.

Internal HLoC*function will be discussed presently but first it is necessary to return to the issue of statistical significance. Chance HLoC*function and Chance HLoC*activity produce remarkably similar patterns and the changes within the interactions are highly significant. But the main effect of the chance*function interaction is only significant at p = 0.065. However, as function and activity are so highly associated and patterns are the same, the interactions will be considered together and in this instance it is reasonable to discuss the interaction in terms of chance*physical impairment. Those with a high chance HLoC ie those who may say - my health is determined by fate or chance or something outside me, report less physical impairment preoperatively. While internal beliefs predominate in the cohort, external beliefs may be seen as adaptive for the scoliosis. As a group, they may be said to have externalised the problem.

After surgery, however, the externalisers report significantly more impairment and report the same level of impairment as the low chance group, who have not changed. Now that the scoliosis has been, it could be said, literally cut out perhaps they are more able to acknowledge impairment. As a group, they now have a real external manifestation of the problem - their brace.

The pattern is similar in the chance*pain interaction. The more external the locus, the lower the reported experience of pain. Again, at follow up, the high chance group report an increase in pain but the change is not significant nor as great as the decrease in pain experienced by the low chance group. Those who do not accept that their health is a matter of chance are better placed to internalise the change in pain experienced and as with the lower health value group, have positive representation of the changed pain.

Returning to the internal*function interaction, it is worth noting here that this is one interaction for which there was less evidence (from preoperative associations) for its inclusion. There was no difference in preoperative function between the high and low internal groups. However, the pattern of change is at odds with those reported above in that the higher internal group report a large decrease in function. One explanation for this pattern may be that the higher internal group are more aware of the impairment as they will be considering their role in increasing it again, whereas the lower internals will be able to take less note of it as their role in changing it is less important to them. This hypothesis would support the continued use of a multidimensional Health Locus of Control in this group. An alternative explanation is that in this case, the null hypothesis is correct.

The acceptance*function and acceptance*activity interactions will, as with chance, be considered together. The strong association between acceptance of the condition and overall health status has been outlined above. In brief, those with better health status are also more accepting of their condition. The interaction analysis highlights this specifically with physical impairment. Preoperatively, less physically impaired individuals report greater acceptance of their condition. At follow up, this high acceptance group has reported a significant increase in impairment. After the surgery, when the condition they had adapted or adjusted to had altered (i.e. they no longer had scoliosis but had something else), so their experience of impairment is greater. Those who had never accepted or adjusted to the condition of scoliosis had the same experience of impairment pre and post operatively.

Strengths of the study

This study attempts to address an issue identified by several writers as under researched - that of the adolescents' experience of hospital and how they respond to surgery. In so doing, it also investigates another poorly documented area - the medium term impact of spinal fusion surgery. Although the study had a relatively small number of participants, the questionnaire responses matched well with those expected and so the results may be generalisable beyond this specific AIS group. The study also aimed to address some of the criticisms of similar studies in that it used a prospective design. In addition, it relied upon brief, well standardised self report measures some of which could be adapted for use in routine clinical practice. The semi structured interview was developed in part from responses and comments of members of the research cohort.

Limitations of this study

This study had a small sample and this has implications for the interpretation of the results. A larger sample could have been obtained by more vigilance and closer coordination between researcher and admissions officer. However, the attrition rate in the cohort was not high and would have been difficult to improve upon without becoming persecutory. There were a large number of statistical analyses carried, thus increasing the probability of finding significant results, without increasing the overall significance of the findings. With 15 ANOVA models calculated, there was an increased risk of Type I errors, ie rejecting the null hypothesis when it is true. On reflection, it may have been appropriate to have combined subscales on some measures (eg the function and activity subscales and possibly the subscales of the MHLoC scale).

Two strands of analysis were not investigated fully. The role of anxiety was not investigated and this may have been possible if a broader anxiety measure such as Speilberger's State-Trait Anxiety Inventory had been used, as several similar studies have. This would have allowed a greater consideration of situation-specific anxiety responses in relation to more fixed anxiety characteristics. Also not investigated was the combined interaction between different health beliefs and outcome. The predictive power of locus of control measures is said to be improved by the addition of a health value scale but the sample size was too small to allow for such an analysis in this cohort.

