An Amended Form of The Observation Scale of Behavioural Distress

(To Investigate Factors Affecting the Distress of Paediatric Outpatients)

A Portfolio of Academic, Clinical and Research work carried out by:

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Academic Section
Introduction to the Academic Section

The academic section of this portfolio comprises five essays written over the previous three years. They are organised within the section in such a way as to progress from an initial position of concern with concepts and philosophy, through theoretical grounding to models of clinical practice. Thus, essay one is concerned with the concepts and philosophical implications of quality of life and institutions - its focus is the philosophy behind the fact of reducing numbers of institutional beds. The second essay shifts this focus towards the theoretical grounding of clinical neuropsychological practice and draws attention to the reciprocal relationship between clinical practice and generation of theory, while essay three moves still further towards the locus of the clinic by investigating the therapeutic relationship and the ways in which the use of a third party - a sign-language interpreter - can impact upon it.

Finally, the remaining two essays examine the applicability of a variety of psychological approaches to two client groups. The penultimate essay discusses the issues surrounding the use of group therapy for older people by citing outcome studies and observations of the group behaviours of younger and older people. The focus now being firmly on the practice of clinical psychology, essay five explores the extent to which people with learning disabilities can benefit from different therapeutic approaches - those of behavioural and cognitive-behavioural work, individual psychotherapy, and group therapy.

The shifting emphasis of these essays highlights the continuum along which clinical psychologists may find themselves, treading a line between theory and practice.
Improved quality of life is a possible but not inevitable outcome of deinstitutionalisation. Discuss this statement in relation to the resettlement of people with learning disabilities.
To address the above topic it is necessary to discuss the definitions of the main terms, being deinstitutionalisation and quality of life (and by inference, institutions). Due therefore to limitations of length, this essay will, following a brief introduction to institutions, concentrate on the practical and philosophical dilemmas of the definitions of deinstitutionalisation and quality of life, from which may be derived the relation between the two and the implications for services for people with learning disabilities.

**Institutions:**

Towards the middle of the nineteenth century, following the establishment of numerous groups such as the Lunacy Reform Movement and the increasing incidence of reports of abuse and exploitation of people in the old Madhouses, the Lunatics Act of 1845 was passed. This required all counties in this country to appropriately provide for the care of such people, which prompted the growth of a great many public asylums - therapeutic environments designed as safe places where the inmates/patients could obtain asylum from everyday stresses and be protected from persecution. The main ambition of such places was to cure people of their ills, however, as many people were chronically ill or untreatably impaired, the hospital populations grew and pressure of numbers inevitably led to deteriorating standards of care until at the end of the last century the main intention was no longer cure but prevention of trouble (Watts & Bennett, 1983). This custodial role is that which many will imagine when considering the nature of asylums or mental health / learning disability institutions in general, and it is the moral implications and social and psychological drawbacks of such places which have led to more reforms and much study of the ‘institutions.’

Erving Goffman is perhaps the most widely reported critic of institutional care, coining the phrase ‘total institution’ (Goffman, 1961) for those places ‘of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed formally administered round of life.’ He described how the main feature of such institutions was the lack of boundaries
between sleep, work and play, where one umbrella system determined every aspect of a person's life, and lead to the homogeneity of its charges.

Goffman outlined the main aspects of institutions as follows (Goffman, 1961):

- They are **total** in that residents work, sleep and play in the same place.
- They are **segregated** from general social life.
- They have **rigid routines** for every detail of a person's life.
- They are **regimented** and apply the same rules to everyone irrespective of their needs.
- They are **depersonalising**.
- There is a large **social distance** between staff and residents.
- Residents have **no control over their lives**.
- Residents have **no normal social roles**.

It is probably perspectives such as these which have contributed to the evolution of a move towards deinstitutionalisation.

**Deinstitutionalisation:**

Deinstitutionalisation is defined by Bachrach (1976) as the contraction of institutional settings with a corresponding increase in community based settings. He also describes it as a **fact**, in that long-stay hospital beds are continuing to reduce considerably in number, a **process**, or a movement from one perspective on patient care to another (that of Community Care), and a **philosophy**, a moral philosophy reacting to the view of institutional care as inhumane (Bachrach, 1988).

The term 'institution' is often used synonymously with 'hospital' yet, while it may be true that some hospitals operate as institutions as defined above, it is not **necessarily** the case that they all do. Nor is it the case that non-hospital care necessarily operates non-institutionally. The fact, therefore, that hospital beds are reducing does not necessarily infer that those people who would otherwise occupy those beds are being deinstitutionalised. Whether or not deinstitutionalisation per se contributes to increased quality of life will be discussed below. Bachrach's overall definition of deinstitutionalisation relies on the creation or increase of community based settings, while his description of the process entails a change in perspective of patient care to one based on community care. It is argued that it is not the basing of a setting in the community per se but the change in perspective that provides the mechanism for deinstitutionalisation. Rowland, Zeelan, and Waismann (1992) outline a number of possible meanings of 'community care' including 'not hospital care', 'care by the community', and 'care in communities' (suggesting that group homes or hostels
function as therapeutic communities.) It is not clear from any of these interpretations what constitutes the shift in perspective necessary for the sort of deinstitutionalisation based on Goffman’s definition and descriptions, and indeed there is no formal definition of community care despite its being part of a parliamentary act.

Thus, the question of whether or to what extent deinstitutionalisation increases quality of life begs a number of questions. What is deinstitutionalisation? By what means is quality of life increased? And indeed how do we define or measure quality of life in the first place? Perhaps the most practical means by which to address this is to agree a definition of quality of life and to investigate whether it is increased for those people discharged from long-stay hospitals. The definition of quality of life may involve a number of dimensions of living such as those included in Goffman’s descriptions of institutional care above, or, changes along those dimensions may serve as mechanisms by which increased quality of life may be effected. Since the concept of institutionalisation implies a reduction in quality of life, for otherwise we would not be concerned by it, a change in those institutional aspects (deinstitutionalisation) necessarily results in a better quality of life. The question posed at the head of this essay may more clearly be addressed as ‘does the move from hospitals to the community lead to an improvement in quality of life?’ And indeed ‘how?’

Quality of Life:

As has been suggested above, it is precisely because people in institutions are perceived, by observers, to have a reduced quality of life that calls have been made to move those people out and thus, it is assumed, improve their quality of life. This at least corresponds to Bachrach’s concept of the philosophy of deinstitutionalisation outlined above. It would be foolish to assume that such a move in and of itself could effect such a change, it being more useful to analyse the shortcomings of a life in such places so that those things may be directly addressed, or at least monitored throughout the transition to the community and thereafter. Goffman has of course done this and so we have an implicit working definition of certain aspects of life which affect its quality - those aspects which Goffman uses to describe institutional care. However, few would argue that this provides a comprehensive description.

If we are to evaluate the success of deinstitutionalisation programs we first need to identify the aims of those programs. If one aim is improved quality of life, we need to be able to state precisely what we mean by the term and then devise or utilize appropriate measures. Many different definitions have been suggested, to the extent that Baker and Intagliata (1982) suggest that there are as many definitions as people studying the concept, and Cummins et al observe that not one of over 80 quality of life
scales they identified had achieved a level of acceptance such that other scales may be validated against it (Cummins, McCabe, Gullone and Romeo, 1994; Felce and Perry, 1995). The search for a comprehensive definition has grown from the need to evaluate services and deinstitutionalisation programs, and thus from the evaluation of other distinct, if not independent, factors such as developmental progress (Tizard, 1964), user satisfaction (Conroy and Bradley, 1985), and social relationships (DeKock, Saxby, Thomas and Felce, 1988), among others. Felce and Perry (1995) describe how evaluation has moved away from the study of factors such as these in isolation, to attempts to more globally assess quality of life, although an approach to comprehensive assessment is still a goal rather than an actuality.

Borthwick-Duffy (1992) suggests three approaches to the definition of quality of life:

- The quality of one’s life conditions
- Satisfaction with life conditions
- A combination of life conditions and satisfaction.

The first of these suggests that quality of life may be measured as proportional, or indeed equivalent, to the objective life conditions of an individual. Those life conditions may be seen as wealth, living conditions, activities and pursuits etc while subjective responses such as personal satisfaction are a separate, though perhaps not independent, domain. Felce and Perry point out that such a position may be derived from the argument that people have a right to life and equality of opportunity, but not to satisfaction with life. Quality of life, therefore, may be measured and compared to norms derived from the general population since no one necessarily has a right to satisfaction with life. Questions of whether people have rights to elusive things such as ‘satisfaction’ are famously insoluble, however the point as made may be considered in terms of the ease with which things may be afforded to people - equality of opportunity is more measurable or tangible, and indeed definable, than ‘satisfaction with life’ and thus it may be more easily ensured that people obtain it. Felce and Perry’s (1995) example of ‘equality of opportunity’ is provided as an example of something to which one may demand a human right, and I have used it as an example of a more easily measurable concept than certain others. However, even this is a problem to define to the satisfaction of all concerned (ie everybody.) The main sticking-point would appear to be the definition of the population to whom one has rights to equality of opportunity - should it be the general global population or one’s cultural peers? If the latter, then is cultural membership predetermined or does one have the right to choose the culture with which to identify? If it is predetermined, then how is that defined, and so on. Borthwick-Duffy’s (1992) first model that quality of life is determined by the quality of one’s life conditions is practical in that it provides an objective measure if one can decide on which conditions provide a representative sample of a person’s life
conditions overall. However it still fails to address the problem of a normative population, and also any model which assesses a person against a normative population rules out the possibility that quality of life for that population may vary. I would suggest that it is a point for debate whether quality of life overall remains constant across the population. Such a model could identify whether the quality of life for the population at time t had varied by time t’ and thus could compare the two results, however it would not provide overall normative information without involving at some point in its definition the idea of fundamental human rights, which would provide a fixed point from which to measure deviation. As has been suggested above, this concept is as, if not more, problematic to define as quality of life itself, and its investigation is beyond the scope of an essay of this size.

The second model presented above is defined in terms of satisfaction with life conditions. Rather than the objective conditions of life themselves, quality of life is defined by the subjective appraisal of those conditions - personal satisfaction. This may address certain problems of the first model, as discussed by Edgerton (1990), pertaining to the notion of objective standards of quality of life, which could just as well be defined by a subjective appraisal. A number of authors (Flanagan, 1978; Lehman, 1988) have suggested that satisfaction with a number of life conditions may reflect overall satisfaction with life, and that this may be equated with quality of life. So for example one may ask, as one item on a questionnaire, ‘how satisfied are you with your salary?’ rather than ‘what is your salary?’ Intuitively it would seem to follow that a measure of quality should be made by a qualitative assessment, rather than a quantitative one. Edgerton (1990) has pointed out, however, that subjective report of satisfaction appears to be independent of life-conditions and as such, if such conditions are deemed a necessary aspect of quality of life, report of satisfaction will not reflect that. If, on the other hand, life conditions are not considered part of the definition of quality of life, subjective measure may be useful. However, Felce and Perry (1995) point out that subjective appraisal of personal satisfaction is considerably influenced by context, and that it is made by a process of comparison with peers (considered by the subject to be comparable). The example they give is that ‘a person may be satisfied with his or her wages until he or she discovers that a colleague of equivalent seniority, competence, and responsibilities at work earns significantly more’ (Felce and Perry, 1995). If personal satisfaction is considered a full reflection of quality of life, then it can be seen how ‘quality of life’ may be increased by quite surprising means. Consider the example given by Felce and Perry above - such an employee’s quality of life may be maintained by keeping that person uninformed of the other salaries. Indeed it may be increased by disseminating false information. This example is relevant to people with learning disabilities in hospitals who can earn wages in the region of £2.50 per week (for reasons of benefit criteria.) Such a person may report being highly satisfied with this situation when he/she looks at other people in the same hospital who earn less,
perhaps as a result of differing day-placement schedules. In this instance, is it better to provide that person with information regarding the salaries of similar but normally employed people in the community and thus reduce that person's quality of life by this definition, or to maintain it by withholding information? The uncomfortable nature of this example suggests that certain objective measures of life conditions are necessary in a useful, meaningful definition, and indeed, one of those would seem to be freedom of access to information. As Felce and Perry (1995) point out, 'if satisfaction is a measure of comparison, people whose circumstances and options to date may make them particularly prone to having low expectations may be the most likely to report satisfaction in situations that the majority would find intolerable.'

It would seem, therefore, that neither life conditions nor personal satisfaction in and of themselves provide a sufficient measure, or definition, of quality of life, and thus, if a definition involving neither is rejected, Borthwick-Duffy's (1992) third conceptualisation involving both must be the alternative. Such a definition involving both life conditions and personal satisfaction must logically involve a means of relating these two aspects in order that their individual shortcomings be addressed.

Cummins (1992) describes how quality of life assessment should involve both aspects of assessment described above, and suggests that both objective and subjective assessments should be considered in relation to the individual's personal system of values. Such values enable one to take account of the amount of importance that the individual attaches to each item being investigated and it is this to which Felce and Perry (1995) draw attention as a strength of this particular model, in that other measures combine the various aspects in an ad hoc fashion and, as Edgerton (1990) points out, only the individual can decide how each item compares concerning their own well-being. As a framework from which to devise a system for evaluating quality of life, this model appears to avoid many of the pitfalls of the previous two. However, studies would still need to be carried out to determine which aspects of life provide a representative sample of life in general as it is overall quality of life with which we are concerned, for if we are not, there is a problem of imposing an external value structure in the form of those aspects of life of which we wish to measure the quality. Nevertheless, it could be argued that an external value structure or set of assumptions pertaining to quality of life is, although not ideal, necessary for a serviceable evaluative tool.
Conclusions:

It appears that there are at least two main ways of considering deinstitutionalisation: The first is where it is considered to be synonymous with moving out of hospital and into 'the community' and I would suggest that it is largely this definition which people mean when they use the term in the context of the comparative evaluation of quality of life. There is an implicit assumption that such a move will increase quality of life, and it is this assumption that is often given as the main reason for the resettlement of people with learning disabilities in the community. Therefore, under this definition of deinstitutionalisation, the implicit definition of quality of life involves a proportion of those factors which change as a result of such a move, factors such as increased staffing, living with fewer people, using community facilities, and so on. The insubstantial definition so derived, and the subsequent attempts to define and measure the concept, suggest rather that the cart has been placed somewhat before the horse in that deinstitutionalisation (by this definition) is put into effect to increase quality of life, and then that concept is, hopefully, defined and measured. It could be argued that defining and measuring the concept first could have better informed the means by which it could be increased.

The second way to consider deinstitutionalisation rather avoids the problem of quality of life by not having to use the term, or by disguising it in an implicit working definition while not labelling it 'quality of life'. Deinstitutionalisation may be considered to be any means whereby the aspects of institutionalisation are removed or lessened, which may indeed involve a move to a community-based service. The problem then becomes one of the definition of institutionalisation, which many, including Goffman above, have attempted with some success. It is clear, however, that although a community-based service may address a number of such institutionalising factors, such a move per se does not necessarily address any. Aside from the concept of deinstitutionalisation, it may also be argued that one should not only undo the wrongs of institutionalisation, but generally ensure as normal as possible a quality of life for users of residential services.

Pertaining to quality of life, three models have been presented, and the pros and cons of each discussed. It is clear that many agree that quality of life approaches the gravity of human rights, but none agree on what it is; and I suggest that moving towards a definition before putting into motion a mechanism designed to affect it would have been a sensible option. Size restrictions have prevented presentation of studies which adopt working definitions, or identify important dimensions, of quality of life and then evaluate specific examples of deinstitutionalisation. Apologies are made for this, and a number of such studies are listed at the end of the references, overleaf.
References


**Evaluative Studies and Suggested Definitions:**


Clinical neuropsychological practice is largely an atheoretical enterprise. Discuss.
It is clear that research and clinical practice have a synergistic relationship, with each informing the other. It is clear that effective clinical psychologists will guide their practice on the basis of established research findings. It is clear that contributing research clinicians will be actively involved in practice, deriving hypotheses from clinical experience in order to better their research which, in turn, will influence their practice. And it is clear that each preceding statement is a romantic platitude more honored in the breach than in performance.

Striker & Keisner (1985)

Neuropsychology

The term "neuropsychology" was probably first used by William Ostler in the middle of this century (Bruce, 1985) and describes a discipline which, drawing upon other fields such as anatomy, biology and physiology; ethology and philosophy (Kolb & Whishaw, 1990) relates the two studies of behaviour and brain processes. Much of the research carried out and theory thereby generated is concerned with localisation of function - which areas of the brain are implicated in the ultimate execution of certain behaviours, and indeed also with less directly behavioural functions such as memory, planning and understanding. Such endeavours often necessarily lead to the construction of models designed to illustrate the way in which certain behaviours are achieved, for example, David Marr's (1980) analysis of visual object recognition being said to move through three stages, an initial representation providing a rough sketch of the visual field, a viewer-centred representation providing the relations between visual features from the viewer's perspective, and an object-centred representation which compiles the features into a three-dimensional independent object. This perceptual example demonstrates both how a behaviour can be broken down into component parts, and also how those parts may themselves often be further dissected. In some cases it has been argued that similar 'box and arrow' descriptions may be applied directly to brain areas, following studies in which cases of local brain injury, be it lesion of a specific site or disconnection of certain pathways to that site, have been shown to exhibit certain specific deficits in the performance of certain tasks (for example Wernicke, 1874.) Such localisation of function has been further demonstrated by experiments involving electrical stimulation of the cortex, for example by Fritsch and Hitzig (1960) and Bartholow (1874), in which electrical stimulation of specific

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1 I shall use the word "behaviour" to include these less obviously behavioural functions - to describe "things that people do" which may or may not be immediately apparent through observation (such as "remember").
areas of cortex was shown to result in specific, repeatable, behaviours such as eye
movements or flexion of the fingers of the contralateral hand. Despite the fact that the
discipline is in no way as straightforward as these studies would infer, especially
following the startlingly irrefutable work of Goltz in 1892 (Goltz, 1960) in which he
removed the entire neocortex from three dogs, demonstrating how active they
remained, and of Hughlings-Jackson, who pioneered the idea of a hierarchy of
functional organisation - changing the focus from where particular behaviours are
localised to the unique contribution to that behaviour made by specific areas of cortex.

The conjunction of psychology and neurology is perhaps most practically demonstrated
by the realisation that observation of behavioural signs and symptoms could better
inform surgeons as to the localisation of brain damage than previously utilised
observation of skull trauma. Equally, diagnoses could be made regarding head-injured
patients based on knowledge of the behaviour of people with known lesions as a result
of previous surgery - and this knowledge could be refined by the development and use
of standardised psychometric tests.

As neuropsychology has developed as a discipline, so it has become possible to,
broadly, achieve two things: We may use our knowledge of the localisation and
hierarchical organisation of brain function to informedly devise treatment programs for
people with head-injuries, and we may draw conclusions about the functional
organisation of the brain by the observation of people both with and without head-
injuries. These two purposes fall under the remits, respectively, of clinical and
cognitive neuropsychology.

Clinical Neuropsychology

The general aim of clinical neuropsychology may be described as the assessment and
treatment/rehabilitation of people with specific functional difficulties consistent with
disruption to the central nervous system by for example stroke, head injury or
dementia; Its main allegiance lying with optimising the functioning of presenting
patients by way of PVS/coma stimulation, acute/early rehabilitation, transitional living
units, behaviour modification, vocational rehabilitation and outreach, amongst others.
The clinical neuropsychologist faced with such a person may conduct an assessment of
impairment of consciousness, cognitive difficulties, communication and interpersonal
skills and behaviour problems (Ponsford et al, 1995), and as part of this, may use a
neuropsychological test battery, designed to measure the degree and type of functional
difficulty or deterioration. Benton (1992) draws a distinction between, in Marr's (1982)
terms, the computational and implementational levels of analysis, in defining “brain-
behaviour relationships” not simply as the relationship between disrupted behaviour
and destroyed brain-tissue, but as that between behaviours and the *functional*
mechanisms in the brain that mediate those behaviours. The clinician may use the test
battery to tease out which specific areas of functioning are disrupted and thereby make
decisions regarding the appropriate target(s) for intervention. Benton's distinction does
not rule out however the significance of actual organic trauma, and the test battery
enables conclusions to be made, or hypotheses to be clarified, regarding the focal or
diffuse nature of any injury and to some extent also its location. Conclusions regarding
the organic or functional aetiology of the difficulty may also be drawn from a
considered test battery, which is particularly important when deciding how most
effectively to intervene.

**Cognitive Neuropsychology**

"Cognitive neuropsychologists believe that by studying patients..., fundamental
insights can be gained into the way the human mind works. These insights should
then feed back to provide a better understanding of the problems of brain-injured
patients, and should lead in turn to the development of better therapies...."

Ellis & Young (1988)

The discipline of cognitive neuropsychology continues the evolutionary line described
for neuropsychology as a whole, above, and as Ellis and Young describe, continues to
be concerned with modelling and understanding human cognitive processes such as
language and memory, perception and planning. It attempts to explain cognitive
processes by examination of the way in which they change as a result of brain-injury,
considering those changes as representations of specific damage to one or more parts of
a model of the normal functioning of those processes. Unlike the proposal of the title of
this essay, *cognitive* neuropsychology can be viewed as almost purely theoretical,
having as its roots theories of the philosophies of science and mind, and considerable
literature regarding the exploration of various methodological approaches - see for
example Robertson (1994) and Caramazza (ed, 1988). It is not the place here to
elaborate the philosophical assumptions and methodological approaches of cognitive
neuropsychology or to question the validity thereof. Rather, the argument to be made
here is that cognitive neuropsychology (along with further clinical research) provides
the available theoretical underpinning of clinical neuropsychological practice:
"Any theoretical interpretation of any disorder of cognitive processing... aims at identifying which aspects of cognitive processing are impaired and which remain intact. If such identification is successful, then a focus for treatment is provided. Without the prior theoretical analysis, treatment can only be unfocussed."

Coltheart & Byng (1989)

Specifically, though, in what ways can cognitive neuropsychology be said to underpin clinical practice and rehabilitation?

The Theoretical Contribution of Cognitive Neuropsychology.

Coltheart, Bates and Castles (1994) describe the rehabilitative aspect of my definition of clinical neuropsychology, above, as “cognitive neuropsychological rehabilitation” immediately suggesting their position on the contribution of cognitive neuropsychology to clinical treatment programmes. By their definition, cognitive neuropsychological rehabilitation is the use of cognitive models of normal processing as an aid to rehabilitation; and the contribution of these models is threefold:

1. A cognitive model of a particular process will often describe that process as a series of subcomponents connected in a specific way (see Marr’s object recognition system, above, or McCarthy and Warrington’s (1984) model of spoken word recognition.) These models of normal processing will enable the clinician to devise or choose appropriate assessment techniques for each part of the system.

2. Once the appropriate assessment has been made, the specific part of the process which is disrupted will be identified, allowing the treatment to be focussed on the impaired element of the system (for example “grapheme-phoneme conversion”), rather than at the whole behavioural task (eg “reading.”)

3. Having identified the impaired element of the process, it becomes necessary to deduce how to effectively treat the person in the light of this impairment. If one is to retrain the person on that part of the process, a comprehensive understanding of how that part operates normally should guide the approach to treatment.

The first of these contributions concerns very directly the issue of assessment. Cognitive models of processing may inform assessment in such a way as to highlight distinctions in the perceived functional difficulty which may otherwise have gone unnoticed. For example, an assessment informed by the cognitive models of reading could attempt to distinguish, and highlight selective difficulties with, word and non-word stimuli, regular and irregular words, and abstract and concrete words. In this
way, preserved functions may be identified, and so not redundantly addressed as disrupted, and disrupted subcomponents of behaviour may be accurately defined. As an example, Coltheart et al (1994) describe a patient of Coltheart and Byng (1989), called EE. This patient suffered from acquired dyslexia, acquired dysgraphia and anomia following a fall, and assessment was based upon a dual-route model of reading, below, in which the reading of regular and irregular words was compared.

EE was found to read irregular words less well than regular words, suggesting the impairment was specific to the lexical part of the system (the left side of the diagram above) and this was confirmed by the finding that irregular words, when read aloud, would be pronounced as if regular. However, this may occur, according to the model, for two reasons: either the word is not recognised by the visual input lexicon and so is treated as a novel letter-string by the non-lexical (grapheme to phoneme) route, or the word is recognised, but the retrieval of its pronunciation from the phonological output lexicon fails, the only way to produce a spoken response, therefore, being again by the non-lexical route. Use of the model enabled further clarification of the functional disturbance in that for homophonic words, the latter difficulty above would result in a difficulty in reading aloud, but not in comprehending written words, while the former difficulty would also affect comprehension. Failure of the visual input lexicon would mean that EE could not access the meaning of a word in the semantic system, but would be able to say the word to himself by the non-lexical route, accessing the meaning of the word via the phonological input lexicon. For homophonic words, however, this strategy would lead to errors in that the meaning of, for example, "hoarse" could be accessed as that for "horse" and vice-versa. (It would be interesting to investigate whether the number of errors is in direct proportion to the number of
words, or their frequency, within each homophonic group.) EE made many errors of this kind and it was concluded therefore that his difficulty lay specifically in the recognition of written words. This provides a compelling example of how a cognitive model of normal processing is able to inform and guide assessment.

The precise difficulty now identified, it becomes possible to focus treatment on the disrupted element of the behaviour. Coltheart et al (1984) suggest therefore that the aim of cognitive neuropsychological rehabilitation is to be restorative rather than reconstitutive. The former aiming to improve directly the operation of the disrupted component, while the latter aims to devise alternative strategies/routes to achieve the same functional result (Howard & Patterson, 1989.) Equally, a thorough cognitive assessment would be able to identify difficulties caused by factors which would rule out or limit such a reconstitutive approach - ie those situations in which the cognitive subcomponent is central to the success of the function, the appropriate treatment approach in this instance therefore being restorative. In the same way as it is debatable the degree to which such cognitive models of functioning equate or approximate to neurophysiological structures, so it is debatable the degree to which particular subcomponents may be restored. In Marr’s terms, to what extent can a computational subcomponent be restored in the light of irreversible implementational disruption? The decision regarding which approach to adopt is informed by comprehensive assessment, as well as other clinical concerns.

The third way in which it is suggested cognitive neuropsychology may contribute to rehabilitation is by informing treatment of restoration of a particular component by a knowledge of the way in which that component operates. This may be viewed as similar to the first contribution but at a finer level of description, ie just as a process is broken down into a series of subcomponents, so may each subcomponent also be described as a sequence of sub-subcomponents. However it is suggested that currently, most cognitive models are not that specific and therefore do not in fact make the contribution in this area that they could. Most models enable understanding of particular difficulties of functioning by proposing particular subcomponents or pathways between subcomponents which may be disrupted, but less so by describing how those subcomponents function themselves. Should these details be provided by cognitive models then there is every reason to suspect that they would become useful to treatment planning in exactly the same way as current models can inform assessment. The only concern is that there lies within this rationale an inevitable reductio ad absurdum in that there will still be subcomponents the operation of which remain a mystery. It is difficult to suggest reasons why many models stop at this particular level of explanation. One could hypothesise that the intention of such research is to explain the processes by which people achieve certain behaviours and that the immediate level of description for those behaviours is that of, for example, “reading”, “memory”, and “recognising
spoken words." That is, people present for treatment with difficulties in these sorts of domains, rather than difficulties with for example allographic letter representation, a component of a particular behaviour which is theoretically derived. The elaboration of these processing components may therefore necessarily follow from the initial models of the clinically presenting behaviour difficulty. This may invoke an abundance of 'first level' models, although it could be equally argued that one 'first level' model could initiate research into many other higher level 'second level' processes such as the model of reading on page 22 which itself suggests five such subcomponents.

It may also be argued that this difficulty is as much linguistic as it is to do with the architecture of functional mechanisms. The distinction between a particular behaviour and a subcomponent thereof being almost one of convention. For a model such as that on page 22, one may imagine a more refined version in which, for example the semantic system is replaced with a more precise system of components, below.

By Coltheart et al's (1994) argument this more precise system is implicated in assessment, but not in designing treatment methods. However, if this more precise system alone were presented as a 'model of the semantic system' it would then be implicated in treatment design. It follows, then, that a qualitatively different type of explanation (or level of analysis) is required to avoid this problematic regress. I wonder, purely conjecturally, whether this difference represents a movement towards the neurophysiological representation of concepts rather than the functional organisation of behaviour, since such models, like McClelland and Rumelhart's (1981) Interactive Activation Model of letter perception which talks of "detectors", "activation" and "inhibition" (and is computer modelled on a parallel - Digital PDP 11/45 - computer)
and Riddoch and Humphrey's (1994)\textsuperscript{b} confusion of computation and implementation ("Connectionist models... take a step towards linking functional analyses of performance to the neurophysiology of brain functions") appear to move in this direction. I suggest that 'direction' does not infer a continuum so much as a discrete leap to a different level of analysis.

Perhaps a more clinically relevant hypothesis as to the apparent bias in the level of explanation of models is that of the degree to which one may be confident that a particular model accurately represents the behaviour of concern. For each behaviour which cognitive neuropsychologists attempt to describe, there are many proposed models most of which, if they are meaningfully distinguishable, must incorrectly represent that behaviour. However, for a particular model, or part thereof, to be falsified, it is necessary to wait for a particular clinical case to occur the difficulties of whom indicate the areas in which the model falls short. Although they represent normal functioning, it is (largely) disturbed functioning which enables criticism of such models and which informs their construction in the first place. Because this population is so small, though, each model is founded on observation of a small sample size; confidence in that model therefore must be conservative. This limit of confidence must increase in direct proportion to the degree to which the model breaks the behaviour into a greater number of subcomponents. This would also be the case for a 'second level' model, which would additionally bear the confidence limit of the model upon which it relies. It is clear that the clinical decision of whether to base one's assessment and intervention upon a particular model is affected by the degree to which one is confident that the model accurately represents the behaviour which is disturbed for the client. It seems to me that the fundamental restriction of subject numbers sets a limit on the degree to which fine-grained elaborate models are clinically useful.

\textit{A synergistic relationship... with each informing the other.}

It is difficult to say to what degree the practice of clinical neuropsychology \textit{is} theoretically grounded in the models of cognitive neuropsychology, although one may cite a number of assertions that in practice the two often remain quite distinct. However, it has been demonstrated above how cognitive modelling of behaviour \textit{may} inform clinical practice, and implicitly alluded to has been the reciprocal relationship of rehabilitation to cognitive research. Riddoch and Humphreys (1994)\textsuperscript{b} point out that the decision of which intervention is most appropriate depends upon a number of factors, one of which includes a theoretical understanding of the difficulty, but which also include the motivation of the patient, the history of previous treatment attempts and the patient's experience of them, the age of the patient and the level and structure of social support that person has available. Perhaps in the clinic, these concerns are more
immediately pressing. They suggest that although a theoretical background may suggest an approach that would have been taken in the absence of that background, it nevertheless makes explicit the model of functioning that the clinician would otherwise have been operating implicitly. It provides a framework around which one may understand why a particular intervention is, or is not, effective - indeed, I would add that observation of the procedure by which a system, any system, may be corrected suggests ways in which that system actually functions. This feedback from rehabilitation to cognitive modelling could in part address the difficulty of Coltheart et al's (1994) third contribution of cognitive neuropsychology, above.

Overall, it may be stated that clinical neuropsychological practice need not be atheoretical. The degree to which, in practice, it shies away from formal cognitive models of normal functioning, is hopefully counterbalanced by a corresponding increase in the effect of clinical experience and skill. It should also be remembered that a clinician operating outwith a formal cognitive model, should nevertheless be working within an implicit theory of function based on an overall familiarity with the literature and personal clinical experience of assessment and treatment.
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*Brain* **107**:463-485.


What are the effects of using interpreters in therapy with British Sign Language users?
“Figure of room, occupancy in a field of general space occurs.”
Verbatim translation of a sentence meaning “it has plenty of room”

**An Interactional Handicap:**

A paradox has been pointed out (Vernon and Brown, 1964) that deafness increases the probability of emotional problems by increasing tension and frustration, yet also gives rise to a barrier to communication that rules out the possibility of psychological assessment and treatment. Although many assessment techniques are inappropriate (Vernon & Andrews, 1990) and false-positive as well as false negative diagnoses are common (Monteiro, 1989) it appears probable, given appropriate assessment instruments and techniques, that deaf\(^1\) people show *comparable* rates of prevalence as hearing people for many psychological complaints such as anxiety disorders, depression, substance misuse, somatoform disorders, paranoid, schizoid, schizotypal, compulsive and histrionic personality disorders, and schizophrenia (Vernon & Andrews, 1990; Schein & Delk, 1974). Thus, Vernon and Brown’s (1964) initial premise is shown to be false and the paradoxical nature of the observation no longer applies - however, as a powerful means of indicating the central difficulty for a hearing therapist without facility in the appropriate sign-language it remains effective - it points towards *communication* as the main handicap resulting from deafness which influences access to psychology and other services. Following this, Elliott et al (1987) point out that communication is both expressive and receptive and as such the *disability* of the client (the deafness) gives rise to a *handicap* experienced by the client, the therapist or both. I would argue that communication is necessarily an interactional process, even in the presence of considerable time-delay between expression and reception, that it is the functional coincidence of expression and reception, and so that the above handicap is necessarily experienced by both parties.

This distinction may be further illustrated by considering an example of a hearing therapist and a hearing client, the difficulty in this example being that the therapist speaks only English and the client speaks only Japanese. The ‘disability’ if we may call it that, is clearly symmetrical - each is unable to communicate in the language of the

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1 The term “deaf” has so many intrinsic variables, such as time of onset relative to language acquisition, cause and severity - and cultural membership alongside audiological factors - that it is almost useless without a variety of further classifiers. For convenience I shall use the word “deaf” to refer to British Sign Language users who are unable to communicate using spoken English, with apologies to all deaf people for whom either or both of these factors do not apply.
other. A therapeutic situation involving an English-speaking therapist and a British Sign Language-using client may be compared in many important respects to this example, and enables us to move away from the idea of overcoming a disability to enabling communication between two parties who use different language-systems. Although BSL is the fourth major language of the United Kingdom (after English, Welsh and Gaelic) there are just three mental health services in this country providing their services in BSL, and very few psychologists, or other mental health professionals, who are able to communicate in BSL at any level, yet alone fluently. Also, the in-service components of most training courses for psychologists, psychiatrists, nurses and so on make access to such courses for potential deaf professionals particularly arduous, if impossible. How then may non-BSL-using professionals and BSL-using clients overcome this barrier to communication, and thus to services which are clearly needed?

**Breaking the Sound Barrier**

It is sometimes assumed that a deaf person will be able to understand spoken English if the speaker were to speak slowly enough, speak louder and exaggerate lip movements (Roe & Roe, 1991). More enlightened people may stress the importance of speaking naturally, if a little clearer, in order to maximise the success of the lip-reader, and indeed in this situation many deaf people are able to understand spoken English with almost flawless accuracy. However, many other deaf people are not able to comprehend spoken English by this means - perhaps unsurprising in the absence of continued aural exposure to the grammar, syntax, vocabulary and idiom of the language. Jeffers and Barley (1975) have estimated that approximately 60% of English speech sounds are indiscriminable or invisible without the accompanying sound, consisting one half of the vowels and diphthongs and three-fifths of the consonants. Roe and Roe (1991) calculate from this that a fluent English speaker who loses his or her hearing could only be expected to distinguish 40% of spoken communication, although they do not elaborate whether this refers to spoken communication at a phonemic level, a word level, or a noun-phrase or sentence level. Equally, meaning derived from inflection and stresses is inaccessible to the lipreader. It can be assumed therefore that a prelingually profoundly deaf person without continued aural exposure to the language could not be expected to reach this level of understanding of spoken English. The utility of this approach in a therapeutic situation therefore is highly questionable for most clients. For a client unable to express spoken English, the question is also begged of how to confirm understanding, and of how this approach facilitates communication in the direction of client to therapist. Of course it does not.