Conclusions and implications

There is some evidence that in adolescents with idiopathic scoliosis, control cognitions are still unidimensional and could be considered along the axis of internal - external control beliefs. Youngsters with AIS report good health and those with a general externalised belief system find it adaptive in how they experience the negative impact of the scoliosis and how they adjust to it. In corrective spinal fusion surgery, the scoliosis could be described as being physically taken away from them. There is also evidence that those adolescents who had generally owned responsibility for their health had better adjustment. In the process of accounting for their heath, those who had taken a more external view of their health and condition, had less opportunity to attribute their impairment post operatively to external factors and so their new experience was represented as an overall health loss. Longer term follow up will be necessary to determine how useful this model is. It may be interesting to investigate whether the change in health scores indicated is a trajectory or a single step -wise change. Repeated measures at the six month stage (prior to the final removal of the brace) and at a further six or twelve month interval may offer more understanding of the role of cognitive factors in recovery. In what way could this emergent understanding be used in clinical practice and at what point in any hospitalisation/surgical intervention could use be made of it? It has been suggested here that the preadmission preparatory/information session is important and that in this session, use could be made of health beliefs to further personalise this intervention. Clearly, the large battery of assessments presented here would not be practical in everyday practice but, as mentioned, adapted or shortened versions of some measures (or even broad questions that tap into the main concepts) may be appropriate. If, for instance, a youngster reports a high external locus and a strong belief that they are healthy, they may then experience the surgery as more damaging to their health than they expect. One would need to be cautious about telling a youngsters that they are not going to be healthy but it would be possible to help them to adjust their expectations of recovery. If, as appears to be the case, youngsters may go into hospital feeling fine but feel much worse several months after leaving, this information may be usefully presented to them. Even healthy people would need time to recover, one could emphasise, and so the individual need not adjust their belief in themself as healthy in order to accommodate their increased disability. In such a preparatory session, emphasis could be shifted away from the process of surgery (although in the youngsters reported on here, that had been very much appreciated) and so allow for more emphasis on the recovery period and how people can expect to feel in the weeks and months afterwards.

Appendices

THE ROYAL NATIONAL
ORTHOPÆDIC HOSPITAL TRUST
in association with the Institute of Orthopædics

Brockley Hill, STANMORE
Middlesex HA7 4LP

Your Ref. Telephone 0181-954 2300

Our Ref. Fax 0181-........

je/ts

3rd July 1998

Dominic O'Ryan
Clinical Psychologist in Training
Basement Flat
47B Endymion Road
Haringey
London N4 1EQ

Dear Mr O'Ryan

13/98 Thoughts and feelings in preparation for surgery for adolescents with idiopathic scoliosis

I have now had independent expert advice on this study, and thank you also for your letter regarding its modification. I have taken Chairman's action to approve this study subject to the following conditions

1. you are omitting Weissman's dysfunctional action scale
2. the questionnaires will be explained and handed out at the pre-admission clinic in collaboration with Mary Chasseaud, Clinical Nurse Specialist
3. you will repeat the psychological examination post operatively.

My expert advice makes the following points:-
You might indeed use the dysfunctional attitudes scale if you carefully piloted it on at least 10 patients in order to assess their reactions immediately afterwards and a week later. While your questionnaire is concerned with patients satisfaction with preparation and hospital care there is no measure of preparation itself nor a rating by the preparer "of the responses of the patient" to the preparation. The second hypothesis would be strengthened by the addition of a brief questionnaire for the preparing nurse or doctor, providing an external view about the preparation itself and the patients' response to preparation.

I reported this to the Joint Research and Ethics Committee on 2nd July.

Yours sincerely

Trevor Stamp

Trevor Stamp MD FRCP
Chairman - Joint Research and Ethics Committee

Basement Flat
47B Endymion Road
Haringey
London
N4 1EQ
0181 - 340 3199

Dr Trevor Stamp
Joint Research & Ethical Committee
Institute of Orthopædics &
The Royal National Orthopædic Hospital Trust
Brockley Hill
Stanmore
Middlesex HA7 4LP

10 August 1998

Dear Dr Stamp

Re: Thoughts and feelings in preparation for surgery
for adolescents with idiopathic scoliosis.

Since our last correspondence, I have met with Mary Chasseaud and Chris Henry to discuss the implementation of the study and Mary is happy for participants to be recruited through her. However, she pointed out that she does not run a preadmission "clinic" as such. The consultants pass some names to her as patients who may contact her for a preadmission meeting. It is not always clear that the surgeons are passing on names using the same criteria. In addition, they pass only a minority of names to Mary and not all of those actually see her. To recruit patients into the study solely through this route would have two main impacts: the sample could be skewed in a way that would be very difficult to control for and more seriously we would recruit only a small number of participants, severely limiting the utility of the study.

Mary, Chris Henry and I would like to propose an additional route through which participants could be recruited. Each month, there is a preadmission multidisciplinary scoliosis meeting, at which the admissions list of patients to be admitted over the next month is discussed. This is attended by Sue Meehan (the scoliosis coordinator) Chris Henry, Mary Chasseaud, Chris Bestington (Social Worker) and Claire Andrews (Physiotherapist). Mary has suggested that she could contact suitable patients identified from the admissions list, explain the study to them and invite them to take part. This process would still leave Mary as the initial point of contact and overall gatekeeper for the study whilst greatly increasing the number of potential participants.

Please let me know if you feel this idea is unacceptable as we hope to implement it at the earliest opportunity.

I look forward to hearing from you soon.

Yours sincerely

Dominic O'Ryan
Clinical Psychologist in Training

cc: Ward Manager
Clinical Nurse Specialist
Consultant Clinical Psychologist

Extension 409/Bleep 639

Dear

I understand that you are due to come to the orthopaedic hospital soon and I am writing to you to introduce myself and to tell you about some research that we are doing on the Adolescent Ward.

One of my jobs in the hospital is to give people information about the operations they are going to have so they know more about what to expect. If you would like to meet up before you are admitted or to talk over the phone, please call me.

Of course, some people do not like to have lots of information before they arrive and you will have the chance to ask questions when you are admitted if you prefer.

My colleague Dominic O'Ryan is a Clinical Psychologist in Training who is interested in how adolescents with scoliosis think about themselves and their health. We are asking all the adolescents with scoliosis who are coming to the hospital for surgery if they would be prepared to fill out some questionnaires. I have enclosed an Information Sheet explaining more about the research and Dominic would like to call you in the next few days to tell you a bit more and to see if you can take part.

If you do not want to take part, you can contact me at the number above or tell Dominic when he calls.

I look forward to hearing from you.

Best wishes

Paediatric Nurse Specialist

Thoughts and feelings in preparation for surgery
for adolescents with scoliosis.

Sub-Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

0171 - 504 5985

Thank you for agreeing to take part in this research. In this envelope, you will find:

- an Information Sheet for you to keep
- a Consent Form to sign and send back
- a Pre-Admission Questionnaire to be filled out as soon as you get this and an envelope to put it in
- a Pre-Operative Questionnaire to be filled out the evening before your operation (don't forget to take it to hospital with you) and another envelope to put it in.

Please read the Information Sheet and the instructions on the first page of each questionnaire.

If you have any questions, please contact me.

Best wishes

Dominic O'Ryan
Clinical Psychologist in Training

Thoughts and feelings in preparation for surgery for adolescents with scoliosis.

Information Sheet

I am asking that you take part in a research study, carried out with patients from the Royal National Orthopaedic Hospital Trust. The study will help us to understand more about what young people think and feel about their health and how they recover from operations.

The more people who take part, the more useful the study will be.

You do not have to take part if you do not want to. At any time you may withdraw from any part of this study without giving a reason and without affecting your normal care and management.

All information will be strictly confidential and we will not identify individuals in any reports.

I would like you to fill out three sets of short questionnaires, each taking 15 - 20 minutes:

One set before you are admitted to the hospital - “Pre-Admission Questionnaire”

One set the evening before your operation - “Pre-Operative Questionnaire”

One set about six weeks after you leave the hospital - “Post-Operative Questionnaire”

I would also like to interview a few of you a couple of days before you leave the hospital and to tape record your answers. This interview will take about thirty minutes. I will choose people at random for these interviews.