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2 British Sign Language will be referred to hereon as BSL.
In the absence of more appropriate means to bridge this gap in communication, some therapists have resorted to written communication, that is, passing written notes between therapist and client. The fact that this cumbersome method is generally inappropriate for psychological assessment and treatment requires no further elaboration, especially when one considers the reduced exposure to the syntax and so on of English alluded to above.

Other ways to bridge the gap include using a friend or member of the family to act as interpreter, or for the therapist with a basic understanding of BSL to attempt pidgin signed-English. The use of a friend or family member introduces issues of confidentiality, and the presence of that person is likely to have a detrimental effect on the process of therapy and the therapeutic relationship, while the attempt to engage in signed communication without a critical degree of fluency and confidence can only serve to frustrate the client as difficult material has to be discussed in terms simple enough for the therapist to understand. The therapist may also be perceived as being less skilled, in exactly the same way as deaf people have been misdiagnosed as learning disabled as a result of difficulties communicating with non-signing professionals. Hindley (1993), in his albeit small sample, found that using a qualified interpreter was preferable to attempting pidgin signed-English oneself. Indeed, apart from fluency in BSL oneself, it would be difficult to argue that any other alternative is preferable to using a qualified interpreter.

Use of an Interpreter:

The use of an interpreter in enabling a deaf person to access mental health services gives rise to a number of issues which should be considered when embarking upon such service provision. Roe and Roe (1991) divide these concerns into three groups: those centred on the client, those centred on the therapist, and those centred on the interpreter:

Client-centred issues:
Although the interpreter is usually seen as a facilitator rather than an encumbrance, it is possible that in psychological therapy, when the material discussed is often of a personal, highly charged nature, the client will begin to perceive the interpreter as an intrusion, albeit a necessary one (Stansfield, 1981). Also registered interpreters in this country are obliged not to “give advice or offer personal opinions in relation to topics discussed or people present...” and to interpret “without anything being added or omitted from the meaning” (C.A.C.D.P., 1996). This may be seen as indifference by a client who is unaware of this professional standard. It can be seen that from this position it would be less likely for the client to commit 100% to the process of therapy.
and to be more guarded. Ironically, as a result of this the interpreter therefore can to a degree become a hindrance to the therapy (although this process may of course be addressed within the therapy itself.) In this way the perceptions that the client has of the interpreter lead to issues within the sessions which would not otherwise have arisen. It is possible also that the interpreter may be seen as allied to the therapist, although further professional standards rule against this consciously occurring. The optimum seating arrangement when using an interpreter is for the client and therapist to sit opposite each other and for the interpreter to sit next to and slightly behind the therapist such that both therapist and interpreter may remain in the client’s field of vision simultaneously. From this arrangement one may imagine a client feeling somewhat outnumbered. Alternatively, the interpreter may be seen by the client as allied with him or her despite the seating arrangements, as it is the interpreter with whom the client appears to be communicating. It is of course necessary for the client to maintain eye-contact with the interpreter when the therapist is speaking, which may serve to compound this effect.

Already it becomes apparent that the client may develop feelings towards the interpreter which may need to be addressed or considered during the therapy. Whether transferential or not, these feelings are especially likely to develop because the interpreter is professionally obliged to give away no personal information or opinions (Menninger, 1958) and it is possible for the therapist to be implicated in these feelings as well. For example, the client may resent the need for an interpreter in order to access appropriate services otherwise freely available to hearing people. Stansfield (1981) suggests that this resentment may lead to mistrust of the interactions between therapist and interpreter - the client would thus be less likely to feel safe or contained enough to explore emotionally charged material. Trust becomes compromised.

Padden and Humphreys (1988) point out that the deaf community is small and very tightly knit, and that interpreters and the members of that community often know each other very well. The deaf community is also characterised by the speed with which news travels within it. It is possible therefore that the client will know the interpreter already (calling into question the appropriateness of using that particular interpreter), but even if this is not the case the client may reasonably feel uncomfortable about disclosing difficult personal material to somebody who may have regular social contact with other members of the deaf community. The ethical position of confidentiality of the interpreter as well as the therapist, then, should be made clear in the initial session ("Interpreters shall treat as confidential any information which may come to them in the course of their work including the fact of their having undertaken a particular assignment" C.A.C.D.P., 1996).
It can be seen how, despite considerable ruling by the professional body for interpreters (the C.A.C.D.P.3), even the most conscientious interpreter cannot help but become more involved in the therapeutic milieu than the clearly defined role of faithfully translating between the two languages.

**Therapist-centred issues:**

Millie Stansfield (1987) emphasises this apparent dissolution of professional boundaries when she points out that one of the main vehicles for change is the therapeutic relationship itself. Simply by being present, the interpreter enters into that relationship and impacts heavily upon it, for example at the most basic level of changing a therapeutic dyad into a triad (Hoyt et al, 1981). Thus, any interaction between the therapist and the interpreter becomes a part of the process and dramatically affects the therapeutic relationship(s). The presence of the interpreter may also directly affect the therapist by giving rise to feelings which otherwise would have remained absent. Schlesinger and Meadow (1972) describe the “shock-withdrawal-paralysis” reaction experienced by therapists faced with a deaf client when otherwise established skills and techniques are suddenly unable to be used. Feelings of being deskilled and helpless occur which clearly have an effect on the nature of the relationship. I suggest that this reaction is not alleviated by the presence of an interpreter - indeed that it may be that the therapist fantasises that the interpreter will actually alleviate such feelings but when this is found not to be the case the reaction is only increased. Therapists used to individual therapy and to an environment in which, although they contain both parties, the boundaries and environment are largely controlled by the therapist, will find that the interpreter - with the aim of facilitating optimum communication - will suggest changes to otherwise comfortable and familiar aspects of the process and environment. For example, suggestions may be made regarding the seating arrangements (mentioned above) and the lighting, communication will inevitably be slower than usual as information is translated back and forth - interrupting the usual flow, and ideally the interpreter should take a break after approximately half an hour. The reason for this break is that after this time the error-rate of the interpretation increases to statistical significance (Brasel, 1976), but this can lead to a sense of intrusion felt by the therapist as the hour is broken. All of this may be perceived by the therapist as an ‘expert in deafness’ taking control away and drawing attention to his or her own shortcomings.

Similarly, the therapist’s own degree of understanding of BSL may be a double-edged sword. A therapist with no facility in Sign may wonder, as may the client, about the accuracy with which the interpreter is proceeding. Many English forms take longer than one would expect to portray in BSL, while others are suspiciously short. This and the seemingly constant eye-contact between client and interpreter can serve to isolate the therapist and increase the sense of paralysis. However, a therapist with some

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3 Council for the Advancement of Communication with Deaf People.
understanding of BSL who nonetheless is not fluent enough to competently conduct one-to-one therapy in that language without an interpreter may experience a quite separate difficulty. It is recommended (C.A.C.D.P., 1996) - and indeed polite - to look at the client at all times, even though that person may naturally turn to look at the interpreter. If the therapist is able to understand a proportion of the signed material this can be extremely distracting as attention is drawn away from the spoken interpretation to which attention should be directed. This effect is compounded by the facts that the interpreter should be seated slightly behind the therapist, and so seems a disembodied voice, and that the client will often vocalise variably clear words. It is not easy using an interpreter, and the fantasy of a rescuer from the shock-withdrawal-paralysis is soon shown to be false.

Interpreter-centred issues:
Many of the above concerns may equally be viewed as interpreter-centred, however, there are further issues which may reasonably be aired here. Mention has been made of seeming dissolution of professional boundaries and distortion of the therapeutic relationship. Elliott et al (1987) suggest, indeed assume, that the therapist will meet with the interpreter before meeting with the client to discuss issues such as these - clarifying the role of the interpreter, the expectations of the therapist and developing ways to deal with misunderstandings during the session for example. In particular they recommend such pre-session contact so that a system of covert signals may be set up. On occasion it is necessary for an interpreter to explore a number of translations of a particular concept and it would be up to the therapist to decide whether further exploration of an important concept was merited, or could be moved from. Evans et al suggest a signalling system for this, and during psychometric testing for the description by the interpreter of errors made by the client - and they argue that this leads to increased trust between the therapist and interpreter which serves to reduce a few of the concerns outlined above regarding alliance and isolation. It is recommended (Stansfield, 1987) that the client be informed of these meetings, but not of their content. The effect of this on the client's perceptions of the role of the interpreter and the trust felt regarding both interpreter and therapist can only be guessed. Roe and Roe's (1991) comments - that it would be better to address issues of communication and confidentiality, and for the interpreter to step out of role as communication facilitator (if necessary) in front of the client such that otherwise extant mistrust and suspicion may be alleviated - are relevant here. I would further add that it may be more productive, if not healthier, for roles to be collaborative rather than secretive, and to be honestly complex and variable rather than artificially and falsely straightforward. That is, if the interpreter is required to step out of role (for example to comment on non-verbal communication) it is better achieved within the session with an apparent crossing of boundaries, with corresponding increase in trust. I would argue that the boundary around the interpreter's role is not being crossed in this instance, but being clarified as
more complex than could be hoped for. If the interpreter is to be presented to the client as simply facilitator of communication, that person should only be used as such.

In terms of psychometric testing, I feel an argument may be made at least for meeting with the interpreter beforehand - and likely for some time - in order to agree on appropriate translation of material and psychologist response. This should be carried out in some detail and may require an exchange of knowledge in that the interpreter will require a basic understanding of psychometric testing, and the psychologist will need to be somewhat versed in deaf issues, language and culture. The interpreter must understand the standardised administration (although it will inevitably be departed from as part of the stipulation is often that instructions are verbally presented), and the psychologist will need to understand if certain items are unhelpful by virtue of being culturally irrelevant, or because the very act of asking the question in BSL gives the answer away. For example the question “how are a ball and a wheel alike?” could not be used as the Signed administration would trace circular figures in the air, divulging the answer (Stansfield, 1981).

The cultural validity of standardised tests, or structured interviews, highlights another way in which the interpreter works apparently outside of straightforward linguistic translation. A good interpreter will communicate not just the spoken words of the therapist, but also the non-verbal and affective content as well. Many concepts do not translate smoothly from one culture to another, and the question is raised therefore of the degree to which the interpreter re-frames the spoken communication to fit most appropriately into the other culture. Gaviria et al (1984) - in a Peruvian study - outline four ways in which culture impacts on the validity of an instrument or technique standardised on a different cultural group and their observations and categorisations are relevant to Deaf and hearing cultures: Semantic validity demands that words in the original and translated versions carry the same meaning; technical validity requires that the very substance of the translated instrument carry the same meaning and familiarity, and yield similar expectations, as the original - the interpreter in Hindley’s (1993) study considered for example a face-to-face interview to be foreign to deaf children; criterion validity requires that items, questions or comments refer to similar normative concepts between the two cultures, and conceptual validity demands more directly that questions asked actually relate to concepts within that culture. If we (reasonably) assume a knowledge of, and familiarity with, Deaf culture from the interpreter, it is clear that all of these concerns are areas in which that person may be of help.

As alluded to above, it is equally desirable for the interpreter to be versed in mental health issues, the process of therapy and so on. Monteiro (1989) sees this as a requirement in that so much of therapy occurs outwith the spoken utterance, the interpreter needs to be aware not only of where the translation from therapist to client is
going (i.e., translating culturally as well as literally) but also of where the translation is coming from - the therapeutic rationale behind the utterance. An interpreter I have worked with, for example, suggested ways in which she may interpret therapeutic silence. Monteiro suggests that an interpreter without such an understanding may even act to the detriment of the therapy.

Such a background is clearly advisable, but, although not arguments against this practice, certain considerations should be borne in mind. To refer back to comments made above, an interpreter with a grounding in mental health issues may be perceived by the therapist as even more threatening and intrusive. Also, an interpreter with such an understanding may find it quite difficult to work with a therapist who acts in a way which conflicts with the way in which the interpreter would act in the other role; and therapeutic approaches or techniques may be perceived erroneously by the interpreter and worked into the translation, conflicting with the approach then actually taken by the therapist.

**Summary:**

A number of issues have been highlighted above, concerning potential reactions to the therapeutic triad of the client, the therapist and the interpreter. Certain of these issues can only be addressed with opinion, either from the literature or myself, while others remain simply highlighted. However, the aim here is not to provide answers to these concerns (since there are probably none which are irrefutable) - rather it is to provide a compendium of concerns which challenge the fantasy that using an interpreter will overcome all of the issues raised when a non-BSL-using therapist and a BSL-using deaf person work together in therapy. Some of these concerns are conspicuous in their absence in the verbatim translation of a Shawnee phrase at the head of this text.

Overall, however, it should be noted that apart from the therapist being fluent in BSL, the preferred means of conducting therapy with a signing deaf person is through an interpreter versed in issues of mental health.
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Discuss the issues and concerns in the provision of group therapy for older people.
Perhaps for reasons of economy, and in advance of other more therapeutically valid reasons, group therapy appears increasingly to be the intervention of choice for older people in terms of both treatment option (Burnside, 1978; Klein et al, 1965) and the number of published outcome studies (Tross and Blum, 1988). Another reason for this trend may also be the variety of types of group which have been devised - insight oriented, existential and supportive psychotherapy groups, cognitive behavioural therapy groups, reality orientation, resocialisation and remotivation therapy, and reminiscence, for example - a number of which may be organised and facilitated by an equally varied range of professionals including psychologists, ward staff, occupational therapists, social workers and psychiatrists.

In order to address the issues and concerns of this approach for older people, I will first examine the research into outcome for such interventions. Having identified the lack of argument for the reduced efficacy of group work as age increases, I will go on to explore those areas of group therapy which may be particularly pertinent for older people. Once the curative aspects of group work for older group members have been discussed it will then be necessary to discuss the ways in which older people are likely to differ in their use of such a forum, followed by an exploration into the effect these differences may have on the practical side of setting up a group.

**Outcomes of Group Therapy for Older People**

Many of the outcome studies in this area have found significant improvement along many dimensions, across numerous group approaches and with various subpopulations of older people (Tross & Blum, 1988). Tross and Blum underline studies which indicate increased social involvement and intellectual functioning in Old Age Assistance clients at a day centre (Kubie & Landau, 1953), increased rates of discharge of geriatric inpatients following milieu group therapy (Rechtschaffen et al (1954), increased sociability in a similar subject group following “group treatment” (Wolk & Goldfarb, 1967), decreased disruption in a psychiatric ward following “ward meetings” (Gunn, 1968), and many more - suggesting that group therapy for older people is effective irrespective of the particular form of treatment (Tross & Blum, 1988) and the professional status of the group facilitator(s) (Gallagher, 1981), the main predictor of success being the degree to which members actually attend the group meetings and facilitators consistently apply the chosen theoretical model (Gallagher, 1981) and maintain an enthusiastic and realistically hopeful position (Katz, 1976). Parham et al
(1982) point out that many such studies may be unreliable due to such factors as group members undergoing more than one type of therapy at a time, and other methodological problems such as the ethical consideration of a non-treatment control group, but such studies may nevertheless suggest positive outcome which could in future be more reliably measured. It appears, therefore, that there is currently no reason to assume that increasing age of group members predicts poorer outcome of group therapy.

Yalom's Curative Factors (Yalom, 1975)¹

Tross and Bloom outline more compelling reasons for the increased interest in group approaches to work with older people than mere economy. They suggest that many of the problems and situations faced as we become older have physiological and social, as well as psychological, features and that such problems may therefore be effectively addressed simultaneously in group therapy. That is, a group therapy environment may provide not only a psychotherapeutic environment but also a forum in which otherwise socially isolated individuals may explore their increasingly diminishing social circles and their changing roles, as well as any individual medical or psychological issues. They report that a number of Yalom’s curative factors are implied by these features - elements of group work which are relevant to the therapeutic effect of such work - and although they misleadingly suggest that these factors are not “age-bound” (Yalom does not report the ages of his respondents) seven of his categories are identified by Burnside (1978) as particularly pertinent for older people:

- **Group Cohesiveness** - Because one’s social circle and meaningful relationships often slowly diminish with advancing age, leading to a sense of dislocation as well as isolation, the cohesiveness of a therapeutic group may address such feelings and, hopefully, foster a sense of belonging which is maintained after the group finishes.

- **Universality** - The degree to which a group enables its members to discover other people with similar or comparable problems to overcome or situations to deal with, and to find out how others address those issues is known as its universality. For a group of people who may have issues to address which are physical, cognitive, affective and social, as stated above, group membership may be able to encourage better adjustment through the inspiration of others.

- **Interpersonal Input and Output** - Conversation with other people can be surprisingly lacking for an older person and so the benefits of interaction such as increased social feedback and reduced social distance are lost.

- **Catharsis** - The ability to use the therapeutic group as a forum for the expression of feelings and opinions can be particularly important for older people, who often feel

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¹ Yalom identified twelve not necessarily independent categories of features of group therapy felt by his patients to have been particularly important.
unable to divulge such feelings (for example if living in a nursing home or being an inpatient in hospital) or have no such forum due to social restriction described above.

- Identification - Identification with other members of the group, or often with the therapist, can be the first stage of expressing one's own uniqueness of self within the group in that it enables a safe space in which self-esteem may be improved. Once self-esteem has increased, it then becomes easier to express one's own individuality. This uniqueness within a cohesive group can provide a therapeutic medium which challenges what may otherwise be depersonalisation through either institutionalisation or isolation.

- Instillation of hope - the social, financial, medical and psychological consequences of ageing can lead very quickly to a sense of hopelessness for the older person. Careful goal setting by group facilitators, as well as a combination of universality and interpersonal input and output, may usefully address and challenge such feelings by providing counterevidence for dysfunctional beliefs and the discovery and sharing of coping strategies. It may then be learnt that personal autonomy may exist outwith the group meeting.

It can be seen that many functional aspects of group therapy may bear significant relevance to the needs of older people, indicating that certain features of group therapy as it is practised with younger adult populations could validly and beneficially be applied to an older client group. However, this does not address the question of whether older and younger people differ in the way they use and benefit from group therapy and group process. Only seven of Yalom's twelve curative factors are considered by Burnside to be pertinent for older groups, suggesting that certain aspects of group work are not "especially important" for this population - that older people may not benefit from those aspects of group work (altruism, guidance, family reenactment, insight and existential factors) (Burnside, 1978). So how do older people differ in their use of group therapy?

**Non-clinical Considerations of Group Process**

Martin Lakin (1988) describes a study he completed in which differences between the group behaviours of non-clinical populations of older (65-80yrs) and younger (18-22yrs) adults were identified from nondirective group work with the stated aim of "[being] interested in seeing how you relate to one another, and we also want to hear about your concerns as well as your satisfactions at your time of life.". Using Lakin, Lakin and Constanzo's (1979) group process dimensions, the following significant (p<.01) differences were observed:

- **Boundary behaviours:** ("Utterances that indicate group belonging, or "we/they" attributes.") Older people made more references to the differences they perceived
between themselves and others, for example “we old folk”, and “the young nowadays.” Lakin makes few suggestions as to why these differences should occur, being rather an observational study from which clinicians may draw their own conclusions. In this case, it is difficult to suggest a reason or meaning behind the more active distinction between the older group and their perceived outgroups. Perhaps in this instance the difference may relate to self-disclosure, below, in which older people appear to assume similarities amongst themselves. Clear boundary behaviour could serve to provide a secure identity and support network which would protect against the consequences of isolation and disability.

- **Leader to group:** (“The leader [facilitator] intervenes to ask a question or to suggest a direction for discussion.”) Less educated older people demanded and received more guidance from the facilitator than the more educated, who did not differ from the younger adult group. It could be suggested that such a difference arises from a differing understanding of the nature and purpose of psychological and group intervention in less educated older people, whose less informed use of the group may require more intervention and explanation from the leader. Without knowing the purpose of the leader intervention within the study, such hypotheses are clearly conjectural.

- **Conflict Behaviours:** (“Disagreements or quarrels that arise in sessions, whether they be mild differences of opinion or emphatic efforts to vanquish opponents.”) Older people were seen to argue more among themselves than the younger group. This observation may seem surprising in the light of the distinctions in boundary behaviours and self-disclosure, however differences of opinion and arguments could be viewed as efforts to create a cohesive, uniform, defined group. If the driving force behind active boundary behaviour is isolation, disability, and perhaps other issues with the gravity of, for example, death and dying, then within-group differences may be more intolerable.

- **Self-disclosure:** (“Sharing inner feelings, intimate personal experiences, or problems not ordinarily told to strangers, and which characteristically contain anhedonic elements, such as losses or personal vulnerabilities.”) Older people disclosed more personal details than the younger group. Lakin describes the difference as the younger group being more “uptight.” Whereas the younger people created anxious pauses and found it hard to talk about emotive personal experience, the older group talked about “profound human experience...feelings of abandonment...problems of widowhood...[and] feelings of rejection” very easily, and reacted empathically and comfortably with each other - although such responses were stereotypic in that it appeared to be expected that people should undergo such feelings or losses. The younger group, conversely, would divulge much less, in a much more tense atmosphere, but the responses would be much more intense, suggesting a great degree of shared anxiety. Lakin cites Dickhoff and Lakin (1963) who suggest that this difference derives from the confidence that older people have that their peers are subject

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2 Although, see Group to Leader below.
to similar stresses and experiences, whereas younger people are more prone to believe that they are unique in their situation, which inhibits self-disclosure. It is suggested that this inhibited emotional tone in the older group should not be challenged by confrontation or the elicitation of tensions, rather that the group emphasis should be on acceptance and support. There is no theoretical citation as to why this should be the case, however.

- **Group Tone:** ("The emotional atmosphere of the group at any particular point and includes three subscales as follows: a) light to heavy b) comfortable to anxious c) attentive to bored.") The older group became bored much less frequently than the younger. They did not differ on the other two subscales. Without being privy to the content of the study groups, it is impossible to suggest the reasons for reduced boredom in the older group. Proposing that older people have more pressing concerns would be trite. Perhaps less so would be the suggestion that the younger group members, feeling themselves unique in their problems, may effect an air of boredom to protect against difficult material, while the older group members identify personally with the concerns.

Lakin, Lakin and Constanzo’s (1979) remaining dimensions were not observed to differ between older and younger groups and, it perhaps being equally important to acknowledge areas in which there are not differences, these dimensions are listed below. As above, the descriptions in italics are taken from Lakin (1988):

- **Subgrouping:** “A “teaming up” of three or more members, usually in solidarity vis-à-vis a position, but also against an individual or another subgroup.”
- **Normative behaviours:** “include rule making, evaluations of others, and prescriptive statements (as in “shoulds” and “shouldn’ts”) and group standards of behaviour”
- **Organization behaviours:** “include attempts to lead, change of focus or direction, and attempts to assign roles or functions to others, or to assume a chairperson role.”
- **Establishing personal significance:** “includes bids for recognition. It is coded whenever one boasts or brags (ie recounts personal achievements or cites family status) or claims attention for a personal attribute, skill or possession.”
- **Support behaviours:** “are verbalized sympathetic or empathetic utterances in the form of agreements with other members or emotional support for them.”
- **Group to leader:** “is coded for questions or requests for direction. It may be taken to indicate relative group autonomy or degree of dependence on the leader.” Lakin mentions, vis-à-vis **Leader to group**, that the older group demanded more leader guidance, however this is **Group to leader** behaviour, by definition. It is unclear whether the group difference was one of variation in demand for guidance or variation in the amount of unsolicited guidance from the leader.
This study provides empirical evidence for the differences and similarities between non-pathological groups of older and younger adults. It could be argued that a study of clinical populations would provide more relevant information upon which to base one's own practice, however it could be that older adult group membership is more heterogeneous (Burnside, 1978) in that clinical populations likely to be selected for, or referred to, groups could be quite unique in their clinical profile - that the members of a group may have an array of difficulties both psychological and physical which would make generalisation from a study of such a group very difficult. Extrapolation from a non-clinical population may therefore be more useful.

Having examined ways in which groups comprised of older people may benefit in similar ways from those for younger groups, and ways in which older people's use of such groups may differ, it remains to examine the ways in which these observations impact upon the practice of group therapy for older people.

**Practical Considerations**

Altholz (1978) points out that while older people are subject to similar issues as younger adults in group therapy, they are more likely to undergo the consequences of such issues alone as a result of isolation and a diminishing social network, as well as less familiarity with psychological services and with the sort of issues which can be addressed with such assistance. Group therapy therefore may offer older people, who are less likely to enjoy the benefits of social support, the opportunity to benefit in the same way as younger people from such a process. The literature seems to support the claim that group therapy is indeed an effective technique with most of the problems presented by older people. However, Altholz points out five areas of consideration when planning group therapy for older clients.

The first area to consider, and one which could be argued to be important for any therapeutic intervention, is the purpose of the group. It is suggested that a frequent reason is to put an end to otherwise endless and unproductive individual work, although this appears to be purely speculative. Equally is the suggestion that group work be undertaken because that is what has always happened in this day-centre, hospital, or nursing home. However, reasonable indications for group therapy can be found by looking at the people within the service or area. By surveying the client group or waiting list, reasons for such an approach may become apparent such as a number of people who would benefit from the socialization and universalization of shared issues.

The composition of the group is identified by Altholz as particularly critical when the group members are older and subject to the consequences of ageing. She stresses that
simply seeing a group of people as “old” does not imply that there is anything which could reasonably be expected to define a sound therapeutic group - falsely assumed homogeneity. Nevertheless, it is easy to carry one’s reaction to such false assumption to equally questionable conclusions: Lewis (1977) describes the composition of groups in which ages are mixed from teenagers to people well beyond retirement which are intended to reduce the sense of isolation felt by the older members. It could similarly be argued that age-equivalent fellow-members provide both a sense of value in age and peer-group identification.

In terms of gender, it is suggested that the default assumption be that mixed gender groups function better for reasons of increased opportunities for socialization due to an environment which is reality-oriented, and that single-sex groups should only be coordinated in order to address gender-specific issues. The question of degree of gender mix, however, is a little difficult to address if one considers the increasing proportion of females compared to males with advancing age. If the group composition is to be a realistic portrayal of the age-specific demographic norm, females will significantly outnumber males in the “older old.” With groups of older people, it will also be necessary to consider physical disability - both in terms of environmental adaptation and the mix of disabilities (for example, involving members with hemiplegia affecting the mouth and those who are moderately deaf would have implications for the ability to communicate.) Communication, including the ability to put cognitions and affect into words, is probably the most significant variable when considering group composition, and with older people this is more likely to be affected by physical complaints than with younger people.

With these few practical considerations, and with those observations of Lakin, there seems to be no reason why group therapy should not continue to be beneficial for people as they become older. Indeed, Altholz suggests one reason which is unique to older people, and that is the lack of an accepted role other than the rather limited one of grandparent. She states that as we become older certain questions are raised for which there are no immediate answers, but which may usefully be addressed within the forum of group therapy (Altholz, 1978) [spacing added]:

“What contributions, if any, are the elderly to make to society? How are old people supposed to act and what are they to talk about? How are they to relate to those persons around them, both younger and older? And perhaps most important, how are they to feel about themselves?”

The persons who can most appropriately help define a role for the aged are the aged themselves.”
References


To what extent can people with a learning disability benefit from the full range of psychological therapies that are used with the general population?
...empathic human contact at a fundamental emotional level can be made with the vast majority of people and...this in itself may be therapeutic (see Decker, 1988). Therefore it simply remains to adjust and apply the techniques in which each practitioner is skilled to the problem being presented at the level at which it can be usefully accepted.”

Waitman & Conboy-Hill (1992)

John Scibak (1983) describes how conceptualisation of mental retardation [sic] has moved from an emphasis on biological factors and psychometric performance to one of behavioural deficiencies and excesses, resulting in a focus on behavioural approaches to treatment. Many studies have evaluated the outcomes of such an approach with a learning disabled population, demonstrating significant levels of success - “In all of these investigations, emphasis has been placed upon the systematic observation and measurement of human behaviour, rather than on the postulation of some hypothetical construct, personality trait, or other intervening variable.” (Scibak, 1983). It is curious to consider which hypothetical constructs or intervening variables it is here being tacitly suggested are less valid to utilize with a learning disabled client, but nevertheless it would seem to be true that the predominant approach, for whatever reason, with this population is indeed behavioural.

This essay will consider a number of different treatment approaches used with the general population in turn, including cognitive-behavioural therapy, and individual and group psychotherapy. However, behavioural approaches will be described first, for two reasons: It is indeed the approach of choice with many therapists, and it is not exclusively reserved for learning disabled people, being as effective with people who are not learning disabled. For clarity of expression, the term ‘the general population’ will be used, erroneously, to describe the population of people without a learning disability.

**Behavioural approaches**

Behavioural approaches to treatment consist of the application of learning theory to modify, accelerate or decelerate, specific behaviours - behaviours such as compulsive gambling, self-harm or smoking. They are largely based on Skinner’s (1938) principles of Operant Conditioning in which the probability of a behaviour occurring is affected by the consequences of that behaviour. Such consequences may fall into one of two
categories - reinforcement and punishment - the former being any consequence which increases the probability of that behaviour occurring again, and the latter being any consequence which decreases the probability of reoccurrence. Both of these categories may be divided further into positive and negative types - positive when the consequence involves the application of an element, and negative when the consequence involves the removal of something. As examples, positive reinforcement could entail giving the person a sum of money, while negative reinforcement could entail the removal of a debt; positive punishment could involve the administering of an electric shock, while negative punishment may involve the removal of certain privileges. These consequences may occur randomly, or according to certain schedules such as ‘Fixed Ratio’ - in which an unvarying number of responses be performed before the consequence occurs, ‘Variable Ratio’ - in which the number of necessary responses varies about a mean value, ‘Fixed Interval’ - in which a fixed interval of time passes before a consequence occurs as a result of a response, and ‘Variable Interval’ - in which the duration of the interval varies about a mean value. These principles are used in various ways and combinations to effect the desired behavioural change, and to understand ways in which undesirable behaviours come about and are maintained.

Such approaches may be used with any organism regardless of linguistic ability or intelligence, however they are far more widely used with people with learning disabilities than those without. This may be a result of the fact that the proportion of learning disabled people who are non-verbal is much greater than that proportion of non-learning disabled people. United by the shared label, learning disabled people may therefore be appraised in the light of this skew - reduced verbal power being assumed to indicate non-verbal interventions, of which a behavioural approach is the most obvious. Also, these techniques may be mastered by direct care staff and may be implemented immediately upon the problem being presented. Thus the use of such techniques enables staff and carers to be empowered and respond constructively to a possibly threatening or distressing situation. It could be argued that weekly psychotherapy sessions with a client and psychologist would leave staff and carers feeling helpless and underequipped to deal with challenging situations.

Behavioural approaches are probably most widely used with people with learning disabilities to address the problem of challenging behaviours - those behaviours which are of ‘such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to and use of ordinary facilities’ (Emerson et al, 1987). This may be for the reason described above of empowering care staff, or because the intervention, once in place, is immediate, if correctly implemented, which would be felt to be necessary in the case of harmful behaviours. Also, with a less able person, problems such as anxiety, depression, bereavement reaction and so on are more likely
to manifest behaviourally as the person may be unable to identify such feelings, may not know how to deal with such feelings, or may be frankly unable to deal with such feelings - for example by not having the ability to talk through frustrations. The reason that such disorders tend to be treated behaviourally for a learning disabled person may be that the symptoms - challenging behaviours - are so much more salient or accessible than the underlying problem. It may be considerably easier to identify causes of, say, anxiety in an able than a less-able person and until such causes are identified, they may not effectively be addressed. Nevertheless this begs the question of the efficacy of treating symptoms while failing to address fundamental causes - anxiety manifested as head-banging may manifest as pica once the head-banging has been ‘effectively’ dealt with.

**Cognitive-Behaviour Therapy**

Behavioural principles such as those outlined above are often used with the general population, for example such an approach may be utilised in a programme to stop smoking, alcohol abuse, or indeed, it may be argued, such principles may operate to ensure reattendance at sessions with a different focus. However, when behavioural techniques are used with the general population they are usually accompanied by cognitive elements. For example, during such a treatment for depression behavioural strategies may include activity scheduling (positive reinforcement) and graded task assignment (a form of chaining), but these will be used alongside cognitive strategies such as identifying, questioning and testing negative automatic thoughts, and distraction. It would be unusual to discover a client in the general population who was treated with a purely behavioural approach; most of the more frequently presenting complaints such as panic, depression, compulsion, substance misuse and sexual dysfunction are all, if addressed behaviourally, additionally addressed from a cognitive perspective. Perhaps one reason for this may be summed up by an occupational therapy assistant to whom I was teaching behavioural approaches - her point was that she wouldn’t want this approach to therapy “done on” her as it would be an affront to her free-will. Could it be that therapists would want to feel a part of their own treatment, to have the opportunity to choose whether or not to take part in the intervention, and so allow, indeed assume, similar needs and desires in their clients? If they do, the question remains why such an assumption is not made with the client with a learning disability - that therapy is “done on” rather than done with.

The most immediate reply to this may well be the objection that many learning disabled people do not possess the intellectual sophistication to, for example, monitor and identify negative automatic thoughts or challenge dysfunctional assumptions, or indeed to allow the therapist insight into the cause of the overt sequelae. Simple cognitive
strategies such as distraction may seem more attainable, although identifying when to use this strategy, knowing when one is ruminating, could be seen as more sophisticated. The answer to this objection, one may propose, is that with a population of people with such a range of intellectual ability, it is unhelpful, unfounded and unreasonable to make assumptions about the level of sophistication of a particular client, and that when selecting a particular therapeutic approach one should be led by the abilities of that particular person.

Individual Psychotherapy

Chris Cullen (1992) upon studying the literature found a distinct paucity of psychotherapy for people with learning disabilities, despite his having found in his own work that many people with even mild learning disabilities have a great deal of trouble distinguishing emotional states. In order to address possible reasons why psychotherapy is often not considered a viable option for learning disabled people, it will first be necessary to discover what people think psychotherapy is:

Edward Nuffield (1983) provides a number of definitions of psychotherapy as follows:

“...a certain kind of social relationship between two persons who hold periodic conversations in pursuit of certain goals; namely, the lessening of emotional discomfort and the alleviation of various other aspects of client behaviour.” (Shoben, 1953)

“...a face to face relationship in which a psychologically trained individual is consciously attempting by verbal means to assist another person to modify emotional attitudes that are socially maladjustive and in which the subject is relatively aware of the personality organisation through which he is going.” (Snyder, 1947)

“...a systematic utilisation of psychological techniques, the chief of which is a close interpersonal relationship by a professionally trained therapist in order to help individuals who seek or need assistance in the amelioration of emotional or behavioural problems.” (Bialer, 1967)

The first and second of these quotations are from the middle of this century and both, although they do draw attention to the importance of the relationship, underline the therapeutic vehicle of ‘conversation’. Possibly, the greater proportion of learning disabled people without language than in the general population may cause therapists to discount such ‘talking cures’ sweepingly across the former population; or, as above in
the section on cognitive approaches, levels of intellectual sophistication may be unreasonably assumed to be too low to accommodate the cerebral exercise of psychotherapeutic debate.