You do not have to agree to be interviewed if you would only like to fill out the questionnaires.

It is important that you give your own answers to the questionnaires and not what you think other people might say.

If you are under sixteen, you will need to ask your parents or guardians.

If you would like to take part, we will ask that you sign a consent form.

- If you have any questions, please call me on 0171 - 504 5985.

Thank you

Dominic O'Ryan BA, MSc
Clinical Psychologist in Training
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

Dominic O'Ryan BA, MSc
University College London
0171 - 504 5985

Consent Form

If you are under sixteen years old, a parent or guardian must sign.

- I have read the Information Sheet concerning this study and I understand what will be required of me if I take part in the study.

- My concerns regarding this study have been answered by ____________________

- I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care and management.

- I agree to take part in this study.

Name
(please print) ____

Signature ____

Date ____

Researcher ____

PRE-ADMISSION QUESTIONNAIRE

COVER SHEET

DATE: .... ID NUMBER: ....

Here is the first set of questionnaires that I would like you to complete.

Please complete it at a quiet time the day you get it.

All your answers will be strictly confidential and will not be given to the doctors and nurses.

You will have your own unique ID number, which will be written at the top. Please write the date in the space provided.

Each questionnaire has statements about the way young people think about themselves and their health. You should think about how much each statement applies to you. You may agree or disagree with each statement.

It is important that you give your own answers to these questions and not what you think other people might say.

Please do not spend too long on each item - your first answer will probably be more accurate. It is important to respond to each item. Only give one answer for each item. There are no trick questions or questions designed to catch you out. There are no right or wrong answers.

Please read each page carefully because each questionnaire has slightly different instructions.

When you have finished, put the booklet back in the envelope, seal it and put it in the post.

Thank you

Dominic O’Ryan
University College London

INFORMATION ABOUT YOU

DATE: .... ID NUMBER: ....

Sex Male/female

Date of Birth ______________________

Ethnic background
Afro-Caribbean
Black African
Chinese
Asian
Indian
White
Other ______________

Please write down details of **any** other operations you have had
(eg what the operation was, how old you were and where you had the operation)

____

____

____

____

____

HEALTH VALUE SCALE

Show the extent to which you agree with the following four statements, using the scale below. Circle the appropriate number to the right of each statement.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1	2	3	4	5

1. There is nothing more important than good health
   1 2 3 4 5

2. Good health is only of minor importance in a happy life
   1 2 3 4 5

3. If you don't have your health, you don't have anything.
   1 2 3 4 5

4. There are many things I care about more than my health
   1 2 3 4 5

5. Now put an X on the line below to show how you feel your health is *at the moment.*

   Poor --- Perfect

SCOLIOSIS SCALE

This is a questionnaire specially designed for people with the same condition as you. Please read each question carefully.

1 On a scale of 0 to 10, with 0 meaning "no pain" and 10 meaning "severe pain", indicate the degree of pain you experience regularly.

0	1	2	3	4	5	6	7	8	9	10

2 Using the same scale, indicate the most severe degree of pain you have experienced over the last month.

0	1	2	3	4	5	6	7	8	9	10

3 If you had to spend the rest of your life with your back as it is right now, how would you feel about it?

1	2	3	4	5
Very happy	Somewhat happy	Neither happy nor unhappy	Somewhat unhappy	Very unhappy

4 What is your current level of activity?

1	2	3	4	5
Bedridden/ wheelchair	Primarily no activity	Light work (eg household chores)	Moderate sports (eg cycling or walking)	Full activities without restriction.