The third of the above quotations, however, from Bialer (1967), does not presuppose the necessity of verbal exchange at all, stressing instead the importance of the nature of the therapeutic relationship. Thus, psychotherapy need not necessarily be seen as an intellectual pursuit. Just as Cullen identifies the emotional needs of learning disabled people, so psychotherapy may be seen instead as an emotional vehicle which may therefore be used by people with little or no language. Also, the lack of language may not validly be equated with the lack of communication - therefore a person with reduced language ability may/will still be imparting a great deal of important information during a psychotherapy session if given the opportunity to do so and a therapist skilled in interpreting such non-verbal communication. Nuffield (1983) suggests art, music, dance and movement therapy as ideal vehicles for communicative expression, and also cites Cowen (1955) who provides a checklist of essential ingredients for successful therapy:

1. A person who seeks psychological help,
2. the presence of a unique client-therapist relationship,
3. an opportunity for the release of emotional tension,
4. the presence of a consistent body of therapeutic techniques, and
5. the impact of non-verbal aspects of therapy and the personality of the therapist.

In order for psychotherapy to be inappropriate, therefore, one or more of these items must be missing from the therapeutic situation. It is pointed out that with a learning disabled person, it is often the carer who seeks help on behalf of the client, and so item one may not be fulfilled; however, a client whose behaviour is such that the carer seeks help may be argued to be seeking psychological help in one of the few ways available. Besides, Nuffield (1983) points out that failure to fulfil item one does not preclude a successful outcome. Regarding the remaining points, it is clear that the onus is as much if not more on the therapist than on the client to ensure the presence of the other items.

Both Cullen (Waitman & Conboy-Hill, 1992) and Nuffield (1983) point out that learning disability and emotional disorder can coexist, often being due to common causes but also the latter arising from a combination of the former and life-stresses; life-stresses which may take more of a toll on people who are less able to cope with the distress. Given the lack of valid reasons why psychotherapy should not be indicated in these instances, it is surprising how infrequently this approach is used.
Group Therapy

Group therapy may be more common for learning disabled people than individual psychotherapy, but just as there is a tendency to fail to provide individual psychotherapy for this population, it could be argued that the nature of the group therapy itself is less psychodynamic than for the general population. However, all of the above considerations will apply to group as well as individual therapy.

Nevertheless there are reasons why group therapy may be especially useful for people with learning disabilities, as outlined by Nuffield (1983): One of the main aspects of group work is the bringing together of individuals with significant commonalities, and according to Nuffield, the two factors of 'retardation and institutionalisation' give many learning disabled people a lot in common. It is hard to know what to make of this suggestion; on the one hand it is clear that both features are probably very significant in the lives of the individuals, but on the other hand it could be objected that they could be irrelevant to the problem presented by particular people. The extent, however, to which these two features could be irrelevant to a particular sphere of the life of a learning disabled person is probably fairly small, although the question of whether the members of such a group wish to be united by these things remains.

The assembly of such a group may benefit the members by encouraging self-expression without fear of chastisement by care-staff and by encouragement of the acceptance of a peer-group, as well as by providing a means by which the presenting problems may be addressed. Sheila Hollins (1992) points out that members may benefit from improved interpersonal relationships, coming to accept personal limitations and increasing social adaptation by their own acceptance of themselves.

So there is some agreement that group therapy may be beneficial to learning disabled people. There should be differences, or allowances, though, as outlined by Szymanski and Rosefsky (1980): Communication should be concrete and possibly based on illustrative examples. New topics should be dealt with step-by-step and by structured questioning, although unstructured questions are equally important - overall, communication should be commensurate with the verbal abilities of the group members. It should be considered that long periods of silence may not necessarily reflect resistance so much as the members not knowing what to say. Careful guidance should enable the members to deal with silences as they occur in future. Similarly, changes of topic may not reflect resistance, arising instead from egocentricity and lack of conversational skill. The question of whether the facilitator(s) should be directive or non-directive should also be based on the ability levels of the members of the group.
Discussion

An assumption has been made throughout this essay that people with a learning disability are not offered the full range of psychological therapies which benefit the general population. There are two possible reasons for this: a) that a proportion of learning disabled people are not able to benefit from certain approaches as a result of being unable to assimilate certain key features of those approaches and, as a result, statistical studies show that overall, learning disabled people benefit less from those techniques; and b) that a) above may not be true for a particular person, but that the therapist's choice of approach is affected by an awareness of this skew in intellectual sophistication - in a sense, that conscious or unconscious stereotyping processes influence the therapist's decision.

Another, more service based, reason for such approaches not being used, or being used less, could be that a diagnosis of learning disability forces a person to be served by a specialist learning disability service. Agents of that service, as a result of the spread of intellectual ability described above, are likely to be more skilled in approaches which may benefit all of the people they meet than those which may only benefit the x per cent of higher ability. It is not unreasonable for professionals to choose that approach with which they are most experienced.

However, there seems to be plenty of evidence in the literature that many of the psychological therapies used with the general population may, even in an amended form, be appropriate for learning disabled people too.
References:


Clinical Section
Introduction to the Clinical Section

As components of my training, I have undertaken and successfully completed four core and two specialist placements, each lasting six months and involving a commitment of three days per week. These placements have been as follows:

1. **Adult Mental Health Core Placement**
   Supervisor: Frank Milton, Chartered Clinical Psychologist
   Location: Kingston and District Community NHS Trust, Kingston Hospital.

2. **People with Learning Disabilities Core Placement**
   Supervisor: Jill Moorhouse, Chartered Clinical Psychologist
   Location: East Surrey Learning Disabilities and Mental Health Services NHS Trust.

3. **Child, Adolescent and Family Core Placement**
   Supervisor: Rita Harris, Chartered Clinical Psychologist
   Location: Kingston and District Community NHS Trust, 84 Ewell Road, Surbiton.

4. **Older Adults Core Placement**
   Supervisor: Ajay Kapoor, Chartered Clinical Psychologist
   Location: Heathlands NHS Trust, Farnham Road Hospital, Guildford.

5. **Mental Health Services for Deaf People Specialist Placement**
   Supervisors: Chris Gilleard, Chartered Clinical Psychologist & Director of Psychology: Issues of Clinical Psychology
   Sally Austen, Chartered Clinical Psychologist: Issues of Deafness and Psychology
   Location: National Deaf Services, Pathfinder NHS Trust.

6. **Child Health Psychology Specialist Placement**
   Supervisor: Sarah Waugh, Chartered Clinical Psychologist
   Location: Paediatric Department, Kingston Hospital. Kingston and District Community NHS Trust.

Copies of the contracts associated with these placements may be found in the appendix of this Clinical Section. The rest of this section comprises abstracts of five clinical
reports submitted in full in the accompanying Clinical Volume. Further details regarding these placements such as client contact details and evaluation forms are also lodged in the Clinical Volume.
Ms D was a twenty-nine year old woman referred to the psychology department by her GP as a result of increasingly intrusive panic attacks. She had been prone to such attacks for many years, but they had recently become more severe following an incident in a local shopping centre when it had to be evacuated as a result of a bomb alert. Symptoms of these attacks included palpitations and tremor, for which she was prescribed propranolol, her stomach would well up, her heart race, hands sweat, and she would feel distant and dizzy.

Perhaps most striking from Ms D’s history was the high incidence of anxiety-based complaints in her friends and family. Her mother was reported as particularly phobic of flying, her father and her fiancé’s mother were obsessively tidy, and her sister and boss’s wife also suffered from panic attacks. There appeared to be no significant life events occurring at the time which may have precipitated increased anxiety levels, and from the assessment it appeared that she fitted very well Clark’s (1986) cognitive model of panic in which a trigger stimulus is perceived as a threat, which precipitates apprehension and its concomitant physiological changes, which are then misinterpreted as catastrophic and therefore threatening and so on. Ms D had identified certain environments which were more likely to lead to a panic attack and these were identified during therapy as leading to thoughts that she would be unable to escape in the event of an emergency and that she was therefore in danger. These places also gave rise therefore to increased apprehension that a panic attack would occur, leading to hypervigilance regarding symptoms of an impending attack (which were also symptoms of apprehension). Ms D had learned that she could avoid risking an attack by avoiding those places identified as being precipitative; this list was extensive including the second floor and above of most buildings, lifts, buses, tubes, and becoming stuck in traffic.

A possible reason for the initial onset of the attacks was identified as the likely modelling of avoidant behaviour and fear by close relatives and friends, consistent with Bandura’s social learning theories (Bandura, 1972).

Treatment involved four hour-long weekly sessions aimed at rationalising the symptoms of apprehension and panic and also associated automatic catastrophic
thoughts as identified from charts completed between sessions. During the fourth session the theory behind re-learning about the threatening situations by way of systematic desensitisation was discussed and a hierarchy devised of a variety of situations placed on a graded scale of threat from 0 to 100. Six further sessions were then implemented during which Ms D was supported in gradually tackling the hierarchy of situations (between sessions) and in which she was taught relaxation and distraction techniques appropriate to her interests. Each session began with a discussion of the homework, and a re-rating of the practised situation for perceived threat then.

Six further sessions targeted at anticipatory anxiety for imminently occurring situations enabled Ms D to prevent herself from becoming increasingly fearful about such situations, and consolidated her understanding of the model such that she could use it in the future, should the need arise. During the final few weeks, the number and severity of her attacks dropped to manageable proportions, and Ms D stopped taking her medication.

References:


Richard K was a thirteen year-old boy who was referred by the family GP as a result of increasingly aggressive outbursts at home. Richard had also recently been excluded temporarily from school and it was felt by the family that the response of the school had been unreasonable.

The family consisted of Mr and Mrs K, Richard - aged 13, and David - aged 11. The two boys had been adopted by the family soon after birth, Richard first, followed two years later by David. Mrs K had been received into care at the age of 2 along with her two sisters and at the time of referral had five nephews and nieces through these sisters but was unable to have children of her own. Mr K was an only child of reportedly "regimented" and "Victorian" parents, and was said by his wife to have found the decision to adopt quite difficult. It was initially hypothesised that Richard's adoption may have been compounding the natural difficulties associated with entering adolescence (Kotsopoulos et al, 1993; Lipman et al, 1992) and that this seeking out of a new position within the established framework of the family was leading to conflict.

Following the two assessment sessions, this hypothesis was modified to include the observation that Mr and Mrs K preferred quite different styles of parenting which reflected their differing childhood experiences. These differences were often manifest when they were required to present a united front to Richard or his brother, for example in the event of some transgression at home or at school and there appeared to be a degree of competition between them during the sessions. Richard and his brother would often side with their mother at these times.

Because the difficulties being experienced were considered to be a function of the interaction of all family members and their beliefs, and because it was felt to be particularly important by the therapist to maintain a position of neutrality within the therapeutic system, a Milan-systemic approach was considered most appropriate (Selvini Palazzoli et al, 1980). The sessions took place once every three weeks for six weeks and were supported by way of clinical supervision, rather than by a reflecting team. At each session, the family would (unbidden) bring along a topic for discussion and this would be explored by way of circular questioning. In this way hypotheses generated during supervision could be tested, and the beliefs of the various family members examined and challenged.
As the sessions progressed, however, the therapeutic emphasis shifted from Milan to a more structural approach (Minuchin, 1974) because it became difficult to explore the families' beliefs when their preferred focus was that of their interrelationships (examining the nature of the boundaries between subsystems.) It appeared that Mrs K had a rather enmeshed relationship with her sons, and that this was a position she worked hard to maintain. Manipulation of the therapeutic space was used in an attempt to challenge this structure. It also became clear that Mr K could not tolerate his wife dealing with incidents with the boys by herself, possibly as this challenged both his perceived role as father and his self-esteem. Throughout the duration of the therapy, Richard began to steal from his father and his father's friends. Mr K's friends became significant in the system, as they would collude with his helpless and quite depressive feelings towards his son (for example that he was "out of control" and that nothing could be done.) These beliefs served to protect Mr K from his own feelings of inefficacy as the locus of the problem was located in his son, rather than in his parenting, however, it also enabled him to absent himself from the care of his son, enabling Mrs K to join with the boys against him still further.

Therefore, the increasing parental conflict led to the boundaries for Richard becoming more and more ill-defined, and Richard then provoked his father into being stronger, more involved, and providing a secure framework within which he could enter adolescence. However, it was easier and less threatening for Mr K to retreat into helplessness, rather than to seem to amend and challenge his theories of parenting.

By this time it was felt that the therapy had unfortunately become stuck with the family, and that it was being used to further isolate Mr K. It was decided therefore to bring the sessions to a close and a variety of further options for help were given to the family to decide upon themselves. Mr K was particularly encouraged to enter individual therapy for his deepening depression. He never attended those sessions offered to him by the Adult Psychology Service, and the family were unable to decide at the time which option to take.

A year later Mr and Mrs K separated.
References:


Mr T was a 69 year old man referred to the Psychology Department by his Community Psychiatric Nurse because he was becoming increasingly angry at home. He was assessed by the Clinical Psychologist. Mr T had recently undergone a certain amount of upheaval, being forced to move house, and reported waking in the night and feeling guilty about a number of things. The Psychologist noticed that he seemed "fidgety" and found it difficult to stop speaking once he had begun, and also that he appeared absent-minded and had word-finding difficulties. A neuropsychological assessment was requested in order to rule out any organic cause of disinhibition, expressive and word-finding difficulties, and also his absent-mindedness, for example personality change consequent with the onset of dementia.

Over a total of four days, the following assessments were administered:

- A short form of The Wechsler Adult Intelligence Scale (Revised) (WAIS-R; Wechsler, 1981; Crawford et al, 1992) to estimate Mr T’s current levels of functioning.

- The National Adult Reading Test (NART; Nelson & Wilson, 1991) to provide an estimate of previous levels of functioning.

- The Digit Span subtest of the WAIS-R, to assess attention and working memory.

- The Middlesex Elderly Assessment of Mental State (MEAMS), as a gross measure of dementia, and to indicate possible specific deficits for further testing.

- The Adult Memory and Information Processing Battery (AMIPB; Coughlan, 1985) Information Processing A Form 1, to assess speed of information processing.

- The Wechsler Logical Memory Test (WLMT; Abikoff et al, 1989a&b), to assess learning and immediate recall of unfamiliar information.

- The Activities for Examining Practic Function (Lezak, 1983), to ensure difficulties on tests with a secondary loading on motor skills were not due to apraxia.
• The Benton Visual Retention Test (Benton, 1963), to ensure poor performance on the WLMT were not due to short-term memory problems as well as verbal memory problems in isolation.

• The Judgment of Line Orientation Test (Benton et al, 1978), to assess perceptual difficulties indicated by the MEAMS.

• The Purdue Pegboard (Tiffin & Asher, 1948) to assess motor speed more thoroughly than the AMIPB.

• The Nelson Modified Card-Sort Test (Nelson, 1976), to establish any tendency to perseverate (suggested by Mr T's conversational style and performance on the AMIPB.)

The results and specific discussion regarding these tests are provided in the Clinical Volume of this portfolio.

Mr T frequently became anxious about his performance, asking if it was normal, and seeking reassurance that a lot of other people had similar difficulties.

Overall, Mr T appeared to have specific difficulties with verbal material, indicated by a discrepancy between Verbal and Performance IQ on the short WAIS-R, and difficulties with the WLMT but none with the Remembering Pictures subtest of the MEAMS. Digit Span was also within the normal range. It was suggested that this distinction may indicate a difference in memory for verbal or non-verbal material, and/or a more specific difficulty with processing verbal material initially. Further, perceptual, difficulties were also indicated by performance on the Judgment of Line Orientation Test and the BVRT and these difficulties may be more severe with letter-forms than numerals, as distinguished by the Fragmented Letter Perception test of the MEAMS, and the AMIPB. No motor difficulties were indicated. Mr T used idiosyncratic strategies on the Block Design and Object Assembly subtests of the WAIS-R which pointed towards some difficulties with planning behaviours, which possible problems of executive function were further indicated by chaotic performance with the Nelson Modified Card-Sort Test and conversational style. However, the poor quality of the data obtained on these tests could not fully support this hypothesis.

It was suggested that there was insufficient evidence to support hypotheses of global deterioration such as from dementia. Specific verbal difficulties may have been long-standing, but changes in the social situation meant that previous coping strategies were increasingly ineffective. Further tests of executive function were recommended, with further individual work to develop more effective strategies for coping.
**References:**


Mrs F was a 70 year old retired auxiliary nurse, referred by the hospital Psychiatric Registrar because of a history of recurrent depression and anxiety. It was also requested that some work centre around Mrs F’s rude and angry outbursts to some ward staff.

She was historically a very independent woman, living alone following two divorces in a mobile home, and having a son and two daughters, one of which was very much like her - preferring to be “isolated” though sociable and being prone to depression if she did not keep busy. Mrs F’s first experience of depression followed an experience with her mother (to whom she was very similar, both working as nurses and being socially active, if independent) when her mother was becoming progressively less able as a result of dementia. Mrs F was charged with looking after her mother and witnessing her decline until she found it very difficult to cope and was advised to “lock her out” when her mother was discharged from hospital one time. The stress of this experience resulted in an admission to hospital for Mrs F for depression 15 years previously. She was again admitted in 1993 for depression following a cholecystectomy.

Mrs F’s believed that she was “ultra-independent”, that she should be in control of all aspects of her life and that she should not need to rely on anybody else for anything. Her sense of her own independence had been consistently reinforced by repeated exposure to people who were dependent upon her as a nurse, and by the role adopted regarding her ailing mother. It was hypothesised that this latter experience brought into focus rather dramatically Mrs F’s own mortality and the possibility of becoming dependent in the future (anathema to her). Her later operation also challenged these beliefs, and the current episode of depression and admission was coincident with Mrs F reaching an age which she had always said she would never reach - an assertion taken as denial of the possibility of deterioration with old age. While in hospital, she would adopt the role of nurse to avoid that of patient, and this blurring of boundaries was found by the nurses to be difficult to cope with.

Twelve weekly treatment sessions were initiated during which her beliefs regarding autonomy and independence were explored using the techniques of “downward arrow” (Burns, 1980; Beck, 1995) and “Socratic questioning” (Padesky, 1993). It was
necessary on occasion to enable Mrs F to acknowledge the loss of her former youthful self, and in a sense to mourn for it. This was assisted by Mawson et al’s (1981) principles of “guided mourning.” The approach taken to this treatment was very much to allow Mrs F to direct therapy by her own insights and behaviours, rather than by being cared for by the therapist. A few strategies were nevertheless given to Mrs F, for example pleasant event reminiscence and the challenging of negative automatic thoughts. Her mood and thoughts were monitored by way of weekly charts.

By the end of treatment, Mrs F had developed a more realistic sense of herself as a seventy year-old grandmother, and had gained a sense of satisfaction from doing things that were a little difficult for her now, rather than feeling angry that forty years ago those tasks would have been second-nature. From this her self-esteem increased and she allowed herself to be cared for, thus giving herself more time to find enjoyable things to do.

References:


Ms A was a 55 year old prelingually profoundly deaf Iraqi lady, who was referred to the service by her Support Worker due to a tendency to somewhat obsessively attend to the sequences of events in such a way as to enable exact re-tracing of them. This behaviour was becoming increasingly intrusive and the family had requested help as her brother (with whose family she lived) was due to retire soon, and so was likely to spend longer periods at home. This assessment formed part of a formal multi-disciplinary assessment to judge how the service may best address her needs.

Ms A had no formal education in Iraq and, although she had held down a job as a sewing machinist at one time, she did not work. Her occupation could best be described as helping raise her brother's family and take care of the house, though at the time of assessment she attended regular Basic Education classes at the local hospital for people with learning disabilities. Ms A did not use speech or wear a hearing-aid, and her lip-reading skills were minimal. She could communicate at a basic level by way of gesture and simple British Sign Language, and she was able to finger-spell a few simple words such as her own name (and those of her family.)

A background history was obtained from the Support Worker, who had known Ms A for six years, from Ms A herself, who explained the family structure, and from her brother. Further information was obtained from observing Ms A both at home and during Basic Education. It transpired that the home situation had changed considerably over the previous five years, with both of Ms A’s nieces leaving home, her sister-in-law taking up full-time employment, and Ms A beginning Basic Education classes. From these interviews it was hypothesised that because of her communication difficulties, she would have not been fully aware of these changes in advance of them happening, and would therefore have been unable to prepare for them. Such preparation would have reduced the anxiety surrounding the change (Carter & McGoldrick, 1989) but it was not possible. Ms A may have reacted to these changes (in both the environment and in her role within the family) by rigidly adhering to prescribed routines, thus ensuring a degree of consistency and predictability. As the number of people around the home during the day decreased, so her ritualistic sequencing behaviour was thwarted less and less, and the negatively reinforcing alleviation of anxiety correspondingly increased. This increase would have been
compounded by the decrease in demands placed on her by her previous role looking after her nieces.

Ms A's brother had voiced concerns that his sister was deteriorating intellectually, and it was not possible to rule this out from simply meeting with his sister, her abilities and behaviours being so heavily influenced by her deafness and lack of education. Indeed, intellectual deterioration could have explained her decrease in domestic behaviour, her sequencing behaviour increasing as her repertoire reduced as a result of being overlearnt, and so a formal assessment of her intellectual functioning was attempted.

No valid tools could be identified for assessing the premorbid functioning of a deaf person, and so the hypothesis regarding a possible dementia could not be proven or disproven at this stage. However an assessment of Ms A's current functioning was conducted in order to provide a clear picture of what could reasonably be expected of her, to see whether her current activity level around the home fitted with her intellectual presentation, and to provide a baseline for future testing. Because her ability was expected, because of her presentation at interview, to lie around the ranges of borderline or mild learning disability, and because no communication skills are required for its use, Ms A was assessed using the Leiter International Performance Scale. A signed administration of Raven's Standard Progressive Matrices was also used such that each result could be used to validate the other.

Her ability was identified as lying around the low average range, and so her domestic inactivity could probably not be fully explained by inability. A full domestic assessment would have been useful, but this was not possible.

From observation at Basic Education and at home, it was suggested that Ms A's behaviour had a negative impact on her family rather more than on herself, and that her family often colluded in the routines in order to minimise the impact they had on the other family members. At her education classes, Ms A was not systematically reinforced in this way, and the behaviours correspondingly had reduced. It was recommended, therefore, that the family not collude with the routines, and to maintain socially reinforcing behaviour at all times, rather than just during sequencing behaviour, as had been occurring previously. It was also suggested that Ms A be more fully occupied during the day, for example with further classes, and during the evening at home, to maximise her skills, and minimise understimulation.

Work with Ms A had to close before outcomes of these recommendations could be observed.
Reference:

Appendix to the Clinical Section
Placement Contract - Adult Mental Health

Name of Trainee: Jim Cromwell

Name and Address of Supervisor:
Frank Milton
Kenley Outpatients Department
Kingston Hospital
Kingston Upon Thames
Surrey
KT2 7QB

Dates of Placement: From 14th October 1994 to 1st May 1995

Date of Contract: 24th November 1994

The structure and content of the placement will be determined by the following guidelines:

Minimum standards for the placement will be as laid out in Appendix 23 of the Clinical Placement Handbook.

Experience with the client group will be guided by Appendix 24 of the Clinical Placement Handbook, regarding age, sex, ethnic/cultural issues, settings, client/problem areas, specialties, and number of clients. It is expected that the trainee will develop certain competencies, know about models of therapy, groups, assessment, and organisational issues, as per Appendix 24.

Overall, sufficient steps should be taken that it be reasonable to expect the trainee to reach the standard expected to pass the placement, and for the trainee to score either two or three on those points outlined on the Placement Evaluation Form (Appendix 6 of the Clinical Placement Handbook) under Supervisor - Trainee Relationship, The Development of Competency in the use of Scientific Method, Therapy and Intervention Skills, The Development of Professionalism, The Development of Awareness and Competence in Service and Organisational Issues, and The Shift to Work Being Grounded in Psychological Principles from Being Orientated in Relation to Specific Techniques.

It is the responsibility of both the trainee and the supervisor to be fully cognizant of these guidelines and to work within them at all times.

Signed:

Frank Milton
Chartered Clinical Psychologist

Jim Cromwell
Trainee Clinical Psychologist

* attached
Office space and supporting services will be available at Royal Earlswood Hospital Psychology Department.

The Psychology Department serves the hospital and the East Surrey area. East Surrey is divided into 4 Locality Teams and a service is provided to each locality by psychologists from the Department.

The Staff in the Department are:

Dr Veena Parmar  
Director of Psychology Services  
full time  
Caterham and Hospital

Ms Gina Ward  
p/t 8 sessions  
Horley, and Hospital

Ms Jill Moorhouse  
p/t 6 sessions  
Dorking Locality, 2 Reigate & Redhill Locality

Dr Monica Lawlor  
p/t  
Hospital based

Ms Joyce Webb  
full time  
Departmental Secretary

Mr Steve Ludlow  
p/t  
Residents Computer Manager

Ms Lisa Sheldon  
full time  
Hospital & Locality work psychology assistant

Ms Mel Davies  
full time  
Hospital & Locality work psychology assistant

Ms Claire Clifford  
full time  
Hospital & Locality work psychology assistant

Mr Adam Burley  
full time  
Hospital & Locality work psychology assistant

Ms Fiona Roberts  
full time  
psychology assistant  
Ellen Terry Day Centre  
(Challenging Behaviour Unit)

Mr Chris Catchpole  
p/t (Fridays)  
Computer Assistant
Weekly supervision will be provided by Jill Moorhouse on Thursdays from 2 - 4 pm. or at an alternative mutually agreed time. Other department members will provide case supervision where cases undertaken by the trainee come from their areas of work. Work load for the trainee will be monitored during weekly supervision sessions with Jill Moorhouse.

Aims of the Placement

This placement Aims to provide the trainee with clinical psychology skills to work with people with learning disabilities, and with the institution and service agencies which affect their lives. The overall aim is that the trainee will leave the placement with skills to work with and have understanding of the client group so that recognition of similarities and differences between other client groups encountered in their training will be possible.

Objectives of the placement

The competencies listed in Appendix 25 of the Psychology Clinical Placement Handbook will be used as a framework to achieve the Aims of the placement.

N.B. Item 4.3 In this placement the trainee will not be expected to keywork a client or chair a Multidisciplinary meeting.

Clinical Experience

Clinical experience will be gained working with people with a learning disability (clients) who:
1) Live at Royal Earlswood Hospital.
2) Live in group homes managed by several different agencies with East Surrey Area.
3) Who live in parental or their own homes within the area.

Experience of working with clients attending:-

1) A Social Services Managed Adult Centre (Colesbrook)
2) A Unit for clients with Challenging Behaviour (Ellen Terry).
3) A respite care facility run by the Trust (Daffodil).
4) An N.H.S. run work experience and day care centre (Horley Workshop)

Visits to these and other services within the area will be arranged if direct client work is not available in these areas.

The Trainee will have a two week induction programme which is timetabled and presented at the beginning of the placement. Following this period an introduction to cases and visits to other areas not covered during the induction period will be integrated.

During the Induction Period the Trainee will have a session with the Secretary where all administration matters will be explained. The Trainee will be expected to provide details of National Insurance Number for medical records recording system and an Insurance Certificate if a car is to be used for Trust business. This will be required within the first two weeks of the placement. The Trainee will be expected to provide the Supervisor and the Secretary with details of days of attendance at the placement including holiday periods booked to facilitate planning the placement.
The Trainee will be expected to attend a departmental meeting from 1 - 2 pm every Wednesday. The Trainee will be expected to attend the Open Forum held at the hospital at regular intervals where trust business is explained to all Staff Members. The trainee will be expected to feedback information from this at the department meeting.

The trainees will be expected to write clinical reports on all their cases, and summary reports for psychology files only where joint intervention or observation only work has been undertaken.

The trainee will be expected to work with 10 clients. There will be a mixture of assessment and intervention. Some experience of group work will be included. Clients will be drawn from adolescent young adult, middle age and elderly population. If possible there will be at least one client from each stage and a balance of male and female clients. One case where ethical issues arise will be incorporated as a joint case possibly with another profession if an individual case is not possible. There may be clinical work where the focus is a child with a learning disability.

Clients will be drawn from mild, moderate, severe and profound or multiply disabled groups.

Clients needing intervention from the following areas of need will be included in the trainees experience: Challenging behaviour, issues of sexuality, issues of loss and transitional issues and interpersonal relationships. Placement issues and support to carers will be incorporated. Skills training and computer assisted learning with clients will be carried out.

Opportunities will be provided for the trainee to liaise with other professions and disciplines to increase their understanding of a comprehensive service to people with a learning disability.

Signed: 
Jill Moorme

Signed: 
Jim Cromwell

Date: May 1995
Trainee: JIM CROMWELL
Supervisor: Rita Harris

1. AIMS

To gain clinical experience of children, adolescents and their families and to develop an understanding of the contexts in which they live. To develop skills in assessment, psychological formulation, and be able to select and implement appropriate interventions. To develop an understanding of the professional systems and procedures in working with children and young people, and the ways in which services for this client group may be provided.

2. OBJECTIVES

a. To observe and work with children, young people and their families, to develop an understanding of the different needs of each age group.

b. To gain an understanding of the network of professionals and other carers involved in working with young people and the implications of this for the role of the clinical psychologist.

c. To observe others working directly with adolescents and their families using a systemic model.

d. To observe and work with other professionals with young people.

3. CLINICAL WORK

a. To develop interviewing skills with children, young people and their families.

b. To have direct experience of working clinically over a period of time with six to eight children, young people and their families. Clinical experience will include:

continued/...
a range of approaches to assessment and treatment.
* a range of presenting problems
* a range of ages (0 - 5 years / 5 - 11 years / 12 - 19 years)

4. **OBSERVATION & INDIRECT WORK**

   a. Visits to other professionals working with children and young people, including health visitors, educational psychologists, school nurses, and a visit to a day nursery.

   b. Observation of supervisor and other members of the psychology team in clinical work and other professional activities, e.g. case conferences.

   c. Where relevant, attend network meetings.

   d. Attend meetings with health visitors and school nurses.

   e. Allocate time to reading material in relation to clinical work on placement.

5. **TEACHING & TRAINING**

   a. To observe and assist other psychologists in a teaching role.

   b. To present a topic to the Child & Adolescent Speciality.

6. **PROFESSIONAL**

   a. To attend weekly supervision.

   b. To attend speciality meetings and departmental meetings (where possible).

   c. To keep accurate and up to date records of clinical work.

RITA HARRIS

JIM CROMWELL
CONTRACT

Older Adult Placement: 25/04/96 - 04/10/96

Trainee - Jim Cromwell
Supervisor - Dr Ajay Kapoor

We undertake to work collaboratively to ensure that this core Older Adults Placement at Heathlands Mental Health, NHS Trust, fulfils the criteria outlined under “Evaluation of the Trainee on an Older Adult Placement - Draft, July 1994” in the placement handbook. This collaboration should be sufficient to ensure ratings of either 2 or 3 for the trainee on all aspects specified in the handbook - specifically:

- The development of competency in the use of scientific method.
- Therapy and intervention skills. The trainee would also benefit from direct observation of the supervisor during sessions with his own clients.
- The development of professionalism.
- The development of awareness and competence in service and organisational issues.
- The shift to work being grounded in psychological principles from being orientated in relation to specific techniques.

It is also highly desirable that the trainee undertake direct clinical work with an adult survivor of childhood sexual abuse.

Signed: [signature]
Date: 25/04/96
(Traineee)

Signed: [signature]
Date: 04/10/96
(Supervisor)
SPECIALIST PLACEMENT CONTRACT

This contract outlines the needs of the trainee such that they may be highlighted and addressed during the placement. The trainee and supervisors will seek to address the following aims:

1. i) To gain an increased understanding of Deaf culture.
   ii) To gain insight into the psychological aspects of deafness.

2. To develop an expertise in the psychological and psychometric assessment of deaf people.

3. To increase knowledge, through both clinical work and discussion, of how deafness may influence therapy and therapeutic approach both directly and indirectly.

4. To explore the effects of using interpreters on the processes of psychological assessment and treatment.

5. To further consolidate existing clinical skills in cognitive-behavioural and systemic approaches to assessment and treatment.

6. To gain experience of other psychological approaches, as available, for example to observe brief dynamic psychotherapy (if possible) and the reflecting team of the family therapy service.

7. To gain an understanding of the defining features and differences of work in a tertiary service, and how the specialist nature of the service influences this.

8. To have direct clinical involvement with an adult survivor of childhood sexual abuse (course requirement).

Signed: ____________________________ (Trainee)  Date: 20/4/96
Signed: ____________________________ (Supervisor)  Date: 23/4/96
Signed: ____________________________ (Supervisor)  Date: 29/11/96
Specialist Placement Contract (Child Health)

Trainee: Jim Cromwell  
Supervisor: Sarah Waugh  
Department: Department of Clinical Psychology  
             Child, Adolescent and Family Service  
             Elm House  
             84 Ewell Road  
             Surbiton  
Base: Kingston Hospital, Paediatric Department  
Start Date: 16.04.97  
End Date: 30.09.97  
Supervision: Wednesdays, 9.00am.

Overall aim of the placement:

To provide experience of working as a psychologist within a paediatric hospital service. This is intended to provide a contrast to working exclusively within a psychology department, to provide experience of working cooperatively with medically-oriented professionals, and to provide an experiential background to the trainee’s ongoing research project.

Method:

1. To involve the trainee in multidisciplinary team meetings within the Paediatric Department, mainly the Diabetes and Cystic Fibrosis Teams, but also involvement in other groups such as the chest clinic and the endocrine clinic, and a visit to the neonatal unit.

2. The trainee will observe the supervisor during paediatric psychology assessment mornings, going on to conduct similar assessments independently.

3. Independent client work will be carried out as agreed by the supervisor. Cases will be chosen which provide a breadth of experience of this area, for example, coping with chronic illness and its diagnosis, psychosomatic pain, fear regarding medical and health-related issues, and so on.

4. The trainee will design and complete a study investigating the opinions of adolescent patients on the paediatric wards in collaboration with the ward sister.
5. The trainee will visit Paediatric Psychologists in other hospitals, to provide a broader picture of work in this area.

6. The trainee will attend certain paediatric seminars, as relevant, as well as routine specialty and departmental meetings.

7. Clinical days will initially be Mondays, Tuesdays and Wednesdays, although this may vary to accommodate other meetings such as the Friday morning CF Team meeting or research pressures. Of those six clinical sessions, the trainee will ring-fence approximately one session per week for clinically relevant reading, for example regarding Cystic Fibrosis.

Signed:
Trainee: ____________________________  Supervisor: ____________________________
Date: 22.5.97  Date: 27.5.97
Research Section
Introduction to the Research Section

The Research Section of this volume consists of four pieces of work completed over the duration of the course. The first comprises a review of the literature regarding prelingual profound deafness - exploring the three theoretically distinct ways in which this may impact on psychopathology and observing actual discrepancies between hearing and deaf populations. This review was completed during the first year of training.

The second part provides an evaluative report of a piece of clinical group work undertaken during the child, adolescent and family core placement. The two groups focussed on social competence training for 6-8 and 8-10 year old boys and this is described in detail from conception to evaluation. This piece of work is intended to fulfil British Psychological Society requirements for a piece of research work to be completed whilst on a clinical placement.

The third piece of work forms the small-scale research project completed during the second year of training. This study examines the sensitivity and applicability of an observation scale for measuring the distress exhibited by children during stressful medical procedures, and is presented as a pilot study to a proposed piece of work investigating the effect of the presence of parents during the child’s recovery from general anaesthesia. This proposed study became untenable during the latter stages of the pilot study, was not therefore attempted and is not presented in this portfolio.

The fourth study presented in this section forms the main piece of research realised during training and was completed during the third year. It provides the main title to this portfolio. Following on from the pilot study above, this piece of work further explores the amended distress scale by assessing its validity, internal consistency, and underlying structure. It also explores factors proposed to influence the distress of children undergoing moderately painful medical procedures by investigating those predictor variables with established measures and distress with the amended instrument; the results of this exploration also provide a contrast between the amended and original versions of the scale. The introduction to this piece of work provides a comprehensive review of the constructs of anxiety, pain and distress.
Prelingual Profound Deafness and Psychopathology
Introduction:

**Introduction:**

**What is deafness?**

Deafness, partial or complete loss of hearing, may be described in a number of ways including severity, time of onset, and aetiology. The British Society of Audiology (BSA, 1988) provide audiometric descriptions of the severity of deafness as follows:

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Hearing loss (dB*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild deafness</td>
<td>20 - 40</td>
</tr>
<tr>
<td>Moderate deafness</td>
<td>41 - 70</td>
</tr>
<tr>
<td>Severe deafness</td>
<td>71 - 95</td>
</tr>
<tr>
<td>Profound deafness</td>
<td>96+</td>
</tr>
</tbody>
</table>

*dB loss in the better ear on pure tone audiometry, average across 250, 500, 1000, 2000, and 4000 Hz. The intensity of conversational speech lies within the range 60 - 70 dB.

Hearing loss may result from a number of different causes such as prenatal rubella, meningitis, prematurity, complications of Rh factor, ototoxic drugs, syphilis, mumps, Ménière’s Disease, and exposure to noise (Vernon & Andrews, 1990). Although, as shall be discussed, it is important to consider the aetiology of presenting deafness, the many causes may be divided into four categories as follows (O’Rourke, 1990): a) **Conductive** losses, which are those which result from a mechanical problem such as malformation of the ear. Because intensity at all frequencies is reduced, amplification can be beneficial. b) **Sensori-neural** losses which involve the cochlea and/or the auditory nerve and so affect fidelity as well as intensity, resulting in distortion. c) **Mixed** losses, which are those with both conductive and sensori-neural elements, and d) **Progressive** loss, which is a rare type that worsens over time (Freeman et al, 1981).

Lastly, and perhaps most importantly, time of onset has a significant effect on the degree to which the hearing impairment becomes a disability, in that severe or profound deafness occurring before one year of age can significantly affect the acquisition of spoken language (Hindley, 1993). Kitson and Fry (1990) state both the incidence and prevalence of prelingual profound deafness to be 1 per 1000. Following from Basilier's (1972) definition of ‘social deafness’ - ‘deafness which with the best hearing aids available (that the person will use) does not allow understanding of speech through the
ears well enough to take part in a brisk conversation’ - Kitson & Fry (1990) describe a more practical system of categorisation:

1. **Prelingual** (congenital or acquired before language development)
   a) Profound (no speech reception through the ears)
   b) Partial (some difficulty in speech reception)
2. **Postlingual** (acquired after language development)
   a) Profound
   b) Partial.

It is this classification which will be adopted below. However, when discussing the psychological implications of the impairment, it is important also to consider the cultural aspects of deafness, including the use of sign language, lip-reading or cued-speech, and membership of organisations for deaf people (Hindley, 1993). As has recently become standard practice, the essay will refer as far as possible to deaf people, who identify themselves as members of the deaf culture, as Deaf with a capital D, leaving deaf with a lower-case d for those people who may or may not identify with Deaf culture but do have a hearing impairment. It will be assumed that Deaf people communicate in a sign-language, while deaf people may or may not. Except where indicated, ‘deaf’ or ‘deafness’ will refer to prelingual profound deafness.

In this study of **prelingual profound deafness**, the question of whether there is a psychology of deafness, and what that means, will be addressed. The different ways in which deafness impacts on psychopathology will be discussed, and various responses or solutions to this considered.
The Impact of Deafness:

"Deafness before the acquisition of language [is] a greater affliction than blindness."

Helen Keller (1929)

A brief look at the literature pertaining to this field quickly gives the impression of deafness as a uniform condition, and of deaf people as an unvarying population. This is clearly not a true picture. However, as a result, it can be inferred that there is a psychology of deafness, distinct from that of hearing people, which either compares deaf with hearing populations, assuming hearing norms, or adopts norms of 'deafness' thus homogenising a demonstrably diverse group. Neither of these conclusions are particularly satisfactory. There are specific difficulties of cross-cultural study which will be outlined later, however, Cole (1991) provides a practical perspective in that

"What makes it possible to talk about a psychology of deafness is that for many Deaf people their experiences have a lot of important factors in common and we can study the psychological effect of these factors."

Cole proposes a model that assumes a normal development throughout childhood and adolescence, which is encroached upon by a variety of experiences associated with deafness. These experiences include the deafness itself, and so the model becomes, to the pedant, somewhat tautologous, however the above model, as a rule of thumb, is a useful maxim to adopt when thinking about the impact of deafness on psychology and psychopathology. This impact may reasonably be expected to take any of three forms: i) The aetiology of the deafness may bring with it further concomitant disorders or experiences, ii) the deafness per se may give rise to a describable psychological effect, and iii) the deafness may itself lead to an intermediate factor which results in a psychological effect. This essay will consist of an exploration of these three forms. It will become apparent that the distinction between ii) and iii) is impractical, and so will be discussed together (Aspects of Deafness.)
Concomitant effects of certain aetiologies of deafness:

It is estimated that 50% of deaf people are deaf as a result of trauma, and many of those are likely to have suffered some degree of brain damage (Kitson & Fry, 1990). Hindley (1993) describes how powerful the effect of brain damage is in the aetiology of psychiatric disorder, citing among others Seidel et al (1975), Shaffer et al (1975) and Brown et al (1981), and the means by which this effect may occur are described as:

"...impairment of intellectual function, specific learning disabilities, associated social disadvantage, social stigma associated with handicap, the effects of brain damage on temperament, and the effects of anticonvulsant drugs."

Hindley (1993)

Of these mechanisms, it can be seen that some involve the direct effects of brain damage, such as specific learning disabilities, while others are concerned with secondary results, such as the effects of social stigma or drugs. However, be they direct or otherwise, they are all means by which concomitant brain injury may impact on a person's psychological functioning. Vernon & Andrews (1990) describe how trauma which results in profound deafness can occur as a result of a number of conditions (described above) and these conditions may give rise to further problems not necessarily directly related to the deafness. Outlined below are two examples of such conditions:

Rubella.

During pregnancy, the otherwise fairly harmless rubella virus can have pervasive and traumatic effects. It quickly assaults the layers of embryonic tissue and reduces cell division in the developing body parts such as the ear, brain, eye, and heart. Vernon (1969) describes the prevalence of deafness due to rubella in his sample of 1,468 as 139, that is, 9.5%. In examining the IQ distribution of post-rubella deaf children, he identified a mean IQ of 95.3 with a standard deviation of 16.8, significantly less than the general population, and it is suggested that post-rubella deaf children do not succeed educationally as well as their deaf peers (Vernon et al 1980). Feldman et al (1971) distinguished an increase in aphasia among rubella-deafened children, which would also compound communication problems resulting from the deafness, and Chess (1977) identified an increased incidence of autism. Also implicated in rubella are psychosis and behaviour disorders such as poor impulse control, excitability, rigidity, distractability, instability, and emotional shallowness (Trapp & Himelstein, 1972; Chess & Fernandez, 1980; Vernon, 1969). Although these effects should be borne in mind, Vernon and Andrews (1990) stress the importance of realizing that the majority of prenatally rubella-deafened persons are, however, behaviourally within the normal range.
**Meningitis.**

Meningitis is an infection of the membranes surrounding the brain. It deafens between 3 and 10% of its survivors and is the leading cause of postnatal profound hearing loss (Raivio & Koskiniemi, 1978; Vernon, 1967a & b). Also, as a result of the introduction of antibiotic treatment, the proportion of those deafened by meningitis being so before the acquisition of language is increasing. This is because once the early symptoms may be verbalised, antibiotic treatment may be quickly instituted, whereas the prelingual infant may only be recognised as meningitic once the disease is somewhat advanced. Vernon & Andrews point out that at this stage, even if treatment enables survival, the chance of sequelae such as deafness is greater, especially as, unfortunately, some of the drugs used for treatment have ototoxic effects (Hindley, 1993.)

Vernon (1969) has found the mean IQ of post-meningitic deaf children to be 95, and that 34% had an IQ of less than 90. (He also states that from a study of 26 meningitic deaf children aged between 7 and 12 months, the mean IQ was 91.50 and the percentage of those 'mentally retarded' [sic], 34.6%.) It was also identified that 38% of the post-meningitic deaf sample had additional major disabilities including, in order of prevalence, aphasia, learning disability, emotional disturbance and cerebral palsy, and that these were more likely following an early onset. Of the 8.3% that were dropped from school for 'emotional disturbance', 29.3% had problems such as aggression, hyperactivity, poor impulse-control and distractibility, psychosis, or anxiety as a reaction to aphasia.

Other aetiologies which may have concomitant effects include prematurity and complications of Rh factor, which both appear to correlate with lower IQ, aphasia, and emotional disturbance, prematurity also being implicated in schizophrenia.

It can be seen from the above studies how the aetiology of a hearing impairment may itself increase the probability of further, psychological, problems, which may be considered in isolation from the deafness. That is, certain sequelae of a particular disorder may manifest in a person whether or not deafness is also indicated, and should not be interpreted as alleged 'symptoms of deafness.' However accompanying deafness must be acknowledged as it may influence the effect of that symptom, as well as the processes of assessment and treatment (see Implications for Services, below).
Aspects of Deafness:

Deafness per se:
A number of different authors have suggested that, among other things, concrete thinking, impulsivity, rigidity, and lack of insight, are the direct results of deaf enculturation (Altshuler, 1971; Misiaszek et al, 1985; Kitson & Fry, 1990.) The term coined by Basilier (1964) for describing these behaviours - surdophrenia - which literally translates as 'deaf mind' - suggests that such behaviours are characteristic of deaf people in general, but there are a number of reasons why the term is unhelpful (BC Swaans Joha, 1991):

- It implies that surdophrenia is a mental illness, and is therefore confusing.
- The criteria and characteristics are inadequate.
- The literal translation implies that all deaf people necessarily suffer from mental health problems.
- The deaf community find it offensive.

The surdophrenic condition was simultaneously described by Rainer et al (1963) as 'Primitive Personality' although Vernon (1978) uses this term to describe deaf people who have been inappropriately provided for, such as those who live dependently and overprotected with their parents and who, when those parents die, have to face the double trauma of bereavement and independent living for which they are not prepared. Although the label suggests a particular personality type, as well as being pejorative, Vernon's use of it implies a problem not of a personality type unique to deaf people, but of a failure to adequately provide for the specialised needs of the deaf person. Perhaps as a result of the over-representation of deaf people in mental illness hospitals (that is by a factor of about 10 - Denmark, 1966) or by the assumption that no speech indicates no language which indicates no thought (Cole, 1991), it seems as if there has been an assumption of a problem or personality type peculiar to deaf people. The literature seems to imply that this assumption is unfounded, for example Vernon's (1978) use of Primitive Personality above being read as service deficiency, or John Denmark's (1985) description of problems related to deafness: Denmark describes 250 patients referred to a specialist psychiatry department for deaf people, underlining the need for such specialised services. The problems of these patients are categorised into three types - those suffering from mental illness, those with problems related directly to deafness, and those with communication disorders (which will be discussed later.) Of the prelingually deaf people studied, all of the problems related directly to deafness were behavioural and adjustment problems resulting from the communication difficulties of being deaf in a predominantly hearing world and/or family. It would not be valid to infer from this that such adjustment problems were necessary sequelae of
deafness as there are certain other conditions the fulfilment of which effect the presence or extent of the problem; for example being raised in a predominantly oralist1 milieu, as Higgins (1987) demonstrates how deaf people from an oralist background are more likely to have a negative-self image, while those from Signing backgrounds are more likely to have a positive self-image.

Rather than supposing that deafness results in its own unique set of psychological problems, it may therefore be more constructive to look at how the experiences of deaf people differ from those of the hearing, and then it may be possible to deduce reasons for those differences.

**Comparative rates of prevalence:**

In order that one may examine such differences, to explore the possible effects of being born deaf on psychopathology, and to identify any clinical evidence for a psychology of deafness, it will first be necessary to examine rates of prevalence. Vernon & Andrews (1990) provide perhaps the most comprehensive analysis of the comparative prevalence rates of non-psychotic and psychotic behaviours between deaf and hearing people. The following is a brief summary. Where observation is based on research, this will be indicated, otherwise it may be assumed that it is based on Vernon's 1969 paper, or his clinical experience:

**Learning disability:** There is a similar distribution of IQ scores for both deaf and hearing populations, although Brill (1963) has shown genetically deaf people to have higher mean IQs than the general population. The main problem is one of poor assessment measures, as described later.

**Attention Deficit Disorders:** There is a higher prevalence of attention deficit disorders among deaf people, as a result of the brain damage or endocrine disorders associated with the aetiologies of deafness (Vernon, 1969).

**Substance Misuse:** Patterns of the misuse of drugs and alcohol are said to be similar for deaf and hearing populations. Hooten (1978) suggests isolation, unemployment and stress could lead to increased levels of alcoholism in deaf people as they are more prone to these, while Altshuler and Rainer (1970) propose that lack of depression (see below) would reduce the prevalence of drinking problems. Overall, the rates of substance misuse are no different from the general population.

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1 *Oralism* asserts a need for the deaf child to develop speech and to use any residual hearing, and insists that exposure to Sign Language retards the acquisition of spoken language (although there is no evidence for this - Kitson & Fry, 1990). Participation in Deaf culture is therefore seen as counter-productive (MacDougall, 1991).
Anxiety Disorders: Obsessive-compulsive disorder, anxiety, post-traumatic stress and phobias occur as frequently among deaf as hearing people.

Somatoform Disorders: According to clinical experience, these are no more prevalent in deaf than hearing populations.

Paraphilias: No research data exists on prevalence rates, but Vernon’s clinical experience suggests no difference between deaf and hearing people.

Disorders of Impulse Control: Impulsiveness seems to be found more often in those people who are deaf as a result of organic factors. Harris (1976) and Levine and Wagner (1974) showed that there is no more impulsiveness in deaf people who have early exposure to sign language, deaf parents, or high levels of academic achievement, so, a lack of these factors may raise the likelihood of problems with impulse control.

Paranoid, Schizoid, and Schizotypal Personality Disorders: There appears to be no increased risk of schizoid and schizotypal personality disorders among deaf people. Neither is there an increased risk of paranoid personality disorder despite there being significant mention of connections between deafness and paranoia in the literature, such as DSM III (Spitzer, 1980) and Cooper (1976). Cooper goes on to distinguish between pre- and post-lingual deafness, describing a clearer relationship between post-lingual deafness and paranoia - perhaps as a result of increased (possibly reality based) suspiciousness, or of misunderstanding (Kitson & Fry, 1990.)

Histrionic, Narcissistic, and Borderline Personality Disorders: Vernon and Andrews describe Histrionic Personality Disorder as being no different in deaf than hearing people, although they admit a lack of research data. Narcissism may have an increased prevalence among deaf people, but there is no explanation other than its possibly being caused by naivety. This naivety could reflect a number of the common experiences of deaf people outlined by Cole (1991) - lack of experience, lack of knowledge, and lack of incidental information being picked up which is critical to the development of what many would refer to as ‘common sense.’ The presence of Borderline Personality Disorder in deaf people does not appear to be mentioned in any literature, while its significant absence is described by Grinker (1969). It is stressed that this absence may be due more to diagnostic difficulty than nonoccurrence.

Avoidant, Dependent, Compulsive and Passive-Aggressive Personality Disorders: The social dynamics of deafness (which are not described) are said to result in a higher prevalence of both Avoidant and Dependent Personality Disorders among deaf people. Compulsive Personality Disorder is no more common, while Passive-Aggressive Personality Disorder is implied to be more prevalent as a result of failures of
communication with authority figures, leading to direct, impulsive ways of acting out (which leads to more trouble), which becomes a passive compliance with an underlying resistance. This seems a rational hypothesis, but, reasonably, the increased prevalence is only implied.

**Schizophrenia:** Kitson and Fry (1990) suggest that schizophrenic psychoses are found equally among deaf as hearing people, quoting Altshuler & Sarlin (1963), although they point out that there are no reliable figures - possibly as a result of problems in diagnosis. Similarly, Vernon and Andrews describe how the proportion of hospital admissions for deaf people for schizophrenia is about the same as for hearing (presumably meaning the proportion of deaf to hearing schizophrenic admissions is the same as the proportion of deaf to hearing people in the general population; the description is ambiguous.) However there are more deaf schizophrenic people in hospitals than hearing (Baslier, 1964) probably as a result of communication problems impeding the monitoring of treatment, and the concurrent misdiagnosis of paranoia or learning disability resulting in admission to more long-stay chronic wards. As an illustration of this, Timmermans' (1989) study found the average stay in hospital to be 148 days, while deaf inpatients remained for 19.5 years (Kitson & Fry, 1990).

**Depression:** Altshuler (1971) suggests that depression is rare in deaf people, possibly as a result of deaf children not being so exposed to parental and societal pronouncements, leading to a less developed super-ego and so less depression; that is, it is “suggested that hearing is required for normal development of object relations and conscience.” (Kitson & Fry, 1990.) Kitson and Fry go on to suggest that Deaf people with normal language development (in sign) do not appear to suffer delayed personality development, but that this population is too small to effectively study. Evans and Elliot (1987) suggest, also, that “contrary to a commonly held belief about deafness, depression is fairly common in our prelingually deaf patients, particularly in the self-referrals seen in our satellite clinics” - suggesting that referral and presentation patterns may mask depression in this population.

**Autism:** Autism has not been shown to be any more or less prevalent among deaf than hearing people unless the cause of the deafness was prenatal rubella, in which case the prevalence is 7.4%, compared to 0.7% for the general population (Chess, 1977; Chess & Fernandez, 1980.)

Certain themes are evident in this summary. Perhaps most striking is that, given appropriate assessment tools, there is no reason to suggest that prevalence rates for deaf people are any different than those for hearing people on at least a half of the above disorders, including schizophrenia, certain personality disorders, and anxiety.

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2 The use of inappropriate tools will be discussed later on (Implications for Services).
disorders. Of those that are different, two show reduced rates - possibly due to presentation rates and referral pattern, problems of diagnosis, or maybe developmental issues, while six show increases in prevalence - some as a result of common organic aetiology, and others as a result of social factors such as being overprotected or isolated, and frustrating failures of communication. Certain issues of neuropathology have been discussed above, and so will not be dealt with again here, however, the main explanation for certain prevalence rates would therefore seem to be the many different experiences associated with deafness which may impact upon issues of psychopathology. Cole (1991) collates these as follows:

**Deafness and background variables:**

<table>
<thead>
<tr>
<th>Age of onset</th>
<th>Degree of deafness</th>
<th>Speed of loss</th>
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<tbody>
<tr>
<td>Time of diagnosis</td>
<td>Deaf or hearing parents</td>
<td>Parental attitudes</td>
</tr>
<tr>
<td>Other problems...</td>
<td>Individual Character</td>
<td>General environment</td>
</tr>
<tr>
<td>(physical, intellectual etc.)</td>
<td></td>
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</tbody>
</table>

**Experiences:**

<table>
<thead>
<tr>
<th>Type of education</th>
<th>Attitudes of professionals</th>
<th>Attitudes of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Separation</td>
<td>Friendships</td>
</tr>
<tr>
<td>Information input</td>
<td>Deaf or hearing world</td>
<td>Stigma</td>
</tr>
<tr>
<td>Lack of experience</td>
<td>Lack of knowledge</td>
<td>Limited role models</td>
</tr>
<tr>
<td>Fear</td>
<td>Over protection</td>
<td></td>
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</tbody>
</table>

**Consequences:**

<table>
<thead>
<tr>
<th>Feeling rejected</th>
<th>Isolation</th>
<th>Lack of identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity confusion</td>
<td>Relationships</td>
<td>Fear &amp; anxiety</td>
</tr>
<tr>
<td>Depression</td>
<td>Lack of control / power</td>
<td>Hard work</td>
</tr>
<tr>
<td>Employment</td>
<td>Training</td>
<td>Self image</td>
</tr>
<tr>
<td>Self esteem</td>
<td>Confidence</td>
<td>Limited opportunities</td>
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<td>Limited social roles</td>
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The categorisation of certain items in these lists is debatable, for example some may argue that parental attitudes and time of diagnosis are a resulting experience, and indeed the distinction between experiences and consequences could seem a little arbitrary. However, they provide an excellent aide memoire for items which the professional should consider, and Cole describes how they relate as follows: “Background variables to do with deafness, the individual’s characteristics, particular family circumstances and the wider social environment interact to dictate the individual’s experiences, some of which can be influential in determining their psychological functioning.” She points out that many of these experiences emphasise disability and goes on to describe in detail how development may progress differently for a deaf person, which demonstrates quite clearly how it is the combination of deafness and the environment which impacts on
psychological functioning, rather than the deafness per se. There are probably three main aspects from these lists which psychological services should consider: professionals and their attitudes, issues of communication, and deaf or hearing world (culture), for these may have serious implications for assessment and the process of intervention.
Implications for services:

**Issues of communication:**

"Language influences the assessment process more than almost any other variable..."

Orr et al (1987)

Alice Thacker (1990), a specialist speech therapist in hearing impairment and psychiatry, provides two explanations for the over-representation of deaf people in mental health services described above: the first is a failure to detect the hearing loss at all, such that certain limitations resulting from the deafness such as impoverished vocabulary, rigid structure and little linking of themes are interpreted, for example, as poverty of content, poor insight and withdrawal. The second is a failure to adapt diagnostic procedures and management appropriately. This is pointed out well by Monteiro (1989) who describes how “it is extremely difficult to diagnose even physical illnesses without effective communication between patient and doctor.”

Clearly, a psychological assessment can be rendered almost impossible without effective communication between therapist and client, which, as Monteiro describes, can render the assessor feeling deskilled and helpless and so, under pressure to offer an opinion, often makes an assessment which has little established basis.

One answer to this problem could be the use of an interpreter. However, this also affects the assessment or therapy session in a number of ways (Orr et al, 1987). For example, the presence of an interpreter turns a dyadic process into a triadic one which Hoyt et al (1981) point out may dilute and distort the relationship, complicating transference issues, and make the interpreter become a centre of authority. Also the interpretation is never a literal word-for-sign conversion as most sign languages, like spoken ones, have different grammatical structures and inferences attached to the concepts. Therefore, the interpreter’s job is also to try to capture the hints and flavours of the conversation, which necessarily introduces that person’s history, expectations, and understanding of psychological concepts into the situation - to accommodate this, Orr et al emphasise the necessity of using an interpreter with expertise in the mental health situation. There is also a question of confidentiality.

If the psychologist chooses to use sign language, it is clearly important that that language can be used fluently. Orr et al point out that it is easy to slip from ASL or BSL (American and British Sign Language) into signed English, which differs in syntax, thereby unintentionally changing the meaning. It is also necessary to recognise that deaf clients may have variable abilities in the chosen method of communication as a result of
a changing educational and familial background. Thus, if for example BSL is the predominant language of choice for a particular client, it may not be the case that that person is fluent in that language, and so may also slip into other signed systems, or indeed other means of communication altogether. Even the most fluent professional would have to be extraordinarily skilled to effectively follow such a conversation. Similarly, though, as a result of a varying background many deaf people are able to adapt their language to the situation. Orr et al, however, describe how this can lead to tension, stress, frustration, misunderstanding, and constriction. Schlesinger and Meadow (1972) point out, also, that communication difficulties can be used as a resistance by clients, for example by signing too rapidly, looking away, or selectively misunderstanding troubling material.

**Issues of Assessment:**

"Misdiagnosis of deaf patients is common. Many are labelled mentally retarded or schizophrenic as a result of their language disability due to deafness, not the actual presence of retardation or psychopathology."

RR Grinker (1969)

As described by Monteiro (1989), there are a number of ways in which communication issues can affect assessment and diagnosis. One is that psychopathology is inferred when in fact there is none, as proposed by Thacker (1990), above, while another is that presenting psychopathology may be missed. The former is further described by Hoyt et al (1981) who demonstrate that “what may appear to be unusual or distorted thinking may actually be a normal and appropriate locution in ASL” and by Evans and Elliott (1981) who report “the tendency to overdiagnose schizophrenia as a wastebasket classification when confronted by a gesticulating, excited patient who cannot be understood.” Denmark (1966) has also written that “the inability in the deaf to express dissatisfaction or anger in the normal way, or quickly enough, by emotionally tonal verbalisation, often leads to the physical display of such feelings. To those without a knowledge of the psychology of the deaf person these reactions, at times explosive in nature, are incomprehensible and may be mistaken for the manifestation of mental illness.”

Neither positive nor negative misdiagnosis is helped by the standard classification systems such as DSM-IV which often unavoidably have to use symptoms based on a mostly hearing population. As illustration, Evans and Elliott (1981) demonstrated how of the fifteen signs and symptoms of schizophrenia they identified from three separate classification systems, six were present in non-psychotic as well as psychotic deaf people. (This paper therefore provides a good working system for identifying
schizophrenia in deaf people.) Thus, even without overriding communication difficulties, strict diagnosis, for those who demand it, becomes problematic in and of itself.

Similarly, of course, assessment tools and psychometric tests are more often than not equally bound up in a hearing milieu. F.R. Zieziula (1982) describes four critical questions to be addressed when selecting a test for use with a deaf person:

1. **Does the test consist of verbal test items or performance items?** Prelingually deaf people will usually have difficulty with English syntax and vocabulary, indeed, the mean reading level for this population is estimated to be at a third- or fourth-grade level. Performance on verbally loaded test items will therefore be clearly impeded.

2. **Do instructions for the test require verbal communication?** Even if the test items are performance-based, the instructions often are strictly verbal. Sometimes, the test developer will allow alternative instruction procedures, which may make translation into sign language a viable option, but even then, the validity of the results must be questioned (see issues of culture, below).

3. **Do any test items discriminate against people with an auditory impairment?** Some test items relate to an individual's ability to hear and function in a hearing world. For example behaviour items in the Vineland Social Maturity Scale include "makes telephone calls" and "talks in short sentences" while the Minnesota Multiphasic Personality Inventory includes statements such as "my hearing is apparently as good as that of most people."

4. **Are hearing impaired people included in the normative sample provided by the test developer?** This can include a separate normative sample of hearing-impaired people, or even whether deaf people are included in the general normative sample. (Which sample is more appropriate is a matter for debate, and would probably depend on the purpose of testing.) When a test does not satisfy this criterion, interpretation of results should be made very cautiously. Indeed, most tests do not - of those that do, Zieziula identifies the WISC-R Adaptation by Ray (Ray 1979), the Stanford Achievement Test (Hearing Impaired Edition), the Geist Picture Interest Inventory: Deaf: Male Form (Geist, 1962), and the Hiskey-Nebraska Test of Learning Aptitude (Hiskey, 1955), to which Orr et al (1987) add the Leiter International Performance Scale (Leiter, 1948).
Issues of Culture:

It is the shared experience of being deaf, described by Cole above, which, partially, determines members of the Deaf community (Higgins 1987), and, while the above criteria relate to the communication issues surrounding deafness, there are also factors of cultural validity to take into account when testing Deaf people. A useful analysis of cross-cultural testing is provided by Flaherty et al (1988) who identify five sorts of validity which should be achieved: The first is Content Validity in which each item of the test is examined to ensure relevance to the culture. The second is Semantic Validity where items in the translated, or otherwise adapted, version of the test continue to mean the same thing after translation (a useful test of this being back-translation where the item is translated back into the original language and examined for equivalence.) Technical Validity is that in which the method of data collection affects the results in different ways, depending on the culture. (Hindley (1993) points out that the interpreter in his research considered a face to face interview to be foreign to deaf children.) Criterion Validity is concerned with whether the test items refer to the same concepts in each culture, and Conceptual Validity considers whether the test items relate to concepts that are not alien to the culture.

While Flaherty et al’s study is concerned with research tools, the issues therein are still as pertinent for the hearing professional working at any level with Deaf people. No attempt has been made here to define Deaf culture, as attempts to define any culture must necessarily be so precise as to be lacking depth, or so general as to be uninformative. Higgins (1987) provides a clearer picture, but for the purposes of service provision, recognition that a client may identify with the Deaf culture should render the professional receptive to whatever that may mean for that client.
Summary:

Deafness has been described above in a number of ways, for example in terms of time of onset, severity and aetiology. The question of whether there is a ‘psychology of deafness’ has been discussed and the various means by which a hearing impairment has been said to influence psychopathology identified - common aetiology, aspects of deafness per se and experiences of deaf people. Many different authors have described this in as many different ways, including the assertion that deafness leads in and of itself to a particular type of person - which seems to be both unfounded and unnecessary. The most practical explanation seems to be one in which deafness can result in different experiences from those of hearing people, and it is this combination of experiences which impacts upon psychopathology. This is not to say that deaf people all share a unique homogenising set of life events, but that there is a set of experiences resulting from being deaf, a subset of which may apply to a particular person. It is also clearly important to consider the cause of the hearing impairment, as this may play a critical role in presenting psychopathology.

Three considerations to observe as a hearing professional when working with a deaf person have been discussed. Communication issues, once identified, may be addressed in a number of different ways, though none of these is without its drawbacks; formal assessment is plagued with pitfalls which cause the assessor to rely almost entirely on qualitative rather than quantitative measures; and Deafness as a culture also has pervasive effects on both formal tools and informal understanding.

To conclude, the question of whether there is a psychology of deafness, of whether prelingual profound deafness affects psychopathology, becomes less meaningful once one acknowledges a culture of deafness. Indeed, when one attempts to delineate a psychology of deafness, recognition of culture becomes unavoidable.

In the absence of comprehensive psychology services, of deaf psychologists, and of appropriately standardised assessment tools, other than by developing as thorough an understanding of deafness as possible the main answer when working with a deaf client must be to be truly client-led.
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Evaluation of a Group Approach to Social Competence Training for 6-8 and 8-10 year old Boys.
Abstract

A brief (seven week) group approach to social competence for 6-8 and 8-10 year-old boys is described in which a group training programme is set up based on the assessment and feedback of the group members and the suggestions of Rinaldi (1992). Group members were selected through members of the Clinical Child Psychology Department on the basis of contact with the service, and pre and post-group measures were taken of specific communication skills and social behaviours. No improvement was observed regarding communication skills or within social behaviours, although potential areas for further research are identified by adopting a less conservative statistical analysis. Possible reasons for these results are discussed.
Introduction

Despite being a frequently used phrase, by the general population and psychologists alike, an agreed definition of 'social skill' has proved to be elusive throughout the literature (Gresham & Elliott, 1993). It could be argued that a more socially skilled person would be more well-accepted by his peers, although one can conceive of a highly socially-skilled person who lives a reclusive life, suggesting a distinction between prosocial ability and prosocial behaviour (Ogilvy, 1994); Also, definitions have been suggested in which social skills are seen as a repertoire of behaviours through which one may affect desirable and undesirable outcomes within the social domain (Rinn & Markle, 1979). Ogilvy (1994) observes that such an operant behavioural definition provides no objective means by which to identify those behaviours which are key, leaving the analysis to subjective assumption on the part of the observer or assessor. A more widely accepted form of definition is that based on social validity (Gresham, 1988), which provides an objective perspective, such as that of Gresham and Elliott (1984):

"Social skills are those behaviours which, within a given situation, predict important social outcomes such as a) peer acceptance or popularity, b) significant others' judgments of behaviour, or c) other social behaviours known to correlate consistently with peer acceptance or significant others' judgments."

Gresham and Elliott (1993) add that, for children, further important social outcomes may be academic achievement, positive feelings of self-worth, and positive adaptation to school, home and community environments. It was observed or reported deficiencies in these outcomes for six to ten year-old boys, who were or had been attending the Clinical Child Psychology Service, which prompted the initiation of a group approach to social competence training within the service.

This evaluative study was designed to determine whether a brief (seven week) training period focussing on specific skills of communication and interaction could be of benefit to primary school boys in terms of improving those skills of interaction and communication and thereby improving those social outcome factors described by Gresham and Elliott (1993) above. The null hypotheses addressed are a) that the above social outcome factors will not change following the completion of the group, and b) that the specific communication skills will not change following completion of the group.
Selection of children

Group members were selected initially by contact with the service. That is, Clinical Psychologists and Counsellors, who were or had been working with children and families who had observed through that contact problems in the areas described above, nominated children for inclusion in the groups. All of those nominated were boys aged between six and eleven years, but those who had moved into secondary school were excluded because it was considered that the differences in peer group structure and developmental stage would make the group too heterogeneous to meaningfully target general concerns with specific examples (Bierman & Montminy, 1993). Group cohesion may also have been compromised. One child, who had been diagnosed as having Attention Deficit Disorder with Hyperactivity, was also excluded for that reason. The developmental changes in normative peer interactions, social reasoning, and peer group structure and influence, described by Bierman & Montminy (1993), informed the decision to run two groups, the first for 8-10 year olds (n=5) and the second for 6-8 year olds (n=8) (Fischer, 1980).

Assessment

Each child was assessed within the five weeks immediately preceding the beginning of his group in order to provide an indication of his particular social competence skills and deficits: Based on the findings of Kazdin (1977) that teacher assessments provided subjective evaluations by people with whom children were most likely to interact, yielding socially valid responses, the class teacher of each child was interviewed for 30 minutes using The Staff Questionnaire on Social Behaviour (QSB) of Spence (1980) which is a 42 item questionnaire of yes/no questions pertaining to socially relevant behaviours. The parents of each child were also requested to complete the same questionnaire by post in order to identify whether problem areas were confined to particular settings, the parental version having an amended title so as not to stress school as the target area. In line with Ogilvy’s (1994) observation that socially valid impact measures and specific measures of the target skills should be assessed, the facilitators of each group jointly rated each child from video using the Communication Skills Rating Chart (CSRC) from the Social Use of Language Program (Rinaldi 1992) (SULP) at the end of the first group session. This scale takes the form of 21 items regarding specific skills of communication grouped into five general domains - prosody/intelligibility, non-verbal skills, listening skills, awareness of listener’s need and turn-taking - each being rated on a four-point (0-3) scale. Specific instructions are provided for the rating of each item, but overall the scale ranges from 'adequate' (0) to 'extremely' (3 - poor, slow, rigid, etc) - higher scores reflecting decreased social competence. This enabled more specific behaviours to be assessed, rather than the more
general domains observed in the Staff Questionnaire, and the analogue situation of the first session allowed specific interpersonal situations to be created and recorded to permit precise measurement (Foster, DeLawyer & Guevremont, 1985).

**Evaluation**

All measures taken as part of the assessment procedure were repeated within eight weeks of the final group meeting. On this occasion, the staff questionnaire was administered by post because the summer holidays precluded the opportunity for further interview. The CSRC was again rated by the group facilitators based on video recording of the final session.

**The groups**

Each group extended over weekly ninety-minute sessions within the Clinical Child Psychology Service for seven weeks. The 8-10 year old group ran first with two facilitators, a Clinical Psychologist and a Trainee Clinical Psychologist, after which the 6-8 year old group began, facilitated by the Clinical Psychologist and a Counsellor. Aside from these differences of age and facilitator, both groups took the same format based on the Social Use of Language Programme (Rinaldi, 1992), the general features of which are reproduced here:

1. ‘Making mistakes is OK’ - achieved by the attitude of the facilitators to their own mistakes, and discussion about learning from errors.
2. Work focuses on areas relevant to each child, highlighted through discussion.
3. The function of the activity is explained and demonstrated, so that its purpose and value may be understood.
4. Activities are organised in a hierarchy of increasing difficulty to encourage and motivate the child.
5. Short and Long-term goals are discussed with group members.
6. Members are active in learning, and encouraged to monitor their own performance and provide constructive feedback to each other.
7. Facilitators model the skills required to encourage and give guidance in attempting new situations.
8. Members are encouraged to develop a realistic view of themselves and their expectations.