5 How do you look in clothes?

1	2	3	4	5
Very good	Good	Fair	Bad	Very bad

6 Do you experience back pain when at rest?

1	2	3	4	5
Very often	Often	Sometimes	Rarely	Never

7 What is your current level of school/work activity?

1	2	3	4	5
100% normal	75% normal	50% normal	25% normal	0% normal

SCOLIOSIS SCALE continued

8 Write the names here of any tablets or medicine you are currently taking for your back.

9 Does your back limit your ability to do things around the house or play sports, etc?

Yes No

10 Have you taken any sick days from school or work due to back pain?

Yes No

11 Do you feel that your condition affects your personal relationships with friends and family?

Yes No

12 Have you ever felt very down, sad or depressed because of your back?

Never Sometimes Often

13 Are you or your family experiencing financial difficulties because of your back?

None Some A lot

14 Do you go out more or less than your friends?

More Same Less

15 Do you feel attractive?

1	2	3	4	5
Yes, very	Yes, somewhat	Neither attractive nor unattractive	No, not very much	No, not at all

16 On a scale of 0 to 10 with 0 being very low and 10 being extremely high, how would you rate your self image?

0 1 2 3 4 5 6 7 8 9 10

HEALTH CONTROL SCALE

This is a questionnaire about the way different people view certain important health related issues. Each item is a statement with which you may agree or disagree. For each item, circle the number that shows how much you disagree or agree with the statement. Please make sure that you answer every item. There are no right or wrong answers.

Strongly Disagree	**Moderately Disagree**	**Slightly Disagree**	**Slightly Agree**	**Moderately Agree**	**Strongly Agree**
1	**2**	**3**	**4**	**5**	**6**

1	If I get sick, how soon I get well again depends upon what I do.	1	2	3	4	5	6
2	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	Going to the doctor regularly is the best way for me to avoid getting sick.	1	2	3	4	5	6
4	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5	Whenever I am ill, I should go to the doctor.	1	2	3	4	5	6
6	I can do lots of things to keep from getting sick.	1	2	3	4	5	6
7	My family plays a big part in whether I stay healthy or get sick.	1	2	3	4	5	6
8	When I get sick, it is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in how soon I get better after an illness.	1	2	3	4	5	6
10	Only a doctor or nurse can keep me from getting sick.	1	2	3	4	5	6
11	Good health comes from being lucky.	1	2	3	4	5	6
12	My health depends upon how well I take care of myself.	1	2	3	4	5	6

HEALTH CONTROL SCALE continued

Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1	**2**	**3**	**4**	**5**	**6**

13	When I feel ill, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
14	When I get better after being sick, it is because doctors, nurses and my family have been taking good care of me.	1	2	3	4	5	6
15	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16	If I get sick, it's because getting sick just happens.	1	2	3	4	5	6
17	I can usually stay healthy by taking good care of myself.	1	2	3	4	5	6
18	I can only do what the doctor tells me to do.	1	2	3	4	5	6

ACCEPTANCE SCALE

Please respond to each of the following items by circling a number from 1 to 5 on the scale next to the item which you feel best describes you. There are no right answers to any of the questions.

Strongly agree	**1**	**2**	**3**	**4**	**5**	***Strongly disagree***

1 I have had a hard time adjusting to the limitations of my condition.

Strongly agree 1 2 3 4 5 *Strongly disagree*

2 Because of my health, I miss the things I like to do the most.

Strongly agree 1 2 3 4 5 *Strongly disagree*

3 My condition makes me feel useless at times.

Strongly agree 1 2 3 4 5 *Strongly disagree*

4 Health problems make me more dependent on others than I want to be.

Strongly agree 1 2 3 4 5 *Strongly disagree*

5 My condition makes me a burden on my family and friends.

Strongly agree 1 2 3 4 5 *Strongly disagree*

6 My health does not make me feel inadequate.

Strongly agree 1 2 3 4 5 *Strongly disagree*

7 I will never be self sufficient enough to make me happy.

Strongly agree 1 2 3 4 5 *Strongly disagree*

8 I think people are often uncomfortable being around me because of my condition.

Strongly agree 1 2 3 4 5 *Strongly disagree*

RECOVERY CONTROL SCALE

These are statements other people have made about their recovery. For each item please circle the number that represents the extent to which you agree with the statement.

Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
1	2	3	4	5

1	How I manage in the future depends on me, not on what other people can do for me.	1	2	3	4	5
2	It's often best just to wait and see what happens.	1	2	3	4	5
3	It's what I do to help myself that's really going to make all the difference.	1	2	3	4	5
4	My own efforts are not very important, my recovery really depends on others.	1	2	3	4	5
5	It's up to me to make sure that I make the best recovery possible under the circumstances.	1	2	3	4	5
6	My own contribution to my recovery doesn't amount to much.	1	2	3	4	5
7	Getting better now is a matter of my own determination rather than anything else.	1	2	3	4	5
8	I have little or not control over my progress from now on.	1	2	3	4	5
9	It doesn't matter how much help you get, in the end it's your own efforts that count.	1	2	3	4	5

That is the end of the Questionnaire. Thank you very much for your help.

PRE-OPERATIVE QUESTIONNAIRE

COVER SHEET

DATE: .... ID NUMBER: ....

Here is the second set of questionnaires for you to complete.

Please complete it in hospital the evening before your operation.

Again, all your answers will be strictly confidential and will not be given to the doctors and nurses.

As before, you have your own unique ID number - your name will be kept separately.

Please read each page carefully and do not spend too long on each item. Only give one answer for each item. You can agree or disagree with each statement - there are no right or wrong answers.

Remember, it is important that you give your own answers to these questions and not what you think other people might say.

When you have finished, put the booklet back in the envelope, seal it and put it in the post.

As before, I will keep this page separate so that your answers will be confidential

Thank you

Dominic O'Ryan
University College London

FEELINGS SCALE

This questionnaire is about how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. ***I feel tense or 'wound up':***
Most of the time
A lot of the time
From time to time, occasionally
Not at all

2. ***I still enjoy the things I used to enjoy:***
Definitely as much
Not quite as much
Only a little
Hardly at all

3. ***I get a sort of frightened feeling as if something awful is about to happen:***
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

4. ***I can laugh and see the funny side of things:***
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

5. ***Worrying thoughts go through my mind:***
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

6. ***I feel cheerful:***
Not at all
Not often
Sometimes
Most of the time

FEELINGS SCALE continued

7. ***I can sit at ease and feel relaxed:***
Definitely
Usually
Not often
Not at all

8. ***I feel as if I am slowed down:***
Nearly all the time
Very often
Sometimes
Not at all

9. ***I get a sort of frightened feeling like 'butterflies' in the stomach:***
Not at all
Occasionally
Quite often
Very often

10. ***I have lost interest in my appearance:***
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

11. ***I feel restless as if I have to be on the move:***
Very much indeed
Quite a lot
Not very much
Not at all

12. ***I look forward with enjoyment to things***:
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. ***I get sudden feelings of panic:***
Very often indeed
Quite often
Not very often
Not at all

14. ***I can enjoy a good book or radio or TV programme:***
Often
Sometimes
Not often
Very seldom

SATISFACTION SCALE

Below is a list of statements about your view of the staff who have been treating you in hospital this week. For each item, please circle the number that represents the extent to which you agree with the statement. Please respond as honestly as you can and remember that your responses will remain confidential and will not be shown to the staff.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1	**2**	**3**	**4**	**5**

1	The staff told me the name of my condition in words that I could understand.	1	2	3	4	5
2	After talking with the staff, I understand about my condition.	1	2	3	4	5
3	After talking with the staff, I have a good idea of what changes to expect in my health over the next few weeks and months.	1	2	3	4	5
4	Staff told me all I wanted to know about my condition.	1	2	3	4	5
5	The staff are very good at explaining the reasons for medical tests.	1	2	3	4	5
6	The staff told me how my condition will affect my ability to get on with things.	1	2	3	4	5
7	The staff have relieved my worries about my health.	1	2	3	4	5
8	The staff told me what the medicines they may prescribe would do for me.	1	2	3	4	5
9	I felt I understood pretty well the staff's plan for helping me.	1	2	3	4	5
10	The staff gave me a chance to say what was really on my mind.	1	2	3	4	5
11	I felt really understood by the staff.	1	2	3	4	5
12	After talking to the staff, I felt much better about my problems.	1	2	3	4	5
13	I felt that the staff really knew how upset I was about my pain.	1	2	3	4	5