Based on these principles, the model of successful communication presented by Rinaldi in which successful communication is divided into five areas (initiating/taking turns,
timing of turns, awareness of listener feedback, giving listener feedback, and handing over/terminating conversation), and the value of awareness of self and others (eg feelings and opinions), each session was structured as follows:

- Arrival of group members followed by a drink and biscuit while members made name badges for themselves. (10 minutes.) Group members and facilitators sat in a circle around a small room on chairs, beanbags, and the floor.
- Warm-up activity designed to relax and gel the group. After session one, this activity also served to reinforce a skill of interaction identified and practised the week before.
- Activity designed to introduce and practise a skill of interaction identified as important by the CSRC assessment measure. Awareness of self and others was fostered within this activity section by using topics of personal value such as ‘favourite television programme’, or ‘how I feel during playtime.’
- A ‘game’ activity designed to define the end of the session, relax the members and consolidate basic awareness of self and others. (10 minutes.)

It should be stressed that the Social Use of Language Programme was not followed verbatim, but used as a framework around which to structure a more flexible, if more intensive, brief group. Topics explored included “What’s important when you are talking to someone?”, “What helps you to listen?”, “Talking about our interests”, “Taking it in turns.”, and “When are people friends?”

Statistical Analysis

For both the CSRC and the QSB questionnaires, the sign test was used to examine whether the ratings obtained after the completion of each group significantly differed from those obtained during the assessment stage. Because the SULP (Rinaldi, 1992) and the manual by Spence (1980) provide no indication that the items in either the CSRC or the QSB may be combined in any way to form an overall index of social competence, each item was analysed separately and a two-tailed probability of the obtained difference calculated. It was considered unreasonable to assume that each item would necessarily change in the desired direction, (for example it was hypothesised that increased confidence could result in either an increase or a decrease in undesirable behaviours) - a one-tailed analysis was therefore ruled out. For the QSB, ‘No’ was coded numerically as 0, ‘Yes’ as 1. The few items on which both were selected were discarded from the analysis.

Two-tailed sign tests were also conducted in order to examine whether ratings made by class-teachers differed significantly to those made by parents.

1 Examples of such activities may be found in the SULP (Rinaldi, 1992).
Because the repetition of the sign test increases the probability of making a Type I error (that is, detecting significant changes erroneously) a Bonferroni correction is applied to the analysis within each research question. Thus, for the CSRC the alpha criteria are $p=0.05/21=0.0024$ and $p=0.01/21=0.0005$, and for the QSB the alpha criteria are $p=0.05/42=0.0012$ and $p=0.01/42=0.0002$. 
Results

Complete results are presented in the appendix for the thirteen boys aged between 6 and 10 years, and fall into two main areas - the effect of the group on communication skills and the effect on social behaviour. Table 1 (appendix) provides a summary of the CSRC assessment measure results, Table 2 a summary of parental ratings on the QSB, Table 3 a summary of teacher ratings on the QSB, and Table 4 provides two-tailed probability estimates of obtained differences between teacher and parent ratings for each item. Missing data in these tables correspond to those items in which there was only one child rated differently before and after the group, the overall differences for group members on those items are therefore not significant. The main question to be addressed is whether social competence of participants is increased following the completion of the social skills training groups. As described above it is not possible to obtain an overall index of social competence from the measures employed, however it is possible to compare the overall competence of the group members on each of the communication-skill and social behaviour items.

<table>
<thead>
<tr>
<th>Item</th>
<th>Direction of difference</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CSRC:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Volume</td>
<td>Improvement</td>
<td>0.0078**</td>
</tr>
<tr>
<td>* Facial Expression</td>
<td>Improvement</td>
<td>0.0156*</td>
</tr>
<tr>
<td>* Posture</td>
<td>Improvement</td>
<td>0.0039**</td>
</tr>
<tr>
<td>* Ability to adjust speech when listener does not understand</td>
<td>Improvement</td>
<td>0.0313*</td>
</tr>
<tr>
<td>* Ability to adjust speech to listener’s mood</td>
<td>Improvement</td>
<td>0.0313*</td>
</tr>
<tr>
<td>* Interruptions</td>
<td>Improvement</td>
<td>0.0156*</td>
</tr>
<tr>
<td>* Handing over conversation / allowing for response</td>
<td>Improvement</td>
<td>0.0078**</td>
</tr>
<tr>
<td><strong>QSB:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Is the child’s facial expression generally inappropriate to the situation?</td>
<td>Teachers rated ‘No’ more than parents at the assessment stage</td>
<td>0.0156*</td>
</tr>
<tr>
<td>* Is the child often cheeky to adults?</td>
<td>Teachers rated ‘No’ more than parents at the assessment stage</td>
<td>0.0313*</td>
</tr>
</tbody>
</table>

* p<0.05
** p<0.01
From the tables in the appendix it can be seen that none of the items on either of the measures are seen to improve, or deteriorate, significantly following the administration of the Bonferroni correction. Considering only the direction of change, and not the magnitude, the sign test is very conservative - gaining freedom from assumptions by losing statistical power. The use of the Bonferroni correction guards against identifying results as significant purely as a result of probability by dividing the alpha criterion by the number of times the sign test is repeated within the research question. This necessarily makes the analysis more conservative still. However, to identify potential areas for further study, those results identified as significant before correction are presented above, although it is important to recognise the probability of such results arising by chance.

From the above summary table it can be seen that on seven of the twenty-one communication skills a significant number of group members are seen to have improved following completion of the group. The qualitative descriptions of improvements which follow are taken from the rating instructions for the CSRC.

Whereas volume of speech was considered to be inappropriately loud or quiet at the assessment stage, by the end of the group it had become significantly more appropriate (p<0.001). At a similar level of significance, use of posture had improved from very little to normal variation and handing over conversation became more natural and created less of a negative impression. Inexpressive or unsuitable facial expression had improved (p<0.05) to the appropriate use of a normal range of facial expression and the ability to adjust speech according to both the level of the listener’s comprehension and mood became significantly less difficult following training. By the end of each group interruptions became less frequent and also created less of a negative impression.

It is notable that the areas of improvement are spread throughout most of the sections of the CSRC measure, being Prosody/Intelligibility, Non-verbal Skills, Awareness of Listener’s Need, and Turn Taking. Of these, only turn-taking and volume (from prosody/intelligibility) were directly addressed within the groups.

There were no significant changes in a negative direction on any aspects of communication skill, although fourteen of the twenty-one skills do not exhibit any significant change. Similarly, no significant changes are detectable on any of the items measured by the staff and parent questionnaires on social behaviour - possible reasons for this being explored below. The only significant results arising from the QSB ratings were a) that parents considered their child’s facial expression to be generally inappropriate to the situation and b) that parents described the child as often cheeky, both of these differences only arising during the assessment stage.
Discussion

The lack of alternative assessment and evaluation measures necessitated the adoption of a particularly conservative statistical analysis from which no significant results were obtained. It can only be concluded from these results that the time-limited social skills group had no identifiable effect on those who participated. From the current study it is not possible to identify reasons for this lack of change, although Ogilvy (1994) identifies common pitfalls, for example social skills training may be necessary but not sufficient for change - restructuring the social environment of the child may also be necessary. She points out that “...without a theory of social skill development, it is just not known how cognitive and behavioural skills interact to produce social competence.” (Ogilvy, 1994) It is possible that the groups did not promote any significant change within the social competence domains examined, for a variety of reasons. Alternatively, there are no formal studies of the reliability or validity of the measures used, or other studies using the measures, and it is possible that the QSB and CSRC are inappropriate tools.

However, a less conservative analysis has highlighted a limited number of areas of change. The most immediately identifiable theme from these results is that the only positive changes following the group approach to social competence lie within the domain of specific communication skills. That all improvements are to be found within this domain is perhaps to be expected when one considers that the focus of each group session was based on Rinaldi’s (1992) five areas of successful communication, and the results of the assessment rating of the CSRC. Group sessions, however, were not generally aimed at those specific skills (see above) and so it is suggested that an overall focus upon issues of communication and interaction may have given rise to specific improvements, perhaps through increased confidence within those situations, or by the boys discovering certain rules or techniques for themselves. The absence of significant change in many of the communication skill items may reflect this lack of direct attention. It is hypothesised that a seven week approach may be too brief to address fully the issues of social competence which would ordinarily have evolved slowly and naturally with the social development of the child (Bierman & Montminy, 1993). It may therefore have been too optimistic to imagine that specific communication skills which were not directly targeted would nevertheless naturally be enhanced alongside the improvement of other skills.

Also, being implausible to address directly within a clinical setting, it was anticipated that the more general social behaviours listed in the QSB (see for example Table 2) would naturally follow on from improvement in the skills of communication and interaction. No improvement in these areas is demonstrated by this study, and this may be ascribed to a number of reasons: i) the sign test is not a very powerful analysis,
although it is the most appropriate, and so it is possible that improvement may not have been detected, ii) the small amount of improvement demonstrated in certain skills is insufficient to have a measurable effect on the more socially valid behaviours, iii) improvement within communication skills does not necessarily incur concomitant improvement in more general social behaviour, or iv) the post-group social behaviour evaluation took place within eight weeks of the end of the group, which may not have been long enough for improvement in this domain to become apparent. It is not possible to judge between these possibilities, although Fox and McEvoy (1993) stress that, although the generality of social skills may be achieved without direct work to that end, such attention may be necessary for reliable and socially valid results. That is, despite it being possible for social skills to be generalised across settings, people, behaviours, times etc without specific intervention to effect that, such specific training ‘in the field’ is likely to consolidate that effect.

It may be of note that of the 84 items of the QSB (assessment and evaluation, each of 42 items) only two items were significantly disagreed upon by teachers and parents. It is difficult to suggest reasons for this small discrepancy since such suggestions as the different perspectives of teachers and parents, their possible differing investments in the child, or their possible differing norms of acceptable behaviour would be more likely to affect all the items, than two specific examples.

Overall it can only be stated that this seven week group approach to social competence for 6-8 and 8-10 year old boys may have been of limited benefit in a narrow range of specific skills of communication and interaction, although it is rewarding to note that the group members reported having benefited - and their parents reported, anecdotally, an increase in more meaningful friendships for their sons following the groups. It is recommended that further evaluative study of such a group should utilise assessment and evaluation measures which allow for more powerful statistical analyses, and should spend a longer period of time teaching skills and consolidating them in more socially valid settings than the clinic.
References


Appendix to Section 3 ii

Missing data in these tables correspond to those items in which there was only one child rated differently before and after the group, the overall differences for group members on those items are therefore not significant.
<table>
<thead>
<tr>
<th>Prosody/Intelligibility</th>
<th>Pre-group Mean</th>
<th>Post-group Mean</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate</td>
<td>1.15</td>
<td>0.62</td>
<td>0.1250</td>
</tr>
<tr>
<td>Volume</td>
<td>1.38</td>
<td>0.69</td>
<td>0.0078 **</td>
</tr>
<tr>
<td>Pitch</td>
<td>0.15</td>
<td>0.46</td>
<td>0.3750</td>
</tr>
<tr>
<td>Intonation</td>
<td>0.46</td>
<td>0.62</td>
<td>0.6875</td>
</tr>
<tr>
<td>Intelligibility</td>
<td>0.62</td>
<td>0.54</td>
<td>1.0000</td>
</tr>
<tr>
<td><strong>Non verbal skills</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye contact (listening)</td>
<td>0.62</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td>Eye contact (speaking)</td>
<td>0.69</td>
<td>0.23</td>
<td>0.2188</td>
</tr>
<tr>
<td>Facial Expression</td>
<td>0.77</td>
<td>0.08</td>
<td>0.0156 *</td>
</tr>
<tr>
<td>Posture</td>
<td>1.31</td>
<td>0.31</td>
<td>0.0039 **</td>
</tr>
<tr>
<td>Muscle tone</td>
<td>1.31</td>
<td>0.69</td>
<td>0.1094</td>
</tr>
<tr>
<td>Proximity</td>
<td>0.88†</td>
<td>0.75†</td>
<td>1.0000</td>
</tr>
<tr>
<td>Recognition of meaning by facial expression/tone of voice</td>
<td>0.77</td>
<td>0.54</td>
<td>0.3750</td>
</tr>
<tr>
<td><strong>Listening skills</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Levels of listening</td>
<td>1.31</td>
<td>0.69</td>
<td>0.1094</td>
</tr>
<tr>
<td>Listener feedback</td>
<td>1.23</td>
<td>0.77</td>
<td>0.2891</td>
</tr>
<tr>
<td><strong>Awareness of listener's need</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to adjust speech when listener does not understand</td>
<td>1.62</td>
<td>1.00</td>
<td>0.0313 *</td>
</tr>
<tr>
<td>Ability to adjust speech to listener's mood</td>
<td>1.75†</td>
<td>0.88†</td>
<td>0.0313 *</td>
</tr>
<tr>
<td>Ability to adjust speech behaviour to listener's level of interest</td>
<td>1.54</td>
<td>1.08</td>
<td>0.1797</td>
</tr>
<tr>
<td><strong>Turn taking</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interruptions</td>
<td>1.69</td>
<td>0.92</td>
<td>0.0156 *</td>
</tr>
<tr>
<td>Initiating taking up conversation (attempts)</td>
<td>1.38</td>
<td>1.00</td>
<td>0.5078</td>
</tr>
<tr>
<td>Initiating taking up conversation (success)</td>
<td>1.00</td>
<td>0.77</td>
<td>0.5078</td>
</tr>
<tr>
<td>Handing over conversation / allowing for response</td>
<td>1.54</td>
<td>0.77</td>
<td>0.0078 **</td>
</tr>
</tbody>
</table>

* n=8. On these items, the raters could not agree on a score for five of the subjects.

Without Bonferroni correction

* p<0.05, ** p<0.01

With Bonferroni correction

p<0.0012 [none], p<0.0002 [none]

Table 1

Summary of Pre- and Post-group mean-scores from Communication Skills Rating Chart. Significance derived from Sign Test.
Table 2
Summary of Pre- and Post-group mean-scores from Parental Questionnaire on Social Behaviour.
Significance derived from Sign Test.

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre-group Mean</th>
<th>Post-group Mean</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is the child bullied frequently?</td>
<td>0.17</td>
<td>0.00</td>
<td>1.0000</td>
</tr>
<tr>
<td>2. Is the child teased frequently?</td>
<td>0.50</td>
<td>0.22</td>
<td>1.0000</td>
</tr>
<tr>
<td>3. Is the child easily influenced by other children to misbehave?</td>
<td>0.73</td>
<td>0.44</td>
<td>0.5000</td>
</tr>
<tr>
<td>4. Does the child have difficulty resisting group pressure?</td>
<td>0.78</td>
<td>0.44</td>
<td>0.5000</td>
</tr>
<tr>
<td>5. Does the child avoid contact with peers?</td>
<td>0.33</td>
<td>0.22</td>
<td>1.0000</td>
</tr>
<tr>
<td>6. Does the child have difficulty keeping out of fights?</td>
<td>0.70</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>7. Does the child have difficulty accepting criticism appropriately?</td>
<td>0.83</td>
<td>0.67</td>
<td>0.5000</td>
</tr>
<tr>
<td>8. Does the child become embarrassed easily?</td>
<td>0.58</td>
<td>0.67</td>
<td>1.0000</td>
</tr>
<tr>
<td>9. Does the child have difficulty standing up for him/herself with other children?</td>
<td>0.36</td>
<td>0.25</td>
<td>1.0000</td>
</tr>
<tr>
<td>10. Does the child find it hard to or fail to talk to other children?</td>
<td>0.50</td>
<td>0.33</td>
<td>1.0000</td>
</tr>
<tr>
<td>11. Are the child's verbal responses very brief and/or infrequent?</td>
<td>0.25</td>
<td>0.22</td>
<td>1.0000</td>
</tr>
<tr>
<td>12. Does the child find it hard to or fail to initiate conversations with peers?</td>
<td>0.42</td>
<td>0.44</td>
<td></td>
</tr>
<tr>
<td>13. Does the child find it hard to or fail to initiate conversations with adults?</td>
<td>0.36</td>
<td>0.44</td>
<td>1.0000</td>
</tr>
<tr>
<td>14. Does the child find it hard to or fail to approach adults with requests?</td>
<td>0.33</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td>15. Does the child become angry when teased?</td>
<td>0.91</td>
<td>0.89</td>
<td>1.0000</td>
</tr>
<tr>
<td>16. Does the child become angry when bullied?</td>
<td>0.86</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-group Mean</td>
<td>Post-group Mean</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------</td>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>17.</td>
<td>Does the child find it difficult to express his/her feelings?</td>
<td>0.55</td>
<td>0.44</td>
</tr>
<tr>
<td>18.</td>
<td>Does the child find it hard to or fail to apologise when he/she does something wrong?</td>
<td>0.67</td>
<td>0.67</td>
</tr>
<tr>
<td>19.</td>
<td>Does the child find it hard to or fail to ask others for help?</td>
<td>0.55</td>
<td>0.33</td>
</tr>
<tr>
<td>20.</td>
<td>Does the child find it hard to or fail to ask others if he/she can join in a game?</td>
<td>0.55</td>
<td>0.33</td>
</tr>
<tr>
<td>21.</td>
<td>Does the child avoid making eye contact or look away during conversation with others?</td>
<td>0.64</td>
<td>0.63</td>
</tr>
<tr>
<td>22.</td>
<td>Does the child find it hard to or fail to ask questions in class?</td>
<td>0.30</td>
<td>0.29</td>
</tr>
<tr>
<td>23.</td>
<td>Does the child interrupt inappropriately?</td>
<td>0.83</td>
<td>0.63</td>
</tr>
<tr>
<td>24.</td>
<td>Does the child talk excessively or at inappropriate times?</td>
<td>0.64</td>
<td>0.67</td>
</tr>
<tr>
<td>25.</td>
<td>Does the child stare excessively during conversation?</td>
<td>0.08</td>
<td>0.06</td>
</tr>
<tr>
<td>26.</td>
<td>Does the child fidget and fiddle excessively?</td>
<td>0.83</td>
<td>0.67</td>
</tr>
<tr>
<td>27.</td>
<td>Does the child slouch badly or use poor posture?</td>
<td>0.50</td>
<td>0.50</td>
</tr>
<tr>
<td>28.</td>
<td>Is the child verbally aggressive during conversation with peers?</td>
<td>0.60</td>
<td>0.63</td>
</tr>
<tr>
<td>29.</td>
<td>Is the child verbally aggressive during conversation with adults?</td>
<td>0.60</td>
<td>0.61</td>
</tr>
<tr>
<td>30.</td>
<td>Does the child fail to say thank you upon receiving things?</td>
<td>0.36</td>
<td>0.44</td>
</tr>
<tr>
<td>31.</td>
<td>Does the child fail to give cues of listening when you talk to him/her eg no head movements or verbal feedback?</td>
<td>0.40</td>
<td>0.33</td>
</tr>
<tr>
<td></td>
<td>Pre-group Mean</td>
<td>Post-group Mean</td>
<td>2-tailed p</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>----------------</td>
<td>------------</td>
</tr>
<tr>
<td>32. Does the child tease other children inappropriately?</td>
<td>0.36</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>33. Is the child's facial expression generally inappropriate to the situation eg laughs, smiles, frowns etc when inappropriate?</td>
<td>0.67</td>
<td>0.44</td>
<td>0.5000</td>
</tr>
<tr>
<td>34. Does the child find it hard to introduce him/herself to others?</td>
<td>0.45</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>35. Does the child fail to or find it hard to tell an adult when something is wrong?</td>
<td>0.73</td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>36. Does the child find it hard to talk to strangers?</td>
<td>0.45</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>37. Is the child unpopular?</td>
<td>0.56</td>
<td>0.25</td>
<td>1.0000</td>
</tr>
<tr>
<td>38. Does the child fail to make friends with peers?</td>
<td>0.50</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>39. Does the child find it hard to or fail to take orders and obey instructions from adults?</td>
<td>0.80</td>
<td>0.67</td>
<td>1.0000</td>
</tr>
<tr>
<td>40. Is the child often cheeky to adults?</td>
<td>0.58</td>
<td>0.67</td>
<td>1.0000</td>
</tr>
<tr>
<td>41. Does the child talk too loudly?</td>
<td>0.60</td>
<td>0.56</td>
<td></td>
</tr>
<tr>
<td>42. Does the child talk too quietly?</td>
<td>0.09</td>
<td>0.11</td>
<td>1.0000</td>
</tr>
</tbody>
</table>
Table 3
Summary of Pre- and Post-group mean-scores from Staff Questionnaire on Social Behaviour. Significance derived from Sign Test.

<table>
<thead>
<tr>
<th></th>
<th>Pre-group Mean</th>
<th>Post-group Mean</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is the child bullied frequently?</td>
<td>0.31</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>2. Is the child teased frequently?</td>
<td>0.31</td>
<td>0.25</td>
<td>0.5000</td>
</tr>
<tr>
<td>3. Is the child easily influenced by other children to misbehave?</td>
<td>0.38</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>4. Does the child have difficulty resisting group pressure?</td>
<td>0.46</td>
<td>0.29</td>
<td>0.5000</td>
</tr>
<tr>
<td>5. Does the child avoid contact with peers?</td>
<td>0.31</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>6. Does the child have difficulty keeping out of fights?</td>
<td>0.46</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td>7. Does the child have difficulty accepting criticism appropriately?</td>
<td>0.75</td>
<td>0.50</td>
<td>0.5000</td>
</tr>
<tr>
<td>8. Does the child become embarrassed easily?</td>
<td>0.54</td>
<td>0.17</td>
<td></td>
</tr>
<tr>
<td>9. Does the child have difficulty standing up for him/herself with other children?</td>
<td>0.31</td>
<td>0.14</td>
<td></td>
</tr>
<tr>
<td>10. Does the child find it hard to or fail to talk to other children?</td>
<td>0.38</td>
<td>0.50</td>
<td></td>
</tr>
<tr>
<td>11. Are the child's verbal responses very brief and/or infrequent?</td>
<td>0.31</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td>12. Does the child find it hard to or fail to initiate conversations with peers?</td>
<td>0.46</td>
<td>0.57</td>
<td>1.0000</td>
</tr>
<tr>
<td>13. Does the child find it hard to or fail to initiate conversations with adults?</td>
<td>0.46</td>
<td>0.25</td>
<td>1.0000</td>
</tr>
<tr>
<td>14. Does the child find it hard to or fail to approach adults with requests?</td>
<td>0.31</td>
<td>0.13</td>
<td>0.5000</td>
</tr>
<tr>
<td>15. Does the child become angry when teased?</td>
<td>0.50</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td>16. Does the child become angry when bullied?</td>
<td>0.50</td>
<td>0.38</td>
<td>1.0000</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Pre-group Mean</td>
<td>Post-group Mean</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------</td>
<td>----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>17.</td>
<td>Does the child find it difficult to express his/her feelings?</td>
<td>0.75</td>
<td>0.43</td>
</tr>
<tr>
<td>18.</td>
<td>Does the child find it hard to or fail to apologise when he/she does something wrong?</td>
<td>0.46</td>
<td>0.71</td>
</tr>
<tr>
<td>19.</td>
<td>Does the child find it hard to or fail to ask others for help?</td>
<td>0.31</td>
<td>0.63</td>
</tr>
<tr>
<td>20.</td>
<td>Does the child find it hard to or fail to ask others if he/she can join in a game?</td>
<td>0.50</td>
<td>0.57</td>
</tr>
<tr>
<td>21.</td>
<td>Does the child avoid making eye contact or look away during conversation with others?</td>
<td>0.33</td>
<td>0.38</td>
</tr>
<tr>
<td>22.</td>
<td>Does the child find it hard to or fail to ask questions in class?</td>
<td>0.54</td>
<td>0.25</td>
</tr>
<tr>
<td>23.</td>
<td>Does the child interrupt inappropriately?</td>
<td>0.58</td>
<td>0.50</td>
</tr>
<tr>
<td>24.</td>
<td>Does the child talk excessively or at inappropriate times?</td>
<td>0.46</td>
<td>0.50</td>
</tr>
<tr>
<td>25.</td>
<td>Does the child stare excessively during conversation?</td>
<td>0.08</td>
<td>0.14</td>
</tr>
<tr>
<td>26.</td>
<td>Does the child fidget and fiddle excessively?</td>
<td>0.83</td>
<td>0.71</td>
</tr>
<tr>
<td>27.</td>
<td>Does the child slouch badly or use poor posture?</td>
<td>0.31</td>
<td>0.14</td>
</tr>
<tr>
<td>28.</td>
<td>Is the child verbally aggressive during conversation with peers?</td>
<td>0.38</td>
<td>0.25</td>
</tr>
<tr>
<td>29.</td>
<td>Is the child verbally aggressive during conversation with adults?</td>
<td>0.23</td>
<td>0.13</td>
</tr>
<tr>
<td>30.</td>
<td>Does the child fail to say thank you upon receiving things?</td>
<td>0.15</td>
<td>0.00</td>
</tr>
<tr>
<td>31.</td>
<td>Does the child fail to give cues of listening when you talk to him/her eg no head movements or verbal feedback?</td>
<td>0.15</td>
<td>0.50</td>
</tr>
<tr>
<td>Question</td>
<td>Pre-group Mean</td>
<td>Post-group Mean</td>
<td>2-tailed p</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>----------------</td>
<td>-----------------</td>
<td>------------</td>
</tr>
<tr>
<td>32. Does the child tease other children inappropriately?</td>
<td>0.54</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>33. Is the child's facial expression generally inappropriate to the situation eg laughs, smiles, frowns etc when inappropriate?</td>
<td>0.08</td>
<td>0.13</td>
<td></td>
</tr>
<tr>
<td>34. Does the child find it hard to introduce him/herself to others?</td>
<td>0.62</td>
<td>0.63</td>
<td>1.0000</td>
</tr>
<tr>
<td>35. Does the child fail to or find it hard to tell an adult when something is wrong?</td>
<td>0.38</td>
<td>0.50</td>
<td>1.0000</td>
</tr>
<tr>
<td>36. Does the child find it hard to talk to strangers?</td>
<td>0.46</td>
<td>0.33</td>
<td>1.0000</td>
</tr>
<tr>
<td>37. Is the child unpopular?</td>
<td>0.50</td>
<td>0.33</td>
<td>1.0000</td>
</tr>
<tr>
<td>38. Does the child fail to make friends with peers?</td>
<td>0.58</td>
<td>0.83</td>
<td>1.0000</td>
</tr>
<tr>
<td>39. Does the child find it hard to or fail to take orders and obey instructions from adults?</td>
<td>0.38</td>
<td>0.25</td>
<td>1.0000</td>
</tr>
<tr>
<td>40. Is the child often cheeky to adults?</td>
<td>0.08</td>
<td>0.13</td>
<td>1.0000</td>
</tr>
<tr>
<td>41. Does the child talk too loudly?</td>
<td>0.46</td>
<td>0.29</td>
<td>1.0000</td>
</tr>
<tr>
<td>42. Does the child talk too quietly?</td>
<td>0.23</td>
<td>0.25</td>
<td>1.0000</td>
</tr>
</tbody>
</table>
Table 4
Comparison of Teacher and Parental Ratings on both Pre- and Post-group Questionnaires on Social Behaviour. Significance derived from Sign Test (for each question, the ratings of the teachers are compared with those of the parents in order to identify any significant differences.)

<table>
<thead>
<tr>
<th>Pre-group ratings</th>
<th>Post-group ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 0.5000</td>
<td>1. 1.0000</td>
</tr>
<tr>
<td>2. 1.0000</td>
<td>2. 0.5000</td>
</tr>
<tr>
<td>3. 0.1250</td>
<td>3. 1.0000</td>
</tr>
<tr>
<td>4. 0.6250</td>
<td>4. 1.0000</td>
</tr>
<tr>
<td>5. -</td>
<td>5. 1.0000</td>
</tr>
<tr>
<td>6. 0.5000</td>
<td>6. -</td>
</tr>
<tr>
<td>7. 0.6875</td>
<td>7. 0.5000</td>
</tr>
<tr>
<td>8. 1.0000</td>
<td>8. 0.5000</td>
</tr>
<tr>
<td>9. 1.0000</td>
<td>9. 1.0000</td>
</tr>
<tr>
<td>10. 0.5000</td>
<td>10. 1.0000</td>
</tr>
<tr>
<td>11. 1.0000</td>
<td>11. -</td>
</tr>
<tr>
<td>12. 1.0000</td>
<td>12. 1.0000</td>
</tr>
<tr>
<td>13. 1.0000</td>
<td>13. -</td>
</tr>
<tr>
<td>14. 1.0000</td>
<td>14. -</td>
</tr>
<tr>
<td>15. 0.2500</td>
<td>15. 0.1250</td>
</tr>
<tr>
<td>16. 0.5000</td>
<td>16. 0.5000</td>
</tr>
<tr>
<td>17. 0.6875</td>
<td>17. 1.0000</td>
</tr>
<tr>
<td>18. 0.3750</td>
<td>18. 1.0000</td>
</tr>
<tr>
<td>19. 0.2500</td>
<td>19. 0.5000</td>
</tr>
<tr>
<td>20. -</td>
<td>20. -</td>
</tr>
<tr>
<td>21. 0.4530</td>
<td>21. 0.5000</td>
</tr>
</tbody>
</table>

*p<0.05

NB The repeated use of the sign test here increases the probability of making a Type I error, that is concluding that there is a significant effect when there is none. Applying the Bonferroni correction to the above data would require a $p$ value of less that 0.0012 to be 95% confident of the difference being significant. None of the above figures reach this criterion.
To Examine the Sensitivity and Utility of an Amended Form of the Observation Scale of Behavioural Distress.
Abstract:
As a preliminary study to determine the suitability of an amended form of the Observation Scale of Behavioural Distress, 61 consecutive children presenting for surgery at a Day Surgery Unit of a children’s hospital were observed and assessed for “behavioural distress”. The evolution of this term is described, with a brief summary of similar attempts to define and measure distress in a paediatric setting. The inter-rater reliability of this amended scale was assessed and was found to be very satisfactory without the need to train raters to agree. The sensitivity of the scale was assessed by conducting a simple analysis of variance and by calculating Spearman’s correlation coefficients in order to examine whether the scale detected changes in distress associated in previous studies with three key variables determined from the patient’s parents. These variables are a) age, b) distress during previous medical and dental procedures, and c) total number of physical stressors during the current visit. The amended scale was only found to detect changes associated with age. Suggested reasons for this are given.

Note:
This study forms a pilot study to a proposed piece of work investigating the effect of the presence of parents on the distress of paediatric patients during recovery from general anaesthesia. During the closing stages of this pilot study, the further investigation became untenable for practical reasons and has therefore so far not been carried out.
Background to the Study:

Surveys of parents who have accompanied their children at induction of anaesthesia have shown that between 94% (Henderson et al., 1993) and 99% (Ryder & Spargo, 1991) of parents felt their presence to be helpful to the child and up to 95% believed themselves to have been helpful to the anaesthetist (Ryder & Spargo, 1991). Importantly the effect on the child has also been examined in this area and found to be positive, reducing “upset” defined as separation anxiety and ‘mood’ (Schulman et al., 1967). It is still unusual, however, in British hospitals for parents to be with their child during recovery from anaesthesia (Hall et al., 1995), despite the increasing incidence of parental presence at induction following a number of studies, such as those mentioned above, and further studies in which the presence of parents at induction was shown not to be disruptive (Schofield & White, 1989).

In 1992, Jolley surveyed parent and child attitudes to the experience of hospitalization and found that none of those questioned reported preoperative anxiety as being in their five most disliked aspects of being in hospital, while children reported the most negative experience to be the postoperative period (Jolley, 1992). Although this study was rather small (twenty parents and twenty children) it nevertheless suggests that recovery from anaesthesia is more troubling for children than induction. This could be due to one of at least two causes, neither of which can be obtained from the study - the first is that parents may have been allowed to be present for the induction of anaesthesia, but not during recovery. This would suggest that parental presence at induction reduces anxiety in the child quite markedly. The second cause would be simply that children find recovery more threatening than induction -implying that targeting induction as the main anxiety-provoking area would be misinformed. Either case suggests that investigation into the possible anxiety-reducing effects of parental presence at recovery would be beneficial in the amelioration of child distress during the hospital experience. Indeed, it is a standard of care stipulated in the Department of Health document “Welfare of Children and Young People in Hospital” that parents be “encouraged and enabled to be participants in the care of their children”, although this is made no more specific (HMSO, 1991).

Following an American survey (Parnass et al., 1993) in which 96% of parents asked were found to value being present in the recovery room, Hall et al. (1995) initiated a trial period of parental presence in recovery at the Birmingham Children’s Hospital during which parents and recovery staff were surveyed in order to elicit their opinions of the experience. Most parents wanted to be with their child at this time and felt that being in recovery was helpful and comforting to the child. Staff reported initial reservations about this arrangement saying that the parents were in the way and a distraction, however, as the study progressed staff who judged the trial experience to be positive increased from 58% during the first fifty cases, to 98% during the final 50 (total cases being 150 consecutive children.) Hall and colleagues stress, however, that they were
unable to determine from this study of parental and staff attitudes, the effect of this arrangement on the children's stress. Also, personal literature searches on both PsycLit and Medline have revealed no studies of the effect on the children of parental presence at recovery, despite the assumption that the well-being of the patient (ie the child) is presumably of primary importance.

It is suggested, therefore, that a study be conducted in which the effect of parental presence in recovery on the child is investigated. Before this is possible, however, it is necessary to identify an appropriate assessment instrument which measures that aspect of the child's experience with which we are concerned, and which is sensitive enough to detect changes of the magnitude one might expect resulting from parental presence. This study seeks to address these issues. In order to do this it is necessary to, firstly, identify the dependent variable - that feature of the child's experience with which we are concerned. Many studies talk of the difficulties experienced by the hospitalized child, for example the "psychological stress of admission and parental separation" (Bevan et al, 1990), the "stressful situation of hospital for the child" (Schulman et al, 1967), and "paediatric surgery can be disruptive and stressful to...[the] child" (Parnass et al, 1988). But what exactly does this mean? Stress has been conceptualised in three distinct ways (Coyne & Holroyd, 1982; Stotland, 1987) to include stressors - events or situations which are perceived as threatening, producing tension, strain - the physiological and psychological response to the stressor, and the two-way interaction between the person and the environment, between the person and the stressors, in which the demands of the situation are appraised in relation to the person's available coping resources. Taking this as a starting point it is important to consider which parts, if any, of this definition are intended when it is reported that children find hospitals and surgery "stressful." The initial part of the above definition, stress as stressor, is implicit in many of the research questions addressed, and indeed in this one, that the experience of recovery for the child is a powerful stressor. It remains to be addressed which aspects of this experience have this effect, but the main concern is the child's experience of stress. Perhaps therefore the second part of this definition will be most useful (as it logically precedes the interactional considerations.) Sarafino (1990) describes the different aspects of stress as follows: Physiological reactions involving the heart and breathing rates, and muscular tremor; occurring alongside of psychological reactions, involving both cognitive and affective processes; and social reactions in which certain situations increase the probability of negative social-behaviours and change the frequency and duration of helping behaviours (Cohen & Spacapan, 1978). Typical cognitive responses to stress are inattention and memory difficulties, while typical affective reactions can be fear, anxiety, depression and anger. The physiological reactions of increased heart and breathing rates and muscular tremor may lend themselves readily to being recorded in a clinical hospital setting, however for a child undergoing the process of recovery, and therefore having just experienced any of a wide range of physiological changes within surgery (and indeed for those about to
enter surgery for whom something is necessarily physiologically unusual already - ie the reason for surgery) these physiological features would be unreliable as indicators of levels of stress. The cognitive responses mentioned by Sarafino above may be too crude to consider as indicators of degree of stress and their measurement would be too time-consuming to be practical, and the social changes could be similarly unwieldy to measure within recovery. However there are a number of instruments available for the measurement of those affective responses mentioned, and researchers have considered them in a number of ways.

**Assessment measures:**

Bevan et al (1990) examined the child’s affective responses at *induction* of anaesthesia, and measured ‘hospital fears’ with the Hospital Fears Inventory (HFI) of Scherer & Nakamura (1968), and mood with the Global Mood Scale (GMS) (Torrance, 1968), also measuring behaviour with the Behaviour Questionnaire (Vernon et al, 1966). The HFI consists of eight items which are fearful to the general population of children, each of which are rated on a scale of one (‘no fear’) to five (‘very much’). Bevan et al’s demonstration that the child’s fears remain at a similar level before, throughout and after the hospital stay with or without parental presence suggests either that the sorts of fears measured are different from those implicitly suggested by Sarafino (1990) above, or that, if those fears measured do reflect a response to the stressor of hospitalization, they do not occur immediately upon the onset of that stressor or remit soon after its resolution. Neither alternative would suggest the use of the HFI for measuring the degree of ‘stress’ experienced at particular times.

The GMS consists of one seven-point scale from ‘playing happily’ to ‘screaming’ and is designed to reflect the overall level of disturbance exhibited by the child. Bevan et al show that the disturbance exhibited is more apparent at induction of anaesthesia than on arrival at the Day Surgery Centre for both their treatment (parent present) and control (parent absent) groups. Although sensitive enough to identify differences between the two areas of reception and induction it is possible that the GMS is not sensitive enough to detect those changes in upset identified by Schulman et al (1967) allied to parental presence (or indeed that in this instance there was no such distinction.)

The Behaviour Questionnaire (Schulman et al 1967), also used by Bevan et al (1990), consists of 28 items describing certain ‘psychological symptoms’ although Bevan et al do not suggest any medical or psychological causes of those symptoms. The original items are certain behaviours rated on a scale of 1 (‘much less than before’) to 5 (‘much more than before’), for example “Does your child make a fuss about going to bed at night?”, “Does your child spend time just sitting or lying and doing nothing?”, and “Does your child make a fuss about eating?” (Schulman et al 1967.) Indeed, although
Bevan et al describe these as symptoms, they use the BQ purely as a measure of behavioural change, amending it slightly for the ages of their subjects (5.1±1.7 years), and altering the rating system from Schulman et al's implicitly comparative responses (above) to responses pertaining to the frequency of those behaviours at the time of measurement, that is 1 ('never demonstrated that behaviour') to 5 ('disturbance was present most of the time.') The BQ was administered 1-3 weeks preoperatively and one week postoperatively, and a significant postoperative increase was identified (p<0.0001). As for the GMS above, however, no difference was detected between accompanied and unaccompanied groups and similar considerations apply. In this instance, however, it is possible that the amendments to the content and administration of the BQ made by Bevan et al changed the nature of the instrument in such a way as to mask any differences between groups; for example one could question the use of the word ‘disturbance’ rather than the more neutral ‘behaviour’ in the amended rating system. Also Bevan et al use the mean of the totals scored as their data points while Schulman et al (1967) use six factors derived from the results of Vernon et al (1966) (I-general anxiety and regression, II-separation anxiety, III-sleep anxiety, IV-eating disturbance, V-aggression towards authority, and VI-apathy-withdrawal.) However analysing these separate factors (which could be that to which Bevan et al refer when describing 'symptoms'), Schulman et al also find no significant difference between separated and accompanied groups, although separation anxiety approaches significance (0.1>p>0.05) and aggression towards authority significantly covaries with anaesthesiologist (0.05>p>0.01).

The description of the items of the BQ as “psychological symptoms” above (Bevan et al 1990) suggests that those behaviours measured arise as a result of some form of psychological change, be it distress, upset, anxiety, and so on. As a measure of changes in those behaviours per se, the BQ is largely unquestionable. Equally those factors identified by Vernon et al (1966) appear to be validly and reliably derived, but there is no indication of the sensitivity of the BQ as a measure of each these factors. Similarly, certain of those identified responses to hospitalisation (factors) could be considered trait features, while others may more appropriately be considered features of state. Thus the utility of the BQ for the purposes of detecting the immediate distress coincident with induction or recovery may be questioned in a similar way to the HFI, above. That is of the six responses to hospitalisation which the questionnaire measures, it is unclear which are most pertinent to the research question, and importantly, which vary immediately with distress and which are perhaps more long-term reactions. The question remains, therefore, whether the BQ is a suitable measure for detecting the affective changes coincident with accompanied or unaccompanied induction (or recovery.)

The measurement of distress within the paediatric population has its own implicit set of difficulties, for example the broad range of developmental sophistication from neonates
to 16 year olds - avoided by Bevan et al, above, by narrowing the age-range of the study. This measurement is made more complicated still by the rapidly changing, and difficult to monitor, levels of awareness in recovery as the patient gradually regains consciousness. The combination of these two complications renders the possibility of the use of self-report measures impossible for a study intended to examine a sample representative of the paediatric population as a whole. For example the utility of The State-Trait Anxiety Inventory for Children (STAIC) (Spielberger et al, 1973) and the children's form of the Manifest Anxiety Scale (Castaneda et al, 1956) - otherwise useful instruments - would be compromised both by the varying levels of consciousness of the subjects (begging the question theoretically of when to administer it and practically of how to identify when that time occurs) and by the age range of the target population, the STAIC for example being inappropriate for children below 8 years of age (Jay et al, 1983.) Observational scales, therefore, would appear to be the most effective way of avoiding the complication of level of consciousness in the sample. The problem remains, however, of the degree to which such scales, which must logically be behavioural, measure underlying psychological distress or straightforwardly measure the rates of certain behaviours the cause of which may be hypothesised later. Similarly remaining to be addressed is the degree to which certain behaviours reflect psychological distress across the broad developmental spectrum of the paediatric population.

Defining and Assessing Distress:

In 1980, Katz, Kellerman and Siegel developed an observational scale for the examination of behavioural responses to bone marrow aspirations (BMA's) in paediatric cancer patients, similar to the Observer Rating Scale of Anxiety (Melamed & Siegel, 1975; Jay et al, 1983) called the Procedural Behaviour Rating Scale (PBRS.) However, it has been pointed out that "the authors, however, do not distinguish between behaviour that might be attributed to anxiety and that which might be attributed more appropriately to pain." (Shacham and Daut, 1981). These reviewers state that the difficulty distinguishing anxiety and pain arises from the facts that the two are constructs, and that they are intimately related (although distinct), in that pain can cause anxiety, and anxiety can mediate the experience of pain. They point out that Katz et al's correlation between the ratings of the PBRS and nurses' ratings of anxiety is a good first step towards identifying the constructs being examined, but that the directly causal relationships between the surgical procedure and the observed behaviour should also be considered. However, perhaps a more vigorous approach would be a factor analysis of the results obtained from the scale. (Also such concurrent validation should ideally include further variables which perhaps would not be expected to correlate (Hammond, 1995) - in this instance pain.) The clinical importance of this distinction is that interventions intended to affect anxiety or pain are often very different, for example
analgesia and relaxation. Although, as stated above, changes in one can lead to coincident changes in the other, precise measurement and distinction of the constructs would enable more precise targeting of clinical interventions.

Katz, Kellerman and Siegel’s (1981a) reply to these concerns emphasises that “it may not be feasible to separate anxiety from pain, since anxiety is the basic affective experience that modulates perceived pain (Bonica, 1977; Chapman, 1977; Schalling, 1976.)” They point out also that further research (Katz, Kellerman & Siegel, 1981b) found that the PBRS correlated significantly more highly with a self-report measure of ‘fear’ than a self-report measure of ‘pain’, and conclude by defining the construct measured by the scale as “behavioural distress” a term which includes all behaviours consistent with negative affect, such as anxiety, fear and pain. This term is also adopted by Ambuel et al (1992) who describe ‘psychological distress’ in a similar way to the above definition of stress (Coyne & Holroyd, 1982; Stotland, 1987) in that it is a response to aversive stimuli which may be internal as well as external, and may therefore include anxiety, fear, discomfort and pain. The distress response to these stimuli is described as multidimensional, with three general categories: Behavioural - such as crying, avoidance, grimacing and so on, physiologic - such as increased heart-rate, blood pressure etc, and phenomenologic - for example self-report of anxiety, fear and so on. As pointed out above, self-report and physiological changes have their own unique difficulties with a post-operative paediatric sample, while behavioural observation can be reliable, clinically practical, and unintrusive. A scale which utilises behavioural observation for the measurement of ‘behavioural distress’ as defined above, would avoid the problems delineated by Shacham and Daut (1981) and would measure those variables alluded to when the ‘stress’ or ‘distress’ of the child is of concern (Bevan et al, 1990; Schulman et al, 1967; Parnass et al, 1993.)

The Observation Scale of Behavioural Distress (OSBD):
(Jay, Ozolins, Elliott & Caldwell, 1983)

The OSBD is a refinement of the Procedure Behaviour Rating Scale (Katz et al, 1980) in which 13 operationally defined behaviours are recorded either as present or absent during the relevant procedure. The OSBD differs from this in three ways: Firstly, it consists of 11 operationally defined behaviours which are listed below (three of the PBRS categories being collapsed into one, and one, Nervous Behaviour, being added.). Secondly, behaviours are recorded in continuous 15-second intervals, and thirdly, a weighting score of severity of distress is included for each behavioural category in the scale as follows: Cry (1.5), Scream (4.0), Physical Restraint (4.0), Verbal Resistance (2.5), Requests Emotional Support (2.0), Muscular Rigidity (2.5), Verbal Fear (2.5), Verbal Pain (2.5), Flail (4.0), Nervous Behaviour (1.0) and Information Seeking (1.5). Definitions of these behaviours are included on the
amended OSBD questionnaire in the appendix.)

During the development of this scale, reliability was checked in the following way: Of the total 42 subjects, seven were chosen at random and the Pearson product moment correlation coefficient, \( r \), between the scores of the two observers completing the OSBD was calculated. Over the four discrete time-phases of hospitalization examined by Jay et al, \( r = 0.99 \). Reliability was also checked using the ‘agreements-disagreements’ method in which the number of agreements within each interval was divided by the total number of agreements plus disagreements. The percentage agreement over the four time phases by this method was 84%. This value, however, does not correct for chance agreement. Such a correction would involve the calculation of the expected frequencies of agreement between independent judges (Cohen, 1960), which requires access to Jay et al’s data. The validity of the scale was assessed by correlation with other measurements conducted in parallel. Total distress scores on the OSBD correlated with other measures as follows:

- Trait Anxiety scores (STAIC, Speilberger et al, 1973)...
  \[ r = 0.63, p<0.001 \]
- Pain Thermometer (Katz, 1979) - anticipated pain...
  \[ r = 0.76, p<0.0001 \]
  - experienced pain...
  \[ r = 0.62, p<0.02 \]
- Parent Evaluation Questionnaire (PEQ) (Jay, 1980)
  - child anxiety at clinic...
  \[ r = 0.38, p<0.04 \]
  - child anxiety last 24 hours...
  \[ r = 0.38, p<0.04 \]

A further validity study (Elliott, Jay & Woody, 1987) obtained Pearson product-moment correlation coefficients between OSBD scores and other measures obtained the following values:

- Nurse ratings of distress...
  \[ r = 0.69, p<0.0001 \]
- Self-report fear measure...
  \[ r = 0.38, p<0.01 \]
- Pain Thermometer (Katz, 1979), anticipated pain ...
  \[ r = 0.24, p<0.05 \]

The above validity studies suggest that the OSBD measures behavioural distress as composed of certain constructs including ‘fear’ as reported by the patient, ‘distress’ as reported by the nurse, ‘anticipated pain’ by self-report, a degree of ‘pain’ again reported by the patient, and parental evaluation of the child’s ‘anxiety’. No mention is made of potential correlation with the state items of the STAIC, while the trait items

1 Considered to be a visual analogue of pain experience on a 0 to 100 scale on which children were asked to rate their level of anticipated, or experienced, pain (depending on the time phase relative to surgery.)
2 Not described.
3 5-point Likert scale, 1 - “no distress” to 5 - “extreme distress”.
4 Prior to bone-marrow aspiration, children were asked “how scared” they felt on a scale of three faces ranging from a happy face - “not at all scared” to a sad face - “very scared”.

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positively correlate at a $p<0.001$ level. While it may be hypothesised that the OSBD therefore measures trait anxiety, this correlation may more reasonably be taken to indicate a predisposition of the child with high trait anxiety to exhibit increased distress behaviours post-operatively. The lack of mention of a correlation with the state anxiety scale, can only be interpreted as a failure to achieve a significant correlation, since such a measure was made, as described in Jay et al’s (1983) method section. This apparent absence of a correlation can only be described as surprising in the light of the other measures with which the OSBD covaries. While this absence certainly merits further investigation$^5$ it is argued here that those constructs defined above with which the OSBD does correlate provide a suitable definition of the distress with which we are concerned to ameliorate. It is also of note that, although a significant correlation was obtained by Jay et al (1983), OSBD total scores did not correlate with self reports of actual experienced pain from the Pain Thermometer in the study of Elliott, Jay & Woody (1978) although they did correlate with anticipated pain, suggesting that the OSBD measures more of the anxiety/apprehension component of behavioural distress than that of pain. Both of these studies involve the same methodology, statistical analysis, and gender-mix. Jay et al used 42 subjects of whom 25 were seven years old or over, those being eight or over completing the anticipatory and experienced pain measures, while Elliott et al used 55 subjects and do not specify which children completed those measures, although 29% ($n=16$) of their subjects were at least eight years old. It is difficult to judge, therefore, between the conflicting results, the most conservative conclusion to draw being that both studies demonstrate that anticipated pain correlated more highly than experienced pain, whether or not the latter was significant.

This measure was chosen as the most suitable with which to measure children’s behavioural distress. However certain amendments were made, as elaborated below.

**The Amended Form of the OSBD (OSBDa):**

The study of Elliott, Jay & Woody (1987), based on a research note of Jay and Elliott (1984) also investigated whether the validity of the OSBD was compromised when the intensity weighting system and interval scoring methodology were disregarded. It was shown by way of an $r$ to $z$ transformation for dependent samples (Glass & Stanley, 1970) that the validity coefficients for the self-report measure of fear and anticipated pain were not significantly different, although those of the nurse ratings of distress were higher for the original mode of administration ($z = -2.5$, $p<0.05$). Jay and Elliott (1984) found by way of a $t$-test for the significance of the difference between these two methodologies that none of the differences in validity coefficients from those correlations above (STAIC, Pain Thermometer and PEQ) approached significance.

$^5$ See the following study in this portfolio.
For reasons of practicality, therefore, given the otherwise intrusive nature of the instrument on staff resources, it was considered valid to abandon the time-sampling aspects of the formal administration, behaviours being scored instead over the entire observation period. As Jay & Elliott (1984, p1107) point out, "...the cost effectiveness of an instrument must be considered in relation to its demonstrated validity." Given that both studies (Jay & Elliott, 1984; Elliott et al, 1987) examined the validity of the OSBD either with or without both of these administration features, that is neither study examining the validity resulting from the use of one or the other, it was considered appropriate to abandon both or neither. The amended OSBD used in this study, therefore, involved neither time-sampling nor weighted scoring. The administration procedure involved two nurses observing each child for one minute and then each individually scoring the child for frequency of each behaviour (see below.) Two nurses were required in order to assess inter-rater reliability for the amended measure, and it was only possible to guarantee two nurses in recovery at the same time for one minute.

Although Elliott et al (1987) describe a measure which correlates more highly with parallel validating measures as more "sensitive", it was considered that one could only strictly infer increased validity, the sensitivity of the measure to be addressed by some other means. Although these authors had demonstrated that the validity remained essentially the same, the rigorous administration having been abandoned, it was not apparent whether the sensitivity was compromised or not. It is clear that a 'yes or no' decision which is taken every fifteen seconds for the duration of the observation time will detect differences between children which would go unnoticed by a measure which makes one overall such decision, and in this way it may be said that the sensitivity of the latter measure would be restricted. In order to correct to some extent for this effect, it was decided to change the 'present or absent' analysis of each behaviour to a four-point Likert scale anchored at 0 (not at all), 1 (a little), 2 (rather a lot) and 3 (all the time.) A similar decision was taken by Bachanas and Roberts (1995), although they chose to use a ten-point Likert scale. For the purposes of this study, it was felt that a four-point scale was more appropriate since the greater the available choice for each item, the greater the probability of inter-rater disagreement. Although as sensitive a measure as possible is the ideal tool, an exquisitely sensitive measure upon which no-one can agree loses its utility. Bachanas and Roberts (1995) do not state how long it took to train their raters to agree up to their 85% level. In the clinical environments of a Day Surgery Unit and a main theatre, with pressure of both shift-patterns and surgical lists, it is not possible to train everybody involved in the study to agree when using the measure, and so a compromise was made between measure-sensitivity and inter-rater agreement. Just as Jay et al (1983) did not train their raters, so the raters for this study (nurses), for the reasons given above, were not trained to agree on their ratings for the OSBDa. However every rater was trained in the administration of the measure, that is,
when to observe, how to rate, and not to compare ratings with the other nurse. For the original OSBD, inter-rater reliabilities were good, as given above.

Apart from the above reasons, a further rationale for not training to agree was that a valid measure which can be demonstrated to be reliable without such training becomes immediately available to anybody who may require to use it. For example Bachanas and Roberts' (1995) version would require training before being used - and it could be debated whether their sample of all possible raters was representative, that is, further teams of raters may be trained to agree, but the agreement upon which they converge may or may not agree with the 1995 sample.

To summarise, the OSBDa consists of the eleven operationally defined behaviours of the OSBD, each being rated on a four-point Likert scale after one minute of direct observation. An example of this instrument can be found in the appendix.

To examine the sensitivity of the OSBDa:

Because it is unknown how large or small an effect the presence of a parent may have, reports regarding the sizes of the effects of other independent variables were investigated in order to obtain some idea of what to expect, such that an appropriately sensitive measure could be found. It was assumed that if the OSBDa were sensitive enough to detect covariation between those variables and the child's distress, it would be likely to be appropriately sensitive to detect differences which we may attribute to parental presence.

**Age**

Bachanas and Roberts (1995), in a study of children’s and parent’s attitudes to health care also identified correlations between these attitudes and the distress behaviours of the child. Also noted was the relationship between the age of the patient and the behavioural responses during aversive medical procedures. Distress was measured during a finger-prick blood-test, using a scale derived from the eleven behavioural items of the OSBD (Jay et al, 1983) using a ten-point Likert scale with higher scores indicating increased distress, as mentioned above. The anchors for the scale, unfortunately, were not given. A hierarchical multiple regression analysis was conducted for distress scores with age entered as the first independent variable, being found to account for 5.5% of the variance in distress ($\beta=0.24$, $p<0.05$) with younger children exhibiting more distress than older children$^6$. The subjects used in this study were aged between six and eleven years (mean=8.2) with an equal gender split, and the

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6 The overall $R^2$ was significant, $F(8,62)=3.94$, $p<.001$, accounting for 34.7% of the variance.
'aversive' procedure could be described as relatively minor. In contrast, Jay et al (1983) measure the distress of their subjects during bone-marrow aspiration procedures which "are reported by both parents [typographical error, meaning patients] and their parents to be the most painful and traumatic events in the entire therapeutic regimen."

The 42 subjects were divided into three age groups: I, 2-6 years (males=12, females=5); II, 7-12 years (m=9, f=8); and III, 13-20 years (m=5, f=3). Jay et al identify a significant drop in distress levels between the ages of six and seven, which they hypothesise may be explained by cognitive-developmental factors. The impact of this difference would not have been identified within Bachanas’ and Roberts’ (1995) sample.

Jay et al (1983) point out that the means between their two older age groups do not differ significantly ($t(32)=0.68$, $p<.50$), while the differences between the mean of the youngest group and those of groups II and III were particularly significant: $t(32)=8.39$, $p<.0001$ and $t(32)=6.58$, $p<.0001$ respectively. It may be argued that, although their result is significant, Bachanas’ and Roberts’ (1995) results mask this stepwise increase in distress both by failing to include younger subjects in the sample, and by using the multiple regression mode of analysis. Nevertheless, both studies demonstrate that less distress is exhibited by older children than younger.

**Stressful experiences during the current visit**

Saylor, Pallmeyer, Finch, Eason, Trieber and Folger (1986) assessed the distress of 19 males and 20 females aged between 5 years, 9 months to 15 years, 11 months (mean=9 years, 8 months) when hospitalized for a wide variety of medical reasons including major surgery, chronic illness and trauma. Distress was measured using a revised form of the BUMP (Zeldow & Braun, 1983) - 'R-BUMP' which is a 28-item checklist of behaviours which are rated by the parent on a 0-4 scale indicating frequency and anchored “never” (0) and “always” (4). The number of physical symptoms experienced by the child during that hospital visit, such as nausea, pain, and difficulty eating, and the number of physical stressors, such as inability to use the toilet, IV insertion and X-ray were identified by way of interview with the parent. The total number of symptoms and stressors experienced was then used as a measure of physical stress experienced by the child. A Pearson correlation analysis was conducted to examine the relationship between these two variables, and total number of stressors was found to account for 28% of the variance in distress ($r=0.53$), being significant at the $p<.001$ level.

**Previous distress during medical and dental procedures**

Consistent with the well-known rule of thumb that a reliable predictor of future
behaviour is past behaviour, Frank et al (1995), in their investigation into the effects of the behaviour of parents and staff on the distress and coping behaviours of the paediatric patient also included as a predictor variable the distress exhibited during previous medical and dental procedures. 77 children aged between 4 and 7 years (mean = 6.2) were observed receiving routine immunisations, 36 being male, 41 female. Distress during each previous procedure was rated by parents on a four-point scale, anchored as “not at all upset” (0), “a little upset” (1), “upset” (2) and “very upset” (3), after which each score was summed and then divided by the total number of previous experiences to provide an index of average prior distress. Distress observed during the current procedure was measured using the CAMPIS-R (Blount et al, 1990), a system of transcribing video observation of verbal behaviours into categories, the child distress behaviour categories being crying, screaming, verbal resistance, emotional support, verbal fear, verbal pain, verbal emotion, and information seeking. Use of this scale requires raters to complete a three-month training program to reach 80% agreement, which ruled it out of consideration for the current study. Rate of distress behaviours was calculated by summing the occurrences of distress behaviours and dividing that total by the number of minutes required for the procedure. Hierarchical multiple regression analysis was conducted for rate of distress behaviour as the dependent variable, with previous experience entered as the third-step independent variable. Previous experience was found to account for 4% of the variance in distress (β=0.18, p<0.05) with increased experience being associated with reduced distress.

Apart from their demonstrated association with changes in behavioural distress, these three variables were chosen for the study because they consist of information easily obtained from either medical notes or brief interview with the parent. Other variables which have been shown to account for variance in distress such as parent and staff behaviour (Frank et al, 1995), child health-care attitudes and health locus of control (Bachanas and Roberts, 1995) and distress behaviour prior to hospitalisation (Saylor et al, 1986) are significantly more costly in terms of both time and staff resources.
**Method:**

The study was approved by the Merton and Sutton Local Research Ethics Committee, and a copy of the letter of approval can be found in the appendix of this study. Informed parental consent was obtained preoperatively. It was not considered necessary to obtain direct consent from each child, as the child had no active part in the collection of data. Children may be considered to have given consent by proxy through their parents and no children objected to their parents’ consent when given.

**Subjects:**

Subjects were all paediatric day surgery patients between the ages of 2 and 16, and their parents, presenting for surgery at Queen Mary’s Hospital for Children within a specified eight week period (n=61) although certain exclusion criteria were applicable (see below.) Because previous studies (Bevan et al (1990), Jay et al (1983), Frank et al (1995)) demonstrated no effect of gender on distress, the gender of subjects was not recorded, and it is assumed that the sample of patients taken within the specified time is representative of the general paediatric population in this respect. Although the sample represents all surgical work undertaken by the unit, the majority of subjects underwent ENT or dental work. Subjects were excluded a) if consent was not obtained from the parent, b) if there was a diagnosis of significant behavioural disturbance (being any of the following: Attention-Deficit Hyperactivity Disorder (ADHD), Conduct Disorder, Oppositional Defiant Disorder, Separation Anxiety Disorder, and Overanxious Disorder) or c) if the child had a learning disability. This latter group was excluded for the following reason: 30-75% of people with learning disabilities are likely to have concomitant disorders such as ADHD (Kaplan & Sadock, 1990) which may have biased the results and which may or may not be formally diagnosed; It would not be reasonable to expect ward and recovery nurses to make the decision regarding the suitability of each such patient for the study and so this group was excluded by way of diagnosis of learning disability in the medical notes.

**Instruments:**

[Examples of all instruments may be found in the appendix.]

**The OSBDa**

This scale is described above.

**Information Questionnaire**

A brief questionnaire was devised in which parents were asked to answer four questions related to their child: ‘How old is your child today?’, ‘How distressed was your child during previous medical and dental procedures?’, ‘What physical symptoms has your child experienced during this visit to the hospital?’, and ‘What stressful experiences has your child had during this visit to the hospital?’ The second question
was followed by ten spaces in which previous procedures could be written, alongside each of which was a four-point Likert scale anchored at 3 ("very upset"), 2 ("upset"), 1 ("a little upset"), and 0 ("not at all upset"), which the parent was asked to use to rate the level of distress for that procedure. Questions 3 and 4 each provided a number of examples of symptoms and experiences, respectively, which the parent was required to tick if applicable, followed by further spaces in which to add any other symptoms/experiences.

For the purposes of the analysis of variance (see Results), the following categories were imposed on this information:

- **Age** was divided into younger (≤7 years) and older (>7 years) children.
- **Previous distress** was calculated as the sum of distress scores divided by the number of previous experiences, and categorised into “less upset” (≤1 average score) and “more upset” (>1 average score).
- **Stressful experiences** was calculated as the number of physical symptoms and stressors present during the current hospital visit. Scores were categorised as “stressor absent” (number of stressors =0) and “stressor present” (number of stressors >0).

**Procedure:**
Upon arrival at the Day Surgery Unit, parents were asked if they would be willing to participate in the study. All nurses were briefed in the purposes of the study, and its practical application, and at least one nurse was always available to answer any questions of parents. An information sheet was also available, the content of which was passed by the Merton and Sutton Local Research Ethics Committee, and those parents who agreed signed a consent form (see appendix for examples of both the consent form and the information sheet.) Of those parents who did not wish to participate, no information was recorded. Those parents who agreed to participate were given an **Information Questionnaire** to complete while their child was in theatre. Whilst in recovery, each child was observed by two nurses for one minute and then each nurse independently completed an **OSBDa**. The nurse collecting the child from recovery was responsible for pairing both completed OSBDa’s with the completed Information Questionnaire. A fail-safe procedure was adopted in which an index number previously allocated to each Information Questionnaire was copied onto each relevant OSBD. However, despite this, a small number of questionnaires did not have corresponding pairs, and of the 61 subjects, 9 were not assessed with the OSBDa and 11 were not assessed with the Information Questionnaire. The former 9 were dropped from the study, while the latter 11 were included in the analysis of inter-rater reliability.

During the first six weeks of the data-collection period it was noted that parents were marking very few physical symptoms and stressors as present for their children, occasionally leaving one or both of these sections blank. In order to address whether
this was a true representation of the facts, or an effect of inattentiveness in completion of the questionnaire in the presence of other over-riding concerns of the parent, the experimenter (JC) visited the unit to administer each Information Questionnaire as a brief interview for one complete surgical list (n=6). It was found that within this sample, few symptoms or stressors were present and it was concluded that the Information Questionnaires accurately captured the situation, in which most children did not suffer significantly from such things (see Discussion.)

**Results:**

**Inter-Rater Reliability**

The degree to which each pair of OSBDa’s concur in their ratings of the children is illustrated diagrammatically in the following grid, *figure 1*:

![Figure 1](image)

It should be stressed that “OSBDa 1” and “OSBDa 2” are convenient labels for distinguishing each scale of each pair. In practice each rater pair was drawn from the entire nursing cohort of the unit. Each child was rated twice, each scale then being allocated randomly to the group ‘OSBDa 1’ or OSBDa 2’. It is therefore erroneous to consider scores from each scale as more consistent than scores between each scale or draw conclusions about the direction of any discrepancy between members of each pair. For each OSBDa completed, an index of overall distress is obtained by summing the Likert values for each behavioural item; the minimum score is therefore 0, the maximum 33. The maximum obtained value however, was 11. *Figure 1* is a contingency table indicating the level of concordance between the two OSBDa’s of each
pair, the axes to the top and the left of the grid indicate possible obtained overall
distress scores for scales 1 and 2 respectively, for example both scales indicate overall
distress scores of 0 for 17 children, while on 4 occasions scale 1 indicates a score of 1
while scale 2 indicates a score of 0. The lower axis indicates total number of subjects
obtaining that overall score for scale 1, while the axis to the right indicates similar
information for scale 2. 52 therefore is the grand total of these axes, indicating the
subject numbers.

A measure of Cohen's Kappa (Cohen, 1960) which provides a measure of percentage
of agreement corrected for chance, may be derived from this information. This
calculation yields a value of 0.49. Thus, both scales give equivalent overall distress
scores for 49% of the patients. That each of the OSBDa scales per child are allocated at
random to the groups OSBDa 1 and OSBDa 2 is of no consequence to this calculation.
Landis and Koch (1977) categorise this level of agreement as "moderate." It is argued
here, however, that agreement as implicitly defined above (both raters give the same
score) is too strictly defined for this sort of data. This definition supposes that a
discrepancy of one point between overall scores is disagreement and is disregarded as
such to a similar extent as a discrepancy of 10 or 11 points. This approach is ideal for
categorical information, but for the OSBDa - in which the information obtained may be
considered an ordinal measure of "amount of distress behaviour" - the difference
between these discrepancies cannot be disregarded. It can be seen from Figure 1 above
that many of these discrepancies lie within one or two points of pure agreement.
Indeed, the figure may be viewed as a rough scatterplot of the obtained scores. Because
the scales provide information which allows meaningful ordering of children by overall
distress, a more appropriate indication of agreement is the degree to which each rater
would similarly arrange the children in order of distress. This is given by Spearman's
correlation coefficient calculated for overall distress scores for each rater: \( r_s = 0.92 \)
(N=52), \( p<0.001 \). Similar results are given below for each behavioural item of the
OSBDa; significance is one-tailed:

<table>
<thead>
<tr>
<th>Description</th>
<th>( r_s )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>0.90**</td>
</tr>
<tr>
<td>Scream</td>
<td>0.48**</td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>0.67**</td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0.63**</td>
</tr>
<tr>
<td>Requests Emotional Support</td>
<td>0.76**</td>
</tr>
<tr>
<td>Muscular Rigidity</td>
<td>0.33*</td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>0.77**</td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0.14</td>
</tr>
<tr>
<td>Flail</td>
<td>1.00**</td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>0.47**</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>0.79**</td>
</tr>
</tbody>
</table>

\( ** p<0.001 \)  
\( * p<0.01 \)
From Figure 2 it can be seen that most of the behavioural items exhibit good agreement between raters, by our ordinal definition. Muscular rigidity is less reliable and the Verbal Pain item cannot be said to be a reliable measure (see Discussion).

(It may be argued in this instance that the random allocation of each OSBDa to group 1 or group 2 necessarily and artificially scatters the scores around the diagonal line of perfect agreement between each scale. Such allocation would also increase the spread of data points around this line, so reducing the correlation coefficient. As a demonstration of the effect of the other extreme, ie with the overall score-pairs for each child being forced into specific groups such that any pair in which there was a discrepancy of overall score, the lower score was consistently forced into group 1 - in a sense, one rater consistently underscored the other when there was disagreement, a further Spearman correlation coefficient was calculated for the two groups. The value of this coefficient is $r_s = 0.95$ (N=52), $p<0.001$.)

Level of Sensitivity

The means and standard deviations of the variables to be examined are presented in Figure 3 below. As a result of the satisfactory agreement between raters, the results obtained from group 1 were used for the remainder of the study:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>6.734</td>
<td>3.697</td>
<td>2.00-15.00</td>
</tr>
<tr>
<td>Previous Distress</td>
<td>0.869</td>
<td>0.830</td>
<td>0.00-3.00</td>
</tr>
<tr>
<td>Physical Stress</td>
<td>0.854</td>
<td>1.429</td>
<td>0.00-8.00</td>
</tr>
<tr>
<td>Overall distress</td>
<td>2.192</td>
<td>2.590</td>
<td>0.00-10.00</td>
</tr>
<tr>
<td>(OSBDa)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 3

A simple analysis of variance of overall distress by age, previous distress and physical stressors\(^7\) was conducted to test whether the differences between the mean overall distress between groups as predicted above by Frank et al (1995), Bachanas and Roberts (1995) and Saylor et al (1987) could be detected. A summary table of this investigation is presented below (figure 4).

\(^7\)See definitions of each group under “Instruments” above.
Figure 4

The mean overall distress for each category is as follows:

<table>
<thead>
<tr>
<th>Age</th>
<th>Mean</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger (x≤7)</td>
<td>3.40</td>
<td>20</td>
</tr>
<tr>
<td>Older (x&gt;7)</td>
<td>1.11</td>
<td>9</td>
</tr>
</tbody>
</table>

Previous distress

<table>
<thead>
<tr>
<th>Previous distress</th>
<th>Mean</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less upset (x≤1)</td>
<td>2.36</td>
<td>22</td>
</tr>
<tr>
<td>More upset (x&gt;1)</td>
<td>3.71</td>
<td>7</td>
</tr>
</tbody>
</table>

Physical stressors

<table>
<thead>
<tr>
<th>Physical stressors</th>
<th>Mean</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressor absent (x=0)</td>
<td>2.67</td>
<td>15</td>
</tr>
<tr>
<td>Stressor present (x&gt;0)</td>
<td>2.71</td>
<td>14</td>
</tr>
</tbody>
</table>

Figure 5

It is clear from Figure 4 that the only significant effect is that of age. This analysis shows no effect of previous distress or physical stressors. Similarly, no interactional effects are demonstrated, though none were anticipated. Because a number of the cell sizes were very small, for example previously 'more upset' N=7 (Figure 5), further investigation was made into the potential relationships between these predicted variables (rather than the variable categories) by way of further Spearman correlation coefficients. This investigation further supports the results of the ANOVA (see Figure 6, below).
No association between distress and two of the three predicted variables can be demonstrated in this sample, using the OSBDa. The results for age, however, are consistent with both Bachanas and Roberts (1995) and Jay et al (1983).

**Discussion:**

Results indicate that the amended OSBD, OSBDa, demonstrates considerable inter-rater reliability *without* those raters having been trained to agree. This suggests that the items are not particularly open to interpretation by individual raters, from which it may be concluded that further raters are likely to understand each item in a similar way, thereby rating their subjects in a similar fashion. In this way it can be inferred that the OSBDa is a scale which may be used by other raters, for other purposes, without specific training in the use of the measure. It could be argued that this study has shown that paediatric nurses agree on their ratings without such training, and that such raters may by virtue of their professional skills be more accurate in their assessment of the behavioural distress of a paediatric patient. Further research would be able to address this point, but it is argued here that the behavioural items are sufficiently defined to override this effect, and that professional nursing skills do not affect the remaining variable of the scale - the choice of Likert score to assign; that is, whether a behaviour occurs 'a little' or 'rather a lot'. Because the nature of the items of the OSBDa are identical to the OSBD, the validity of the scales is assumed to be comparable; indeed, as demonstrated by Elliott, Jay and Woody (1987), drastically altering the way in which the scale is scored does not significantly alter the correlations with validity measures.