SATISFACTION SCALE continued

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1	2	3	4	5

14	I felt free to talk to the staff about private thoughts.	1	2	3	4	5
15	I felt the staff accepted me as a person.	1	2	3	4	5
16	I felt that the staff didn't take my problems very seriously.	1	2	3	4	5
17	The staff were not friendly to me.	1	2	3	4	5
18	The staff I saw were people I would really trust.	1	2	3	4	5
19	The staff gave me a thorough check up.	1	2	3	4	5
20	The staff looked into all the problems I mentioned.	1	2	3	4	5
21	I was satisfied with the staff's decision about what medicines I needed to take.	1	2	3	4	5
22	I feel the staff did not spend enough time with me.	1	2	3	4	5
23	The staff seemed rushed during their examination of me.	1	2	3	4	5
24	The staff gave directions too fast when they examined me.	1	2	3	4	5
25	The staff seemed to know what they were doing during the examination.	1	2	3	4	5

That is the end of the Questionnaire. Thank you very much for your help.

Thoughts and feelings in preparation for surgery for adolescents with scoliosis.

Sub-Department of Clinical Health Psychology
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Date

Dear

Thank you for completing the first two questionnaires of this study for me. It is now a few weeks since your operation and I hope you are well. You will remember that I would like you to complete one last questionnaire. Please fill this out at a quiet time as soon as you can and send it back to me. I am also sending you another copy of the Information Sheet so you have a record of my address and phone number.

Thanks again for your help with this research.

Best wishes

Dominic O'Ryan
Clinical Psychologist in Training

POST-OPERATIVE FOLLOW-UP QUESTIONNAIRE

COVER SHEET

DATE: .... ID NUMBER: ....

Here is the third and final set of questionnaires for you to complete.

Please complete it at a quiet time the day you get it.

Again, all your answers will be strictly confidential and will not be given to the doctors and nurses.

As before, you have your own unique ID number - your name will be kept separately.

Please read each page carefully and do not spend too long on each item. Only give one answer for each item. You can agree or disagree with each statement - there are no right or wrong answers.

Remember, it is important that you give your own answers to these questions and not what you think other people might say.

When you have finished, put the booklet back in the envelope, seal it and put it in the post.

Thank you

Dominic O'Ryan
University College London

FEELINGS SCALE

This questionnaire is about how you feel. Read each item and circle the reply which comes closest to how you have been feeling **in the past week**. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. ***I feel tense or 'wound up':***
Most of the time
A lot of the time
From time to time, occasionally
Not at all

2. ***I still enjoy the things I used to enjoy:***
Definitely as much
Not quite as much
Only a little
Hardly at all

3. ***I get a sort of frightened feeling as if something awful is about to happen:***
Very definitely and quite badly
Yes, but not too badly
A little, but it doesn't worry me
Not at all

4. ***I can laugh and see the funny side of things:***
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

5. ***Worrying thoughts go through my mind:***
A great deal of the time
A lot of the time
From time to time but not too often
Only occasionally

6. ***I feel cheerful:***
Not at all
Not often
Sometimes
Most of the time

FEELINGS SCALE continued

7. *I can sit at ease and feel relaxed:*
Definitely
Usually
Not often
Not at all

8. *I feel as if I am slowed down:*
Nearly all the time
Very often
Sometimes
Not at all

9. *I get a sort of frightened feeling like 'butterflies' in the stomach:*
Not at all
Occasionally
Quite often
Very often

10. *I have lost interest in my appearance:*
Definitely
I don't take as much care as I should
I may not take quite as much care
I take just as much care as ever

11. *I feel restless as if I have to be on the move:*
Very much indeed
Quite a lot
Not very much
Not at all

12. *I look forward with enjoyment to things*:
As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. *I get sudden feelings of panic:*
Very often indeed
Quite often
Not very often
Not at all

14. *I can enjoy a good book or radio or TV programme:*
Often
Sometimes
Not often
Very seldom

SCOLIOSIS SCALE

This questionnaire is for people like you who have had treatment for the same condition as you. Thinking about how things have been since your operation, please answer the following questions. Please read each question carefully.

1 On a scale of 0 to 10, with 0 meaning "no pain" and 10 meaning "severe pain", indicate the degree of pain you experience regularly.

0 1 2 3 4 5 6 7 8 9 10

2 Using the same scale, indicate the most severe degree of pain you have experienced over the last month.

0 1 2 3 4 5 6 7 8 9 10

3 If you had to spend the rest of your life with your back as it is right now, how would you feel about it?

1	2	3	4	5
Very happy	Somewhat happy	Neither happy nor unhappy	Somewhat unhappy	Very unhappy

4 What is your current level of activity?

1	2	3	4	5
Bedridden/ wheelchair	Primarily no activity	Light work (eg household chores)	Moderate sports (eg cycling or walking)	Full activities without restriction

5 How do you look in clothes?

1	2	3	4	5
Very good	Good	Fair	Bad	Very bad

6 Do you experience back pain when at rest?

1	2	3	4	5
Very often	Often	Sometimes	Rarely	Never

7 What is your current level of school/work activity?

1	2	3	4	5
100% normal	75% normal	50% normal	25% normal	0% normal

SCOLIOSIS SCALE continued

8 Write the names here of any tablets or medicine you are currently taking for your back.

---

9 Does your back limit your ability to do things around the house, play sports, etc?

Yes No

10 Have you taken any sick days from school/work due to back pain?

Yes No

11 Do you feel that your condition affects your personal relationships with friends and family?

Yes No

12 Are you or your family experiencing financial difficulties because of your back?

None Some A lot

13 Do you go out more or less than your friends?

More Same Less

14 Do you feel attractive?

1	2	3	4	5
Yes, very	Yes, somewhat	Neither attractive nor unattractive	No, not very much	No, not at all

15 On a scale of 0 to 10 with 0 being very low and 10 being extremely high, how would you rate your self image?

0 1 2 3 4 5 6 7 8 9 10

16 Has your back treatment changed your function and daily activities?

Increased Not changed Decreased

17 Has your back treatment changed your ability to enjoy sports/hobbies?

Increased Not changed Decreased

SCOLIOSIS SCALE continued

18 Has your back treatment changed your back pain?

Increased	Not changed	Decreased

19 Has your treatment changed your confidence in personal relationships with others?

Increased	Not changed	Decreased

20 Has your treatment changed the way others view you?

1	2	3	4	5
Much better	Better	Same	Worse	Much worse

21 Has your treatment changed your self image?

Increased	Not changed	Decreased

22 Are you satisfied with the results of your back treatment?

1	2	3	4	5
Extremely satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Extremely dissatisfied

23 Compared to before your treatment, how do you feel you look?

1	2	3	4	5
Much better	Better	Same	Worse	Much worse

24 Would you have the same treatment again if you had the same condition?

1	2	3	4	5
Definitely yes	Probably yes	Not sure	Probably not	Definitely not

25 Now put an X on the line below to show how you feel your health is at the moment.

Poor -- Perfect

That is the end of the Questionnaire. Thank you very much for your help.

Thoughts and feelings in preparation for surgery
for adolescents with scoliosis.

Semi Structured Interview

"I'm trying to get an idea of what it has been like for you to have been in hospital?"

[Thoughts and feelings about their health/general health beliefs
Initial beliefs about the experience
Knowledge, information and experience
Coping and support
Discharge/endings]

General health beliefs

How did you feel about your health in general before you came into hospital?
/and since?

Initial beliefs about this experience

What were your thoughts and expectations about coming here?
    What would it be like here
    What difference would it make to you
What did you think would be the best///worst aspects of the coming into hospital?
How did you feel about coming into hospital? Ready or not ready
The ward - 1st impressions/comfortable/atmosphere

Knowledge, expectations and experience

How did your expectations relate to your experience
What was important to you about the information you were given? What do you remember?
What had most meaning to you at the time/// and since?
    understand why things happened
How does the information you were given relate to your experience of the operation /// of staying in hospital afterwards?
What would it have been like if you had not known anything?
What was the ward like for youngsters your age?
What did you talk about on the ward - with the other youngsters - with the staff?

Coping and support

Who or what helped you cope with being in hospital?
Who did you get help and support from - expected/unexpected

Discharge and endings

Leaving hospital - ready to go/outstanding issues/enough time
What has made a difference for you
What has been important
What has not been important
What would you do differently

Anything Else?

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