The question of the reliability of the scale raises the methodological issue of how most effectively to address issues of agreement and disagreement, and of how those concepts may be defined. Bachanas and Roberts (1995) use Cohen's Kappa as their measure of inter-rater reliability and impressively reach a value of 0.89 after a period of training each rater to agree. It is not made explicit how such training is undertaken, but a reasonable suggestion would be that the raters assess a subject, and then negotiate together to reach a consensus on the rating given. This would be repeated until such negotiation was unnecessary and the raters had learned to rate in similar ways, at a previously determined appropriate level of agreement. This point upon which the raters

<table>
<thead>
<tr>
<th>OSBDa with...</th>
<th>N</th>
<th>$r_s$</th>
<th>2-tailed sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>42</td>
<td>-0.3398</td>
<td>0.028</td>
</tr>
<tr>
<td>Previous distress</td>
<td>29</td>
<td>0.2385</td>
<td>0.213</td>
</tr>
<tr>
<td>Physical Stressors</td>
<td>42</td>
<td>0.0501</td>
<td>0.753</td>
</tr>
</tbody>
</table>

*Figure 6*
converge and agreement is achieved depends on the training procedure involved, the people being trained and the points from which they begin to converge. At least two of these variables cannot be accounted for should further training of raters be attempted, for example in the event of another researcher wishing to use the measure, and the first variable above is also unaccountable if the specific training procedure is not described. As described above (An Amended Form of the OSBD) the point upon which future raters converge may well be different from that upon which the initial raters arrive as described in the initial study, the variance depending on the three variables alluded to above. It is argued here that an instrument only becomes reliably universally applicable if all the conditions of the initial reliability study are satisfied in subsequent instances of that instrument’s use. Pragmatically this is impossible to achieve, but the effect can be minimised if a scale can be shown to be reliable without introducing further variables to be accounted for in future (such as a procedure for training to agree.)

The second issue to arise from this question is that of the definition of ‘agreement’. Bachanas and Roberts (1995) can only be applauded for their above value of Kappa, in the light of the strict definition of agreement which it supposes. It has been argued here that correlational measures of concordance provide an alternative means by which to measure agreement, but that the definition that these means suppose is necessarily different. This definition is inherent in the correlational measure employed, and is probably best left implicit in the statistical procedure itself; however, for Spearman’s correlation as used in this study, the implied definition of agreement is the degree to which each rater would similarly rank their subjects in order of distress. A correlational measure of agreement takes account of the degrees of disagreement, rather than the incidences of perfect agreement. Such a measure may be more appropriate for data in which the degree of disagreement is meaningful, however, it is for the researcher to decide the type of agreement in question when deciding which such measure to employ. Again, there is scope for further study on this point.

Both the analysis of variance and the correlational analysis of the three variables predicted to be associated with changes in distress show that only changes associated with age-group are detected by the OSBDa in this study. There are a number of potential explanations for this finding. The first is that the OSBDa as described is not sensitive enough to detect the size of change associated with changes in the two non-significant predictor variables. This study was designed to establish whether the OSBDa is sensitive enough to detect the degree of change associated with the three predictor variables, and from these results it cannot be concluded that the OSBDa is not sensitive enough, the correct conclusion to be drawn being that further study is required to address this point. A further explanation is that other variables diminished the sensitivity of the study per se, particularly sample size. As pointed out above, the numbers of subjects per ANOVA cell, once all data was collected, were unfortunately small - an unavoidable occurrence due to practical constraints. Although the significance
and size of the correlations of the non-significant variables are known from the corresponding studies, the effect sizes are not, and it is possible that the power of the current analyses was significantly compromised by reduced sample size. It should be pointed out, however, that Saylor et al's (1987) sample size was 39. Although a reduced sample size increases the probability of making a type II error, it also increases the probability of unwittingly assigning subjects to different groups in such a way as to suggest an effect when there is none. Although this is possible for Saylor et al's study, it is considered unlikely given the strength of their obtained correlation. Nevertheless, a more serious objection may be made concerning the measure used in their study. This was a behavioural measure designed for adults which was revised for that study by five psychologists and psychiatrists marking those items they considered inappropriate for children, those items of which three of the five judges considered inappropriate being discarded. Although this method is commonplace, it is often appropriate to then test the resulting scale for validity and reliability. These factors are asserted by the authors regarding the unrevised measure and are not assessed for the revised version, although this shortcoming is drawn to the reader's attention by the authors. It is possible that the resulting significance is erroneous. A further potential confounding variable in the current study is the number of physical stressors experienced by the children in this study, which can be seen from figure 3 to be very low. This reflects differences in the subject cohort - the current study being day surgical patients who had spent a limited amount of time in the hospital when this measure was taken, thereby reducing the opportunity to be subject to a larger number of stressors; Saylor et al's (1987) cohort had been hospitalized for at least 48 hours prior to the measure being taken. A broader spectrum of children was therefore available to be examined.

Regarding the distress of the children during previous medical and dental procedures, the relationship between effect size and sample size mentioned above is relevant. It is unfortunate that the current sample divided into one group of 22 ("less upset") and one of 7 ("more upset"). A further aspect of the current study which may act to mask this and the other expected effect is that, as can be seen in figure 1, most children exhibited no or very little distress behaviour. This restricted range of distress would serve to mask potential effects of the predictor variables unless those effects were large, such as for age. If it were possible to re-anchor the Likert scale of the OSBDa to ignore high frequencies of behaviour (eg "all the time"), more selectively examining the range more often exhibited by the children in this study, these effects, should they exist, may be detected.

Overall it is without question that the OSBDa is highly reliable, and it is argued that its validity is comparable to that of the original OSBD (Jay et al, 1983). Unfortunately, its sensitivity remains to be proven by further research.
References:


Appendix to Section 3 iii
17 October 1996

Mr James A Cromwell
Clinical Psychologist in Training
5 Winfield House
Vicarage Crescent
Battersea
London SW11 3LN

Dear Mr Cromwell

The effect of parent/carer presence in the recovery room on the behavioural consequences of surgery on paediatric patients - Pilot Study

Thank you for your study application. This was discussed by the Committee at our meeting on 25 September and approved, conditional on the upper age limit being reduced to 16, since this is a paediatric study.

I look forward to hearing from you.

With kind regards

Yours sincerely

Dr Hervey Wilcox
Chairman LREC

All Correspondence to: Chairman’s Office (LREC), The St Helier NHS Trust, Wrythe Lane, Carshalton, Surrey. SM5 1AA
The Effect of Parent/Carer Presence in the Recovery Room on the Behavioural Consequences of Surgery on Paediatric Patients. Pilot Study.

Parent Information Sheet

When children wake up following general anaesthetic, they sometimes become distressed because the room in which they awaken (the recovery room) often has not been seen before, and the staff and fellow patients can be strangers as well. The process of recovery from a general anaesthetic can also be a cause of worry for the child in itself.

You are being asked to help in a study which looks at whether or not children are less distressed when their parents or carers accompany them in the recovery room. That is, when the child wakes up, the parent is with the child. The study is in two parts, and you are being asked to help in the first part only. The second part of the study is not yet running.

The first part involves checking an Assessment Questionnaire which measures children’s distress. This is necessary because we do not know if it is sensitive enough to detect the changes in distress which might be expected if parents/carers are present in the recovery room. We know that certain things are related to the amount of distress a child experiences while in hospital - these things are age, distress during previous medical and dental procedures and number of physical symptoms and stressful experiences undergone during the visit. By dividing children up in terms of these three things, we can check whether the Assessment Questionnaire (which will be filled in by the hospital staff) is sensitive enough to detect those differences in distress which we would expect. The Assessment Questionnaire involves hospital staff writing down whether or not they saw the child exhibiting certain distress behaviours.

The role that you would play in the study is to fill in the attached Information Questionnaire. This will enable us to see how any upset experienced by your child relates to his/her age, physical symptoms and stressful experiences, as described above. We will then be able to look at whether the Assessment Questionnaire picks up the differences in distress that we would expect. You will not be asked to do anything else. Your child will not be asked to do anything. As a result of taking part in the study your child will experience nothing which would not otherwise have happened, he/she will merely be observed by hospital staff.

The following information refers to the second part of the study in which you are not being asked to take part. It is merely to explain the purpose of part one of the study.

If the Assessment Questionnaire is shown to be sensitive enough to detect changes in distress, the second part of the study will be as follows: For a certain period of time half of the children coming for surgery will be accompanied in the recovery room by their parents/carers and the other half will not. The distress experienced in the recovery room will be measured using the Assessment Questionnaire, and then the two groups will be compared to see whether those who were accompanied experienced more or less distress. This information can then be used by hospitals when deciding whether or not to encourage parents to accompany their child in the recovery room.

If you have any questions, please do not hesitate to ask the person who gave you this form.

Signed by the person in charge of the project: [Signature] Date: 22-10-96

The District Medical Ethical Committee has approved the above statement.

Signed by the Chairman of that Committee: [Signature] Date: 25-10-96.
Consent Form

*** The parent/carer should complete the whole of this sheet himself/herself ***

The Effect of Parent/Carer Presence in the Recovery Room on the Behavioural Consequences of Surgery on Paediatric Patients.

Pilot Study.

We would be very grateful if you would answer the following questions (deleting as appropriate) and, if you agree to take part in the study, sign and print your name at the bottom of the form. Thank you for your help.

Available is a Parent Information Sheet which details the purpose of the study and the way in which it is being carried out. Please feel free to ask the person who gave you this form for the Information Sheet and to ask any questions you may have.

- Have you read the parent information sheet ?........... YES / NO
- Have you had the opportunity to ask questions and discuss the study ?...........................................YES / NO
- Have you received satisfactory answers to all of your questions ?...........................................YES / NO
- Have you received enough information about the study ?...........................................YES / NO
- If you have spoken to somebody, please write that person's name here : __________________________

- Do you understand that you may withdraw from the study,
  - at any time
  - without having to give a reason for withdrawing
  - and without affecting your future medical care ?...........................................YES / NO

- Do you agree to take part in this study ?...........YES / NO

Signed: ___________________________ Date: ____________

Name in BLOCK LETTERS: ___________________________
**Information Questionnaire**

**Confidentiality Issues:** There is no way that either yourself or your child can be identified from the index number above. This number enables us to pair this questionnaire with the Assessment Questionnaire completed by the hospital staff.

If you have completed the consent form, please answer the following questions:

1. **How old is your child today?** (Please write age in years in this box)......

2. **How distressed was your child during previous medical and dental procedures?** Please write as many previous procedures as you can on the spaces below (for example “tooth out”, “appendix removed”, “grommets”), and, for each one, circle the appropriate number for how upset your child was. If you cannot remember the reason your child was in hospital, write “not known” but still circle the appropriate number:

<table>
<thead>
<tr>
<th></th>
<th>Very upset</th>
<th>Upset</th>
<th>A little upset</th>
<th>Not at all upset</th>
</tr>
</thead>
<tbody>
<tr>
<td>i)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ii)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>iii)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>iv)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>v)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>vi)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>vii)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>viii)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ix)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>x)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you wish to add more previous medical and dental procedures, please write them on the back of this sheet and rate each one as above.
3. What physical symptoms has your child experienced during this visit to the hospital? Please tick the boxes next to those symptoms which your child has experienced, and then write any other symptoms in the spaces provided below:

   i) Feeling sick...........□
   Other symptoms:

   ii) Vomiting.............□

   iii) Headaches...........□

   iv) Stomach aches........□

   v) Other pain.............□

   vi) Difficulty sleeping...□

   vii) Difficulty eating.....□

   vii) Cramps.................□

4. What stressful experiences has your child had during this visit to the hospital? Please tick the boxes next to those experiences which your child has had, and then write any other experiences in the spaces provided below:

   i) Confinement to bed...□
   Other symptoms:

   ii) Inability to use toilet..□

   iii) Injections.............□

   iv) Having blood taken...□

   v) X-rays or other scans...□

   vi) Painful procedures....□

If you wish to add further comments, please write them in the space below.

Thank you for completing this form. It will be taken from you when your child returns to you after surgery.
<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Not at all</th>
<th>A little</th>
<th>Rather a lot</th>
<th>All the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Has tears in eyes or running down face.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scream</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(No tears, but somewhat raised voice.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Has to be held down due to lack of cooperation.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Does not follow instructions.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requests Emotional Support</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Seeks reassurance either verbally or non-verbally.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscular Rigidity</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Any of the following: Clenched fists, white knuckles, eyes clenched shut, body stiffness, gritted teeth.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Says “I’m afraid”, “I’m scared” etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Says “Ow!”, “Ouch!”,”Oooh!” etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flail</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Random-seeming movement of limbs with intention to make aggressive contact.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Physically holds on to nurse or other adult.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Seeking</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>(Asks questions about what’s happening.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please fold in half and attach to the medical notes.
An Amended Form of The Observation Scale of Behavioural Distress

(To Investigate Factors Affecting the Distress of Paediatric Outpatients)
Abstract

This study addresses three main domains of investigation. Initially, the construct of distress is investigated by way of a review of the literature, including a discussion of the ways in which the term has been used and the construct measured in other studies. From this, an illustrative model is proposed highlighting the role of situation-specificity in distress and anxiety.

Secondly, the amended form of the Observation Scale of Behavioural Distress (OSBDa) is further investigated in terms of its validity, internal consistency and item structure. The scale is found to correlate very highly with nurses’ ratings of severity of distress on a 10cm visual analogue scale anchored “No distress” and “Extremely Distressed” and the state-anxiety of the child while waiting to be called into the clinic room. A significant relationship was also found with the level of pain experienced by the child, as assessed by self-report, whereas no such relationship was demonstrated between total distress score and child state anxiety, or self-report of anticipated or experienced pain. The differences between the results of the current study and of similar validity studies carried out on the original scale yield specific hypotheses about the particular constructs measured by the scales, and further inform the nature of distress.

The OSBDa is then used to investigate the relationship between procedural distress and certain variables proposed to be associated with distress; these are, for both parents and children, locus of control and state and trait-anxiety, and for children the amount of pain anticipated prior to the procedure. These variables have been investigated for children undergoing very stressful medical procedures in a previous study (Jay et al, 1983). The current study, however, investigates these relationships for children undergoing much less stressful procedures (introduction of a cannula for blood-test or general anaesthetic, and skin-test.) Results obtained indicate that behavioural distress may not be predicted by either parental or child locus of control - which reproduces the findings of Jay et al for the original scale, or parental or child trait anxiety - which contradict the results of Jay et al (1983). Similarly, the amount of pain the child expects to experience is not found in the current study to predict behavioural distress, while it was for more stressful procedures with the original scale. These results are discussed in terms of both the differing procedures and the changes made to the distress scale. Finally, caution is advised for interpretation of these results due to the size, age-distribution and levels of distress of the sample.
Introduction

It has been widely reported in the literature that surgical intervention gives rise to many different fears in children: fears of what will actually happen, fears of what may potentially happen, and fears of what it is imagined will happen - realistically or otherwise (Schmidt, 1990). For example, children may harbour fears of ‘being put to sleep’, be afraid that something terrible will go wrong, or believe that terrible things will happen such as that all one’s blood will leak out during a venipuncture (Sheridan, 1975) or that eye-surgery involves having one’s eyes permanently removed (Petrillo & Sanger, 1972) - and such fears inevitably lead to increased anxiety and distress. Visintainer and Wolfer (1975) delineate the foci of such fears as follows: a) physical injury/harm and death, b) separation from parents (or other trusted adults in a similar role), c) the unknown, d) uncertainty about what is and what is not acceptable behaviour, and e) loss of control or independence, and this underlines the many different aspects of the hospital visit and environment which promote hospital fears in children. This categorisation, and the distinction above of fears of likely, unlikely and implausible events occurring, demonstrate that only a small proportion of such fears are concerned with known, surgical factors, while much is concerned with the unknown and the uncertainty surrounding the whole process. Although drawn from an inpatient surgical population, it can be seen that Visintainer’s and Wolfer’s (1975) categories of fears may usefully be applied to non-surgical, medical or investigative procedures performed on an outpatient basis, although the distribution and nature of fears may be somewhat different, and of course such fears and anxieties have been discussed (Frank, Blount, Smith, Manimala & Martin, 1995; Gross, Stern, Levin, Dale & Wojnilower, 1983.)

Frank et al (1995) draw attention to the fact that even the most benign procedures can be experienced as stressful by the child - supporting Visintainer and Wolfer’s observations that many of the foci of such fears are concerned with the unknown - not with the procedure itself but with the child’s usually limited understanding of the procedure. They also mention that this pattern is similarly demonstrated by parents in that distress surrounding a procedure (for which the child is the patient) does not appear to be related to the severity of the procedure. Frank et al offer no suggestions as to why this should be so, though we may hypothesise that parents’ fears fall into similar categories as children (above), and/or that a major factor in the level of distress exhibited by parents is that exhibited by the child.

The distress of children in hospital is of concern for a number of reasons: Of course it is primarily concerning in and of itself and those working in this area would prefer to reduce the upset of such children as much as possible. However it has also been shown
that children who exhibit the most distress are also the least cooperative and report the most pain (Klorman, Michael, Hilpert & Sveen, 1979.) If a child is distressed during a procedure, for example a phlebotomy, that distress is manifested in a number of ways including bodily efforts to resist restraint, muscular rigidity, verbal or physical stalling of the procedure and flailing of the limbs (Elliott, Jay & Woody, 1987; Katz, Kellerman & Siegel, 1980). This makes the procedure become much harder to complete, rendering it a battle between the child and the staff (who often outnumber the child) and an even more distressing experience for the child. The procedure enters a spiral of increasing distress and the child leaves the situation with further reason to be anxious and afraid on the next occasion.

As mentioned, as well as a reduction in cooperative behaviour, increased distress is also associated with an increase in reported pain (Klorman et al, 1979). Pain is the "most pervasive symptom in medical practice, the most frequently stated 'cause' of disability, and the single most compelling force underlying an individual's choice to seek or avoid medical care" (Karoly, 1985) and as such it's relationship with distress is perhaps the most commanding reason for targeting the distress of children in a hospital environment. The nature of pain and its relationship with distress and anxiety will be explored below, but first it will be necessary to discuss what is meant by the concept of 'distress'.
The Nature of Distress

Mention has been made in section 3iii, above, of studies concerned with the upset manifested by children whilst in the hospital environment, many of which have focussed on specific procedures such as the particularly unpleasant and painful bone-marrow aspiration (BMA) and lumbar-puncture (LP) (Jay, Ozolins, Elliott & Caldwell, 1983), dental extraction (Johnson & Baldwin Jr, 1968), and routine immunisations (Frank et al, 1995). Such studies often treat the concept of distress very differently. Although the clinical motivation for such studies is usually of a similar nature - that is, to ease the process for the child and make it less distressing, upsetting, stressful or anxiety-provoking - the very number of these terms draws attention to the fact that these studies often adopt quite different concepts as the variable in question. For example, Johnson and Baldwin Jr in their 1968 study of the relationship between maternal anxiety and the behaviour of young dental patients avoid the problem of having to formally define the emotional response to the stressor of dental extraction by choosing to examine instead the specific observable behaviours of the children. The authors rated each child’s behaviour during a series of time intervals throughout the extraction, using a four-point rating scale devised by Frankl, Shiere and Fogels in 1962. The rating categories of this scale being: 1) Definitely negative: Refusal of treatment, overt resistance and hostility, extreme fear, forceful crying, and massive withdrawal or isolation or both. 2) Slightly negative: Minor negativism or resistance (accessible to treatment technics) and minimal to moderate reserve, fear, nervousness or crying. 3) Slightly positive: Cautious acceptance of treatment, but with some reluctance, questions, or delaying tactics; moderate willingness to comply with dentist, at times with reservation, and to follow directions. 4) Definitely positive: Good rapport with operator, no sign of fear, interest in procedures, and appropriate verbal contact. The mean percentage agreement between the two raters for this scale was 93.2%, suggesting (although this figure has not been corrected for chance agreement) that the instrument reliably measures the concept of ‘behaviour’ as tacitly defined by the rating categories and which in this instance appears to approximate level of distress.

It is often such tacit definition of psychological concepts which characterises clinical studies - the definition of a concept by way of the instrument with which it is measured - for the investigation into the nature of the particular concept should already have been attempted by the author of the instrument. Thus, users of such instruments often describe concept x “as measured by” instrument y; for example, Johnson and Baldwin Jr (1968), above, examine the anxiety of mothers “as measured by scores on the manifest anxiety scale (MAS).” (MAS reference: Bendig, 1956). This reference to the scale is the only reference made to the nature of the concept. It would be easy and mistaken to allow such definitions to become circular - that is for example the MAS
measures anxiety, and anxiety is defined as that concept measured by the MAS. The onus of course is on the researcher to assess the validity of the conceptual investigation made by the instrument authors, and similarly on the reader to draw independent conclusions. One of the most productive means by which to investigate distress, then, is to examine existing attempts to devise measures of that concept.

**Anxiety and pain as components of distress**

Dar, Shacham and Tomarken (1986) undertook a study of the predictive power of ratings of anxiety and pain on distress manifested during a myelography procedure (injection into the spinal cord of a radiopaque substance to enable imaging of the cord.) The study was concerned with adult subjects and all variables were measured by way of interview with the subjects 24 hours preceding and 24 hours following the procedure. The study does not define distress at length, although it opens with the following sentence:

> “Psychological Distress, the reaction to an aversive experience, is a common response to painful or threatening medical procedures.”

Dar et al (1986)

This provides perhaps a good first step from which to explore the concept, and they continue to conclude from this position that pain therefore is likely to be a significant component of distress - a position vilified by Black and Chapman (1976) who propose that distress and pain are so strongly associated as to compose a single experience of “suffering.” Equally, anxiety has been suggested as occupying a similarly intertwined position with pain (Leventhal & Everhart, 1980) and thus, by inference, with distress. However, Dar et al (1986) point out that only “modest correlations” have been reported between anxiety and pain in studies of surgical patients and thus assert that these two constructs are more likely to be independent components of distress, but components nonetheless (Martinez-Urrutia, 1975). (Issue may be taken with the description of “modest correlations” as this does not indicate whether those correlational values were nevertheless significant, if modestly so, but this is not reported.) Although they suggest that anxiety and pain may be components of distress, Dar et al’s correlational study sets out explicitly to establish the presence of associations between them. This may appear to be oddly circular, like correlating distance and time with speed, but a non-significant correlation would have extreme ramifications for the definition of distress - just as a significant correlation would correspondingly support the definition of distress, at least partially, in terms of anxiety and pain.
The data, being gathered via interview, therefore consisted of the subjects’ perceptions of each variable. For example, subjects were asked to rate both how painful and how distressing the procedure was for them on a Likert scale described confusingly as “10-point scales with 0 labelled ‘Not at all’ and 20 [sic] labelled ‘Extremely’” and there is no indication as to how these concepts were further explained, if at all. Further, these questions were posed consecutively and, although it may reasonably be argued that patients know what they mean by “distress”, their personal, unspoken definitions of the concept may have been distorted by attention being drawn to the concept of “pain” in the first instance. This effect is however purely hypothetical. The results of the study, nevertheless, lend some weight to the search for a formal definition of distress. Anxiety was measured as the mean Likert scores (similar to the 21-point scale above) on “afraid” and “panicky” taken from the Mood Adjectives Checklist (MACL) (Nolis, 1965) while pain was measured on the Likert scale described above. Anxiety and pain were found to account for a high proportion of the variance in reported distress (partial $r=0.60$, $p<0.0001$ and $r=0.62$, $p<0.0001$ respectively) and were also found to be quite independent constructs in terms of their independent correlations with different groups of further MACL pairs. None of these further pairs (Ached-Pained, Exhausted-Fatigued, Depressed-Sad, Angry-Irritated, Afraid-Panicky, Energetic-Lively and Cheerful-Happy) were retained in the regression analysis which yielded the significance values for anxiety and pain above, suggesting that distress is not predicted by these factors, and therefore they are highly unlikely to be significantly interwoven in the construct. (This is not to say that if two variables correlate, then they are part of the same construct, but that for the latter to be the case, one would expect the former to necessarily be at least partially so.) These results imply that anxiety and pain are independent components of the distress experience.

**Distress in the absence of pain**

In their development of an instrument for measuring children’s distress in a paediatric intensive care unit, Ambuel, Hamlett, Marx and Blumer (1992) discuss definitions of distress and draw slightly different conclusions. They point out that many studies examining distress have taken place at a time and place at which children are for some reason experiencing pain, see for example the three studies described in the opening sentence of this section (The Nature of Distress). This of course is also the case for Dar et al’s (1986) study above. Ambuel and colleagues, however, challenge that distress can occur in the absence of pain, and cite the example of children in critical care environments where pain is immediately managed pharmacologically, but who nevertheless often demonstrate considerable distress behaviours. Interestingly they later describe two specific measures “designed to assess distress and coping in hospital inpatient environments” (Ambuel et al, 1992) but which in fact are intended to measure
pain - being the Children’s Hospital of Eastern Ontario Pain Scale (McGrath et al, 1985) and the Pain Assessment Inventory for Neonates (Johnson et al, 1989). Their assertion that distress may exist in the absence of pain seems nevertheless reasonable, as their clinical example demonstrates, and intuitively it is possible to imagine a variety of situations in which children exhibit distress without pain, for example when separated unexpectedly from a parent. The instrument developed (The COMFORT Scale; Ambuel et al, 1992) is based upon this definition:

“Psychological distress is an organism’s response to aversive internal and external stimuli and may include discomfort, anxiety, fear, and, at the extreme, pain.”

Ambuel et al (1992)

and the assertion that this response takes three forms - behavioural, physiologic, and phenomenologic (self-report of anxiety, fear, pain, etc.) The COMFORT scale is based upon the first two response domains, since self-report would render the instrument more intrusive and more complicated because developmental differences would influence self-report and is not usually possible in the intensive care environment. It is designed to provide a measure of distress for this setting and consists of items which are not intended to vary with experienced pain - it would perhaps be more accurate to say, however, that the items alone would be unlikely to provide a reasonable indication of pain experience. These items are Alertness, Calmness/Agitation, Respiratory Response, Physical Movement, Mean Arterial Blood Pressure, Heart Rate, Muscle Tone, and Facial Tension (reflecting the behavioural and physiologic components of the concept), and each of these are rated on distinct five-point behaviourally anchored scales.

The scale was shown to have high inter-rater agreement (as assessed by Pearson correlations of the total scores from the two observers for each subject, $r=0.84$, p<0.01) although intriguingly the two most objective measures, that of heart rate and arterial pressure demonstrate the lowest agreement of the individual items. The internal consistency of the scale is high (0.90) and the clinical validity of the scale was shown to be good by Pearson correlation with the results of a 10cm visual analogue scale (VAS) anchored “absolutely calm” and “extremely distressed”, and completed by an independent experienced nurse. The correlation between this VAS and the COMFORT total scores was 0.75. Finally, a principal components analysis of the data indicated that the scale had two dimensions accounting for 84% of the variance - “behavioural distress” (accounting for 58% of the variance) and “physiologic distress” (accounting for 26%). The two dimensions correlated 0.69.

The scale therefore appears to measure distress as defined tacitly by the nurse completing the VAS rather well. This, and the fact that the items were derived from
literature regarding distress and pain and from surveying experienced nurses, suggests that the scale has a quite satisfactory degree of content validity. Reliability is also high from inter-rater agreement, above. A working definition of distress, may therefore be derived from the structure and content of this measure. The two factors derived from the principal components analysis are perhaps unsurprising since the items were devised from the intention to measure behavioural and physiological components of distress. It is nevertheless useful to observe that further miscellaneous factors were not obtained, suggesting that the items were well selected and constructed. However, the scale was constructed from the initial premise that distress may exist in the absence of pain. It has not been shown whether a scale including items more sensitive to variation in pain (and which yielded perhaps a 'pain' factor upon analysis) would account for a greater or lesser proportion of the variance and would correlate to a greater or lesser extent with further measures such as the VAS. It is proposed that one may to some extent conceive of a distressed child in pain but without, for example, high anxiety. Such a measure based only on discomfort, fear and pain may equally correlate with a VAS of 'distress', however as an indication of the components of distress, the structure of the COMFORT scale provides a good if incomplete illustration.

**Distinguishing the Concepts**

The two main studies here discussed have adopted different positions with respect to the relationships between anxiety, pain, discomfort, fear and distress. Dar et al (1986) suggest that anxiety and pain are highly reliable predictors of distress, while further variable pairs reflecting other affective states do not account for any additional variation in distress. Ambuel et al (1992) conversely demonstrate the significant associations between their scale items and total distress score in the absence of further items overtly representative of pain behaviour. The main methodological difference between these studies is that Dar et al (1986) examine exclusively phenomenologic distress, while Ambuel et al (1992) avoid this component and study instead behavioural and physiological responses to distress. Comparison of these studies therefore enables only the following conclusions: Distress may be effectively gauged by measuring alertness, agitation, respiration, movement, facial expression, mean arterial blood pressure, heart rate and muscle tone (Ambuel et al, 1992); and phenomenologic distress may be effectively assessed by measurement of reported anxiety and reported pain (Dar et al, 1986). This allows that any of the above affective and behavioural responses may function as either causes of distress (for example increased anxiety leads to increased distress), effects of distress (for example increase distress leads to increased anxiety), or that they may function as components of distress (for example anxiety, along with certain other variables, is distress.) In terms of the components of distress it may be tentatively concluded from this review that distress is more than pain behaviour, and
that it also comprises anxiety.

Despite their initial theoretical position, it is difficult to say whether the COMFORT items reflect pain or anxiety behaviours, and this is a difficulty highlighted by Shacham and Daut (1981) in their critique of the Procedure Behavioural Rating Scale (PBRS) devised by Katz et al (1980). This observation has been outlined in the above section (3iii), but will be further discussed here as its relevance is clear. Based on the premise that observational measures of distress are necessarily unobtrusive, do not require training in interpretation of data (such as for projective tests) and do not rely on the varying ability of the subject to self-report, Katz et al (1980) devised a scale of 13 operationally defined behaviours as follows, each rated for its presence or absence during four time phases: “Pain verbal”, “Cry”, “Muscular Rigidity”, “Emotional Support”, “Scream”, “Restraint”, “Carry”, “Flail”, “Refusal position”, “Cling”, “Stall”, “Requests termination”, and “Fear verbal.” The total scores, being the total number of incidences of each behaviour during each time phase, were shown to correlate 0.66 (p<0.001) with independent nurses’ ratings of distress made on a 5-point Likert scale anchored 1- “Not at all anxious” to 5 - “Extremely anxious”. The scale was developed as a measure of “anxiety in children with cancer undergoing aversive medical procedures” (Katz et al, 1980; italics added) and in their opening sentence they refer to anxiety as a major source of distress, suggesting a causal relationship between the two concepts, although they do not mention distress in the rest of the paper, speaking only of the anxiety arising during the procedure.

Shacham and Daut’s (1981) objection concerns this supposed relationship. They state that the behavioural items of the scale are referred to as anxiety behaviours, but that they may equally be supposed to be pain behaviours, particularly as one item is explicitly named “Pain verbal” and is defined as “Says ‘Ow,’ ‘Ouch,’ ‘It hurts,’ ‘You’re hurting me,’ etc.” (Katz et al, 1980). Just as it has been observed above that many such studies involve painful procedures, so is it pointed out that behavioural items such as these may indicate pain as much as, if not more than, anxiety. Katz, Kellerman and Siegel (1981) concede this point, stating that the objection is to the theoretical distinction between anxiety and pain behaviour rather than to the clinical utility of the scale, and close by suggesting that it would be more accurate to describe the construct in question as “behavioural distress, a general term encompassing behaviours of negative affect including anxiety, fear and pain.” (Katz et al, 1981; italics added). Both Katz et al (1981) and Shacham and Daut (1981) agree that anxiety and pain relate to each other in a complex fashion and that precise definition of the concepts would help to distinguish them, although this may be impossible clinically. As components of distress, thorough definition of anxiety and pain will similarly therefore inform its definition.
An Exploration of Anxiety and Pain

Anxiety

A comprehensive exploration of the nature of anxiety will not be undertaken here as it would be outwith the focus of this portfolio, although a basic definition and an example of use of the term will be provided. At a most general level, a working definition is provided by Reber (1985):

"...a vague, unpleasant emotional state with qualities of apprehension, dread, distress and uneasiness."

Reber (1985)

This is followed by a distinction between anxiety and fear, in which the latter is (often) taken to assume a specific target object, such as fear of spiders, while anxiety is usually without such a target. However, attention is also drawn to features of apprehension and dread, which may be considered as relating to some sort of target situation. The qualities of apprehension and dread referred to here also point out a potential methodological conundrum. It would be possible in theory to investigate to some extent the causal relationships between psychological and environmental variables for example by way of lag sequential analysis (Greenbaum, Cook III, Melamed, Abeles & Bush, 1988; Cook & Greenbaum, 1987). It is of note however that the temporal primacy of anxiety would make the identification of its cause (an event later in onset) particularly difficult to achieve. One may object that the cause of the anxiety response is the apprehension but the sequential problem remains for this latter concept. It is also of note that distress is included as a feature of anxiety, whereas Katz et al (1981) describe anxiety as a feature of distress. This complication is illustrated further in a study by Lumley, Melamed and Abeles (1993) in which levels of anxiety in hospitalised children were determined by measuring behavioural distress and physiological arousal, which appears to be their working definition of the concept. Behavioural distress was indexed by way of the Operating Room Behaviour Rating Scale (ORBRS; Melamed, Dearborn & Hermecz, 1983) which codes 12 distress behaviours such as “fine repetitive movements, tensing, crying, kicking, turning head away” (Lumley et al, 1993) while physiological distress was assessed by measurement of mean radial pulse in beats per minute. The parallels between these distress behaviours, given as indices of anxiety, and the items of the PBRS (Katz et al 1980) in the previous section (The Nature of Distress) are clear. It is obvious then that there is a degree of overlap between the two concepts, that each concept shares a common theme or that the relationship between the two is more than unilateral - that each affects the other in comparable ways.
Besides the informative dialogue between Shacham and Daut (1981) and Katz et al (1981) mentioned in the previous section, it is very difficult to find any literature addressing the potential distinction between distress and anxiety. There is a great deal written about or involving both concepts but, as has been shown, many seem to use the terms interchangeably, and many define either one at least partially in terms of the other. As a potential means to distinguish distress and anxiety it may be useful to treat one, distress, as involving anxiety or as being an anxiety-like response to a particular target incident. This is derived from the observation that many of the items used as measures of distress such as in the PBRS (Katz et al, 1980) and the ORBRS (Melamed et al, 1983) can be considered themselves as to some extent having a particular environmental focus. For example, the items Pain Verbal ("...It hurts..."), Stall ("...I'm not ready yet..."), and Requests termination ("Verbally asks/pleads that the procedure be stopped") from the PBRS clearly have an objective identifiable environmental focus. That is, "It hurts", "...I'm not ready yet [for that]..." and "Verbally asks/pleads for the procedure to be stopped" - each of these is concerned with the imminent procedure. Other items in which it is less clearly specified in the operational definition can still be reasonably assumed to have a focus. For example the items "Cry" and "Turns head away" from the ORBRS may be considered as crying because of the procedure and turning head away from the procedure.

Anxiety, conversely, may be usefully considered as not necessarily having that focus. The State-Trait Anxiety Inventory for Children (Spielberger, Edwards, Lushene, Monturi and Platzek, 1973) measures two specific types of anxiety - the State scale measures “Subjective, consciously perceived feelings of apprehension, tension, and worry that vary in intensity and fluctuate over time” while the Trait scale measures “relatively stable individual differences in anxiety proneness” (Spielberger et al, 1973). The latter concept of trait-anxiety, being by definition a stable form of anxiety-proneness is theoretically removed therefore from situation-specific changes in affect, changes which we may expect for example in state-anxiety. State-anxiety as defined above is reported to vary according to the extent to which a “situation is perceived as dangerous or threatening” (Spielberger et al, 1973) and the degree to which such a situation is so perceived, and so likelihood of that variation in state-anxiety, is predicted by the trait-scale.

Theoretically, therefore, these anxiety concepts can be placed on a line corresponding to degree of variation in that concept attributable to a particular situation. State-anxiety may be conceptualised as close to the anxiety-provoking situation, while trait-anxiety is unaffected by it and so may be placed further away. If we imagine distress as a further type of anxiety which is very much affected by circumstance, it can be seen that of the three concepts it lies closest to the situation (see Figure 1, overleaf).
The degree to which variation in distress, state anxiety or trait anxiety may be attributed to the threatening situation may be considered proportional to each concept's proximity to the situation.

A greater proportion of the variance in distress may be accounted for by the nature of the situation. The threatening aspect of the situation is determined however not only by the nature of the situation itself, but also, as mentioned, by levels of trait-anxiety. As such, this model is not intended to indicate such causal inter-relationships between the concepts - it is merely to be considered as an illustration of the sphere of influence of the situation upon each anxiety concept.

Pain

Pain is a complex experience involving sensory, emotional and evaluative components (Turk, Meichenbaum & Genest, 1983) and has been defined by Sanders (1985) as the sensory and emotional experience of discomfort, usually associated with actual or threatened tissue damage or irritation. This definition draws attention to the emotional as well as sensory experience, and the threat of damage as distinct from actual damage, suggesting a psychological as well as purely organic component of the pain. The distinction between organic pain, in which discomfort is caused mainly by damage to tissue, and psychogenic pain in which it arises from mainly psychological processes has traditionally been made (Sarafino, 1990) and may well still be a useful distinction to make. However the two have often been taken to be mutually exclusive in the sense that psychogenic pain is all in the mind (Karoly, 1985) and imaginary (Bakal, 1979) while organic pain is more 'real'. It can though be argued that pain is an experience (see Sanders, above) and as such necessarily has some degree of psychological process associated with it - it is a construct falling neatly into the historical no-man's-land between mind and body. One may usefully describe pain which is attributed to observable tissue damage and resultant nociceptor activity (the afferent peripheral fibres associated with pain signals) as organic, while that which cannot be so attributed may be termed psychogenic. Both categories of pain however give rise to a necessarily subjective experience of pain in the three senses of being private, experiential, and individual (Reber, 1985) and so both lie within the domain of psychology (although to
varying extents.) Bakal succinctly reduces the gap between these two categories by pointing out that psychogenic pain thus described gives rise to a pain experience directly comparable with that of organic pain: "Psychogenic and organic pain both hurt." (Bakal, 1979).

The physiology of pain perception supports the assertion that psychological and physiological variables inter-relate to comprise the experience. Pain signals from the periphery are transmitted along small diameter pain fibres, A-delta and C fibres, to the substantia gelatinosa of the dorsal horn of the spinal cord where they are modulated via processing in higher brain centres concerned with past experience, attention, cognitions and affect (Melzack and Wall, 1965; Turk, 1996). It is proposed that anxiety is one of the more significant psychological components of pain perception (Gatchel, 1992), suggesting a complex web of interrelations between anxiety, pain, distress and the stressful situation.

The Relationships Between Pain and Anxiety

Katz et al’s (1981) assertion above (see Distinguishing the Concepts) that anxiety and pain behaviours may be impossible to differentiate clinically will be further explored here. A variety of studies have examined the complex inter-relationships between pain and anxiety - most commonly in the domain of dental treatment due to the ease with which healthy people with similar demographic profiles may be recruited, and that the procedures are well-established and practised (Litt, 1996).

Van Buren and Kleinknecht (1979) compared dental patients’ post-treatment scores on the McGill Pain Questionnaire (MPQ; Melzack, 1975) sensory and affective scales, and affective and present pain intensity scales. Both pairs of scales were highly correlated ($r=0.52-0.76$ and $r=0.37-0.78$ respectively) and it was concluded that anxiety and pain varied together, although no causal assertion can be made, and that the MPQ could not discriminate between the two concepts. This latter conclusion begs the question of whether this inability to discriminate the concepts is a function of the sensitivity of the MPQ or of the perceptions of those involved. Further investigation (Fernandez and Turk, 1994) has suggested that participants’ ratings of sensory and affective dimensions of pain are in fact coincident unless, as demonstrated in a previous study (Gracely, McGrath and Dubner, 1978), the subject’s attention is drawn to the theoretical distinction between the sensory and affective components of the experience by the nature of the questions asked. It would appear that the distinction is not one made naturally and that the usual experience is in fact unidimensional - although such a distinction can be made with prompting. However, consistent with the identification of discrete forms of anxiety varying to different extents with the situation, demonstrated in
Figure 1 above, Litt and Lurie (1996) took measurements of "general dental anxiety, situational anxiety and distress, and pain expectations" preoperatively and of the "most severe pain experienced and...retrospective evaluation of the experience in terms of whether it was better or worse than expected." They found that situation-specific anxiety was associated with procedural pain, while general dispositional anxiety was not - that is, that anxiety overtly related to the situation was covariable with perceived pain. Also, situation-specific anxiety did not contribute significantly to postoperative evaluation of the experience, which was associated more with pain expectations and pain experienced - that is, the procedure was more likely to be reported as better than expected if more pain was expected prior to the treatment. From these conclusions the authors observe that the construct of interest comprises a sensory pain experience and situation-specific anxiety, which may be termed distress - a proposal which echoes that of Katz et al (1981). Also suggested is a potential causal relationship between situation-specific anxiety and experienced pain: although the analysis is purely correlational, one may conjecture that the temporal order of pretreatment situation-specific anxiety and post-treatment report of experienced pain indicates a causal relationship between these two variables. We must assume that self-report provides an accurate indication of perceived pain, rather than of anxiety and expected pain, and indeed studies have demonstrated that for highly anxious people there is a higher association between pain remembered three months after treatment and pain expected just prior to treatment than between pain remembered at three months and pain actually experienced (Kent, 1984, 1985). This indicates that postoperatively reported pain becomes gradually more coloured by previous expectations over time, suggesting that immediate self-report provides a more valid indication of experienced pain.

In conclusion, therefore, severity of perceived pain covaries with degree of pre-treatment situation-specific anxiety and perceived pain may reliably be indexed by immediate post-treatment self-report. Also the lack of a distinction made by participants in Fernandez and Turk's (1994) study above between sensory and affective components of pain highlights a further general concern: Although it may be of considerable conceptual and theoretical interest to dissect human experience into separable components, such as sensory and affective features of pain, it's clinical relevance may not be comparable in and of itself. The relevance of such a conceptual dissection lies in the ability, following such an exercise, to more confidently make hypotheses regarding covariation between the concept under consideration and other independent predictor variables. Thus, for example, from an assumption that distress comprises partially of perceived pain and of situation-focussed anxiety, one may hypothesise that variables proposed to predict one or both of these component concepts may also predict variation in distress.
Predicting Distress

From the above discussions it is clear that the relationships between distress, anxiety and pain are complex. Each would seem to overlap to varying extents with the others - for example pain may be considered to have an affective component similar to situation-specific (and/or possibly state-) anxiety; Anxiety may be conceptualised as being comprised of a set of qualitatively different sub-types such as Spielberger et al's (1973) distinction between state- and trait-anxiety and Litt and Lurie's (1996) general and situation-specific anxiety. Both of these suggest a dimension of lesser to greater situation-specificity, at the greater-specificity end of which one may consider distress. Distress, anxiety and pain cannot therefore meaningfully be considered as completely distinct. Investigation into the concept of distress suggests that it may most usefully be considered, as Katz et al's (1981) general definition suggests, as "behaviours of negative affect including anxiety, fear and pain" to which we may add that it usually pertains to a specific environmental, or perceived, focus such as unfamiliar or painful medical or dental treatment. All of the instruments considered in the previous sections which have been intended to measure distress have comprised items which may be considered variously to index pain behaviours and anxiety behaviours, and indeed both in so far as these constructs are interwoven. These items can be seen to be notably similar across instruments despite the varying theoretical positions regarding the definitions of distress underlying them. Whether distress is considered to encompass anxiety of a certain type, pain behaviour and so on, or not, it is clear from the instrument items and the validity measures of the scales that ultimately the instruments are tapping very similar constructs. Quite how distress, anxiety and pain interrelate will never be proven for, as Cronbach (1971) points out, these terms refer to constructs and as such they rely on consensus for their definition. That is, there is not an objective pool of data to examine - the concepts may be considered to be defined as a resultant of previously proposed and variously valid definitions and uses of the terms in the literature. An attempt to provide an illustration of such consensual definition has been made in the preceding sections.

Factors Affecting the Distress of Children in Hospital

In an investigation into the relationships between the behaviours of staff and parents and those of the paediatric patient, Frank et al (1995) examined 77 four to seven year-old children receiving routine immunisations using the Child-Adult Medical Procedure Interaction Scale (CAMPIS-R; Blount, Manimala, Frank, Morris & Smith, 1993) to code behaviours and the State-Trait-Anxiety Inventory (STAI; Spielberger, Gorsuch & Lushene, 1970) to assess parental anxiety. Of the categories of parent coping- and
distress-promoting behaviours, staff coping- and distress-promoting behaviours, child's previous experience and parental trait-anxiety, parental behaviour accounted for the largest significant proportion (53%) of the variance of child distress behaviour (crying, screaming, verbal resistance, emotional support, verbal fear, verbal pain, verbal emotion and information seeking) the majority of which could be attributed to parental distress promoting behaviour ($T=8.29, p<0.0001$) - being defined as criticism, reassuring comment, giving control to the child, apology and empathy (all categories from Blount, Corbin, Sturges, Wolfe, Prater & James, 1989). A further 4% was attributed to the previous medical and dental experience of the child. The question may be raised of how the categories of distress and coping promoting behaviours were derived, as no mention is made of this in the study, however, these categories are operationally defined and as such the study may more properly be understood as a test of this categorising system.

It is of note that parental trait-anxiety was not shown to predict child distress behaviour in this instance, when one might hypothesise that it would. While interpreting this result, however, it should be considered that parental trait-anxiety scores were found to be almost one standard deviation lower than that obtained from the normative sample (Spielberger et al, 1970). It could be argued that of this group, even those at the anxious end of the distribution could not reasonably be described as anxiety-prone, thus variation within this distribution may not be expected to be related to variation in child distress, whereas variation around the normative mean perhaps would. Also, the variables were entered in a hierarchical regression with parental anxiety entered last after parent coping- and distress-promoting behaviours, staff coping- and distress-promoting behaviours and child experience. If parental anxiety contributes to variation in child distress behaviour which is shared by parental behaviour, then the remaining variation may not be significant. It seems reasonable to contest that parental anxiety and behaviour are interrelated variables and that the effect of anxiety may operate through the behaviour of the parent. Once all aspects of the parents behaviour are partialled out, it is difficult to identify similarly powerful ways in which the effect of parental anxiety may be manifest, other than for example in those behaviours exhibited outside of the experimental remit.

The effect of parental trait-anxiety on similarly defined child distress has also been examined by Jay et al (1983) and found to be significant ($r=0.46, p<0.01$) and they suggest therefore that parents with more anxious personality styles have children who

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1 Similarities between these behaviours and those items from previously mentioned distress-measures should be noted.

2 Jay et al (1983) use the Observation Scale of Behavioural Distress as their instrument and tacit definition of the concept. This measure has been described in the previous chapter (To Examine the Sensitivity and Utility of an Amended Form of the Observation Scale of Behavioural Distress) and will also be summarised below.
do exhibit higher levels of distress. However, this effect may also be attributed to the sorts of *behaviours* exhibited by high trait-anxiety parents and so it would not have been picked up by Frank et al (1995) above. If, though, Jay et al's more personality-based explanation is correct, then another cause for these differing results should be sought. In this instance it may well be attributable to the differing medical procedures being undergone by the patients in each study - while Frank et al's patients underwent routine immunisations, Jay et al's patients were subject to the extraordinarily stressful bone-marrow aspiration (BMA). Despite the varying levels of experience with this procedure across the subject pool, it may be argued that patients experiencing the BMA for the first time and those who have extensive experience of it cannot meaningfully be compared to healthy children undergoing a relatively benign and likely familiar immunisation.

Parental state-anxiety was not found by Jay et al to vary with child distress, and this might be expected given that the situation to which the state-anxiety measure is specific was waiting for the procedure, while the situation in which child distress was measured was the procedure itself. However it was found that parental *self-report* of anxiety just before the procedure was well correlated with child distress ($r=0.48$, $p<0.01$). Also, Greenbaum et al (1988) show that of those mothers with high state-anxiety, maternal *agitation* was followed by an increased probability of child distress behaviour (while for those with low state-anxiety maternal agitation was more often a *response* to the child's distress). Although it may perhaps be expected it is not clear from the study whether high state-anxious mothers exhibited increased agitation, if they did this would suggest that increased state-anxiety *per se* may not be sufficient to predict child distress behaviour, but that those mothers' increased agitation may be a response to their anxiety, rather than to the situation or the distress of the child. Again it is difficult to compare the studies because in contrast to BMA, Greenbaum et al's procedure was outpatient diagnostic medical examination. In relation to Frank et al's (1995) study, however, it is suggested that maternal agitation may be added to the category of parental distress-promoting behaviours.

In addition to these anxiety measures, and anticipated and experienced pain (outlined below), Jay et al (1983) measured locus of control for both parents and children with the Rotter Internal-External Locus of Control Scale (Rotter, 1966) and the Nowicki-Strickland Locus of Control Scale for Children (Nowicki & Strickland, 1973) respectively in order to assess whether perceived controllability of events for both children and parents is related to the distress manifested by the child. It may be hypothesised that a more external locus of control would be associated with increased levels of distress as perceived control over the situation would be low and uncontrollable events have been shown to be more stressful than controllable ones (Miller, 1979). Equally, however, unless those with an external locus of control have
correspondingly increased levels of general anxiety one may argue that entering a situation in which control is removed would be less startling and distressing. It would be difficult to predict therefore in which direction the effect would be demonstrated. Jay et al find no covariation between these variables and child behavioural distress, although Crisson and Keefe (1988) in a study of adults' chronic pain do demonstrate a relationship between chance locus of control and distress ($p<0.001-0.05$) - they also show a relationship between chance locus of control and self-report of ineffective coping strategies for controlling and reducing pain. Locus of control is here assessed using the Multidimensional Health Locus of Control Scales (MHLC; Wallston, Wallston & DeVellis, 1978) which yields three dimensions of locus of control - internal, powerful other, and chance, while 'distress' is defined as self-report of the degree to which each symptom from the Symptom Checklist-90 Revised (SCL-90-R; Derogatis, 1983) is considered distressing. This use of the term is significantly different from all of those described above, and may not be considered comparable, however the results are useful in considering potential relationships between locus of control and distress, especially with regard to the observation that those with chance locus of control report that their coping strategies for controlling pain are ineffective. This would suggest that this locus of control could be related to increased pain in the absence of an effective strategy, and thus related to distress as more behaviourally defined in the previous sections. It is considered therefore that Jay et al's (1983) non-significant result may not be generalised to less traumatic medical procedures and that a relationship between locus of control and distress may be hypothesised in this situation.

In advance of Litt and Lurie's (1996) study, Jay et al (1983) also examined the relationship between distress and the amount of pain both anticipated preoperatively and experienced during the procedure (though rated afterwards.) These ratings were made on a “Pain Thermometer” (Katz, 1979), considered as a visual analogue of pain represented on a 10cm 0-100 scale. They found that both anticipated and experienced pain correlated significantly with behavioural distress ($r=0.76$, $p<0.0001$ and $r=0.62$, $p<0.02$ respectively) the differing values of which suggest that distress consists rather more of the apprehension surrounding the procedure than of the actual pain being experienced. This mirrors somewhat the finding of Katz (1980) that his similar definition of distress correlated significantly higher with self-reported fear than self-reported pain.

From this background of research, a number of potential variables may be identified which may be hypothesised to be related to distress in children experiencing more everyday hospital procedures than bone marrow aspiration - parental and child state and trait anxiety, parental and child locus of control, and child self-report of anticipated
pain. The current study proposes to investigate the relationships between these variables and child distress as measured by an amended form of the Observation Scale of Behavioural Distress (Jay et al 1983) and also to further validate this measure. An explanation of the means by which this will be achieved follows.
Aims of the Study

The Amended Observation Scale of Behavioural Distress (OSBDa)1

The OSBDa is a slightly amended version of Jay et al's (1983) Observation Scale of Behavioural Distress (OSBD) - a rating scale for assessing distress in children and adolescents aged between 2 and 20. It consists of eleven operationally defined behaviours, derived from the Procedure Behaviour Rating Scale described above2 (Katz et al, 1980), being Cry, Scream, Physical Restraint, Verbal Resistance, Requests Emotional Support, Muscular Rigidity, Verbal Fear, Verbal Pain, Flail, Nervous Behaviour and Information Seeking. The formal definitions of these behavioural categories may be found in the appendix. The OSBD records occurrence of behaviours in continuous 15 second intervals over the duration of the procedure and uses a system of numerical weights for each behavioural item since certain items are indicators of more severe distress than others (Jay et al, 1983). The OSBDa differs from this administration by abandoning the time-sampling and weighting system in accordance with the findings of Elliott et al (1987) that validity measures for the scale were not significantly compromised by disregarding the weighting system, and collapsing the 15 second interval data onto simple occurrence or non-occurrence of each behaviour over the entire procedure. The only other difference between the OSBD and the OSBDa is that in order to attempt to increase the sensitivity of the measure, the scoring system has been changed to one in which over the entire duration of the procedure each behavioural item is rated on a four-point Likert scale anchored 0 ("not at all"), 1 ("a little"), 2 ("rather a lot"), and 3 ("all the time"). An index of total distress is obtained by summing each Likert score.

The previous study in this portfolio demonstrates the inter-rater reliability of the OSBDa to be very good (Spearman's correlation coefficient $r_s = 0.92, p<0.001$). However, in that study the validity was assumed to be comparable to the standard OSBD following Elliott et al's (1987) demonstration above that radically altering the scoring system did not significantly vary the obtained validity coefficients. The current study aims to repeat three of Jay et al's (1983) validity measures on this amended scale, for children undergoing less traumatic medical procedures, by calculating correlation coefficients for OSBDa total distress scores with children's trait-anxiety scores from the STAIC (Spielberger et al 1973) and pain thermometer (Katz, 1979) ratings of anticipated and

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1 The OSBDa, and the OSBD, and all points raised in this summary description are described fully in the previous study in this portfolio "To Examine the Sensitivity and Utility of an Amended Form of the Observation Scale of Behavioural Distress."

2 See above: "The Nature of Distress - Distinguishing the Concepts"
PAGE NUMBERING AS ORIGINAL
Methodology

Ethical Approval

Consent for the study to take place was obtained from the Kingston and Richmond Health Authority Local Research Ethics Committee. A copy of the written confirmation of this consent by chairman's action, dated 27th June 1997, can be found in the appendix.

Participants

[Throughout this paper the word “parent” will be used to refer to both parents and other adults acting in a parental role. The word “children” will be used in preference to “patient” for all paediatric patients including adolescents. This is because “patient” is easily confused with “parent” during reading.]

Participants were 34 children between the ages of 2 and 16 (inclusive), and their accompanying parents, attending outpatient appointments at the Children’s Outpatients Department (COPD) and the Dental Unit of Kingston Hospital, Kingston-upon-Thames, within a specified time interval (six weeks)\(^1\). On those days when lists occurred on the same day for both departments, the department most unrepresented in the sample at the time was attended for gathering data. For each list attended all those on the list were attempted to be recruited. Those who were not recruited were so as a result of either lack of consent being given by the parent, lack of cooperation from the child, exclusion criteria (below), or unavoidable logistical problems of each clinic such as children being called for their procedure before being seen by the experimenter and children being preoccupied by other professionals (for example play specialists) while waiting to be called. Those attending the Children’s Outpatients Department underwent an investigative procedure, either phlebotomy or skin test while the dental patients were involved in a variety of dental procedures all under general anaesthetic. For those COPD children, the procedure during which distress was measured was the investigative procedure being the reason for the hospital visit, such as those given above, while for those in the dental unit distress was measured during the induction of anaesthesia. Anaesthesia was administered in the majority of cases (by preference of the anaesthetist) by way of a cannula in the arm or back of the hand. In one case it was administered by way of a mask after it had become apparent that the former approach was not going to be possible, for reasons of lack of cooperation on the part of the child.

\(^1\) C.O.P.D. n=28, Dental Unit n=5, Unrecorded n=1.
The sample included 13 males and 18 females (three children’s genders were unrecorded) distributed by age as follows:

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
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<tr>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
</tr>
</tbody>
</table>

There were no 14, 15 or 16 year-olds.

Parental gender was distributed as follows: Female=32, male=2. The age of parents was not recorded. Most children were accompanied by one parent. For those who were accompanied by both (n=4) it was decided arbitrarily to ask the mother to take part.

**Exclusion Criteria**

Those children not accompanied by a parent, or with a diagnosis of significant behavioural disturbance\(^1\) or a learning disability were excluded. This latter group were excluded for the following reason: 30-75% of people with learning disabilities are likely to have concomitant disorders such as ADHD (Kaplan & Sadock, 1990) which may or may not be formally diagnosed; As for the preceding study\(^2\) it was unreasonable to expect those involved in the research to make decisions regarding the suitability of each such patient for the study and so this group was excluded by way of diagnosis of learning disability in the medical notes.

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\(^1\) Being any of the following: Attention-Deficit Hyperactivity Disorder (ADHD), Conduct Disorder, Oppositional Defiant Disorder, Separation Anxiety Disorder and Overanxious Disorder.

\(^2\) “To Examine the Sensitivity and Utility of an Amended Form of the Observation Scale of Behavioural Distress.”
Instruments

NB: Examples of all instruments may be found in the appendix.

The OSBDa
This scale is described fully in the previous chapter and summarised above. It was used by the experimenter to measure the distress of the child during the procedure.

Rotter Internal-External Locus of Control Scale (R-LOC³) (Rotter, 1966)
Each parent completed this scale during the period between arrival and being called to the procedure in order to assess any relationship between parental perceived ability to control events and levels of distress exhibited by the children.

Nowicki-Strickland Locus of Control Scale for Children (NS-LOC⁴) (Nowicki & Strickland, 1973)
Each child aged eight or above completed this scale during the waiting period between arrival and being called to the procedure in order to assess any relationship between perceived ability to control events and levels of distress exhibited during the procedure.

State-Trait Anxiety Inventory (STAI; Spielberger et al, 1970)
Both State and Trait scales of this measure were completed by each parent during the waiting period in order to assess whether situation-specific state-anxiety or more characterological trait-anxiety could be used to predict behavioural distress in the child.

State-Trait Anxiety Inventory for Children (STAIC; Spielberger et al 1973)
Both scales of this measure were completed during the waiting period by each child aged eight years old and over to examine any relationship between state-anxiety in the waiting area and distress during the procedure. The Trait scale was used as a means by which to validate the OSBDa and again to assess whether trait-anxiety could be used to predict distress.

Pain Thermometer (Katz, 1979)
During the waiting time, children aged eight years old and over were asked to indicate with a line on a 10cm thermometer anchored at the bottom as “Won’t hurt” and at the top as “Will hurt lots and lots” the amount they expected the procedure to hurt. After the procedure, they were asked to indicate on a similar thermometer anchored at the bottom “Didn’t hurt” and at the top as “Hurt lots and lots” the amount the procedure actually hurt.

³ It should be noted that the abbreviations R-LOC and NS-LOC are unique to this study and not specified by the authors.
**Visual Analogue Scale (VAS)**
At the Investigations Clinic, the clinic nurse marked on a 10cm horizontal line, anchored “no distress” to the left and “extreme distress” to the right, the amount of distress exhibited by the child at that time. Three of these were completed in this way for each child at different points during the procedure: 1) Upon entering the room 2) During the procedure and 3) Upon leaving the room.

**Procedures**
At both departments, children and parents were approached while waiting to be called to the procedure after the child had had anaesthetic cream applied to the cannula site. At the dental unit children were informed by a nurse during application of this cream about the induction procedure they were going to experience. At the COPD, children additionally had a brief session with a play-specialist who would explain the nature of the investigative procedure. In both locations, children and parents were approached after this information had been given.

The nature of the study was explained individually to each parent and child pair and an information sheet explaining the study in detail was given to each parent (see appendix). Parents were asked to provide written consent to be involved in the study, and a clause on the consent form was drawn attention to which indicated that the signature confirmed the verbal assent of the child as well. A copy of the consent form can also be found in the appendix. For parents who refused to take part in the study (n=1) no information was recorded and the experimenter left the clinic room when the child was being seen.

Having consented to the study, each parent was given the R-LOC and instructions for its completion were given verbally as well as attention being drawn to the instructions on the front sheet. Older children (eight years old and above) were given the NS-LOC to complete independently. Following these locus of control scales, parents were asked to complete independently both scales of the STAI while older children were asked to complete the STAI-C, which was read aloud by the experimenter according to the standard administration. The oral administration of the STAI-C was given in such a way that children would have felt as much as possible that the parent could not hear the questions being asked. On a few occasions children or parents would ask for items to be clarified, and such questions were answered with considerable effort being made not to change the meaning of that item. The older children were also asked at this time to mark on a pain thermometer the amount of pain they expected to experience during the procedure. As well as the anchors marked on the pain thermometers, the far end was
also verbally anchored by asking the child to imagine the worst pain imaginable and to compare the anticipated pain with that.

As the child entered the room of the investigation clinic, as the procedure was carried out, and as the child left the room, the clinic nurse marked on three separate VAS the amount of distress exhibited by the child at those times. It was impractical to carry out this part of the study at the dental unit. During the procedures in both departments, however, the OSBDa was completed by the experimenter to assess the degree of behavioural distress manifested by the child during the procedure, that is, from the moment the doctor or anaesthetist takes the child’s hand to insert the cannula to the moment the child leaves the chair after the procedure. Following the significant measure of inter-rater reliability for the OSBDa arising from the study in the previous chapter⁴, and the operationally defined items, it was not considered inappropriate for the experimenter to complete this scale. On most occasions the experimenter was blind to the responses given for the R-LOC, NS-LOC, and STAI. Because of the administration for the STAI-C it was not possible to be truly ignorant of the responses being given, but it was considered that the definitions of each behavioural item of the OSBDa were clear enough to protect against effects of experimenter expectation.

After the procedure was completed and the parent and child were back in the waiting room (and, for dental patients, fully recovered), children who had completed a Pain Thermometer of anticipated pain were asked to mark on another Thermometer the amount of pain actually experienced. The extreme end of this scale was anchored verbally in a similar fashion to the previous scale.

At the end of each clinic list, further information was noted for each subject as follows: The gender and age of the child, which parent was accompanying, which clinic the child had attended, and whether investigation clinic patients were prepared beforehand by a play-specialist and/or distracted by a play-specialist during the procedure. Pre-clinic preparation involved a demonstration of the procedure to be experienced which was carried out by the play-specialist on a specially constructed Mickey Mouse doll containing red-paint which could be drawn out via a cannula.

⁴ "To Examine the Sensitivity and Utility of an Amended Form of the Observation Scale of Behavioural Distress."
Aims, Hypotheses and Statistical Analyses:

1. *The OSBDa can be appropriately validated against the child’s state and trait-anxiety, anticipated and experienced pain, and nurses’ judgements of distress during the procedure.* Assessed by calculation of Pearson’s product moment correlations between OSBDa total scores and validity variables.

2. *The OSBDa has a meaningful internal structure.* This will be derived in an exploratory fashion by way of a Multidimensional Scaling procedure. No hypotheses are made regarding such structure in advance.

3. *The OSBDa has a high degree of internal consistency, contributing to its reliability as a practical tool.* This will be assessed by calculation of Cronbach’s Alpha. Attempts will be made to maximise the internal consistency of the instrument by cumulative deletion of items to increase the value of alpha.

4. *The total distress of the child, as measured by the OSBDa, may be predicted from levels of parental and child state and trait-anxiety, parental and child locus of control, and the amount of pain anticipated by the child.* These associations will be measured using Pearson’s product moment correlation.

**Notes regarding statistical analyses:**

Following the use of parametric tests in the analysis of both the OSBD (Jay et al, 1983; Elliott, Jay and Woody, 1987) and of similarly constructed measures (Frank et al, 1995; Bachanas and Roberts, 1995; Ambuel et al, 1992) it was considered acceptable to make similar assumptions about the distributions of data (in the population) in the current study. Thus, Pearson’s product moment correlation has been used to test two of the four hypotheses above, although attention is drawn to the measures of skewness and kurtosis in Table 1 below. The size of the obtained sample rules out the use of the more sophisticated multiple regression techniques.

The sample size also precludes the valid use of factor analysis to examine the structure of the OSBDa, thus multidimensional scaling has been selected instead as it makes fewer assumptions about the distribution of the data, and is robust enough to endure small sample sizes.
Results

[All analyses were carried out using SPSS for Windows v6.1.3.]

Analysis of the Instrument

Validity Measures:

The content validity of the OSBDa was assessed by calculating correlation coefficients for total scores on the OSBDa with children’s pain thermometer (Katz, 1979) ratings of anticipated and expected pain, STAIC measures of state anxiety (Spielberger et al 1973), and nurses’ ratings of “distress” during the procedure on the 10cm visual analogue scale. Children’s trait anxiety scores from the STAIC were also examined as a replication of Jay et al’s (1983) validity test of the original OSBD. Table 1 provides descriptive statistics for the total OSBDa scores.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>S. D.</th>
<th>r</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAIC-C1 (State scale)</td>
<td>15</td>
<td>33.87</td>
<td>7.00</td>
<td>0.78</td>
<td>0.001**</td>
</tr>
<tr>
<td>STAIC-C2 (Trait scale)</td>
<td>15</td>
<td>37.33</td>
<td>6.62</td>
<td>0.14</td>
<td>0.613</td>
</tr>
<tr>
<td>Anticipated Pain</td>
<td>14</td>
<td>42.57</td>
<td>31.92</td>
<td>0.26</td>
<td>0.366</td>
</tr>
<tr>
<td>Experienced Pain</td>
<td>11</td>
<td>15.36</td>
<td>16.45</td>
<td>0.65</td>
<td>0.032*</td>
</tr>
<tr>
<td>VAS during procedure</td>
<td>28</td>
<td>38.07</td>
<td>34.37</td>
<td>0.81</td>
<td>0.000**</td>
</tr>
</tbody>
</table>

Table 1
Descriptive statistics for total OSBDa scores.

Table 2
Validity measures. Significance at the $p < 0.05$ level is indicated by one asterisk *. Two asterisks ** indicates significance at the $p < 0.01$ level.
Pearson product-moment correlations of OSBDa total scores and the above variables were calculated, as indices of content validity, and obtained results are outlined above in table 2: As may be seen from this table, three of the five validity measures correlate significantly with OSBDa total distress scores, experienced pain \( (p<0.05) \), child state anxiety \( (p<0.01) \) and nurse rating of distress during the procedure \( (p<0.01) \). Jay et al (1983) found in their sample of children undergoing much more stressful procedures that child trait anxiety and ratings of anticipated pain correlated particularly strongly with total OSBD scores \( (p<0.001) \) but for this study of less stressful procedures, the finding is not reproduced. The instrument may, nevertheless, be understood to validly measure some construct involving similar components to state anxiety, experienced pain, and nurses' understandings of the term "distress." A further analysis of these results, and of the difference between these and Jay et al’s (1983) results, is presented in the following Discussion (Section 3, iv, d).

**Structural Analysis**

An analysis of the underlying structure of the amended scale OSBDa was carried out by applying multidimensional scaling to the data. Squared Euclidean distances were created from the data and tied observations were untied to obtain a two-dimensional representation of the data, reproduced overleaf (Figure 2) while the applicability of this model is portrayed in Figure 3 by way of a scatterplot of the linear fit between the data and the model. The accuracy of the fit can be clearly seen from this graphical representation, lending credence to the two-dimensional model, while more formally, the stress for the resulting matrix equals 0.07516, the squared correlation (RSQ) between the disparities and the distances equaling 0.97307, therefore the distances in the model account for 97% of the variance in the transformed data. An interpretation of this representation is ventured in the following discussion section.

For completeness, Figures 4 & 5 provide similar information for a one-dimensional plot. The stress for this model equals 0.18361, and the RSQ equals 0.90059, and, although these figures are acceptable, the resulting model fits the data less well, and is very difficult to interpret. A three-dimensional model is not appropriate for the data because the data-set is not large enough to support the extra parameters of a third dimension.
Figure 2 - Derived Stimulus Configuration, Euclidean Distance Model, N=34.

Figure 3 - Scatterplot of Linear Fit, N=34.
One Dimensional Plot


Figure 4 - 1D Derived Stimulus Configuration, Euclidean Distance Model. N=34.

Figure 5 - Scatterplot of Linear Fit for 1D model, N=34.
Reliability Analysis:

Because the OSBDa is explicitly designed to measure the transient phenomenon of behavioural distress, such reliability tests as consistency across time (test-retest reliability) would be misinformed. The most appropriate test of the reliability of this instrument, therefore, is Cronbach’s Alpha - measuring the internal consistency of the scale and providing, essentially, the average of all combinations of possible split-half analyses.

For completeness, descriptive statistics for individual items in the scale, as derived from the entire data set, N=34, are provided below in Table 3.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>0.791</td>
<td>1.2255</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>0.8235</td>
<td>0.9683</td>
</tr>
<tr>
<td>Flail</td>
<td>0.2353</td>
<td>0.5537</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>0.1765</td>
<td>0.5758</td>
</tr>
<tr>
<td>Muscular Rigidity</td>
<td>0.6765</td>
<td>0.9761</td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>1.0882</td>
<td>1.1634</td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>0.6471</td>
<td>1.0698</td>
</tr>
<tr>
<td>Scream</td>
<td>0.6471</td>
<td>1.0698</td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>0.1765</td>
<td>0.6262</td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0.6765</td>
<td>0.8780</td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0.4412</td>
<td>0.9595</td>
</tr>
</tbody>
</table>

Table 3
Means and Standard Deviations for individual items of the OSBDa. N=34.

The variation in means and standard deviations in this table rules out the use of Parallel or Strict Parallel analyses of internal consistency, providing further support for the use of Cronbach’s Alpha. As Alpha is related to the average of all the inter-item correlations (Breakwell et al, 1995), these correlations are presented below in Table 4.
<table>
<thead>
<tr>
<th></th>
<th>Cry</th>
<th>Emot-sup</th>
<th>Flail</th>
<th>Inf-seek</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>1.0000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Support</td>
<td>0.7346</td>
<td>1.0000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flail</td>
<td>0.7881</td>
<td>0.7580</td>
<td>1.0000</td>
<td></td>
</tr>
<tr>
<td>Information Seeking</td>
<td>-0.758</td>
<td>0.0032</td>
<td>-0.1342</td>
<td>1.0000</td>
</tr>
<tr>
<td>Muscular Rigidity</td>
<td>0.5760</td>
<td>0.3546</td>
<td>0.4815</td>
<td>0.1586</td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>0.5865</td>
<td>0.7400</td>
<td>0.5779</td>
<td>-0.1143</td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>0.8686</td>
<td>0.6461</td>
<td>0.8561</td>
<td>-0.0979</td>
</tr>
<tr>
<td>Scream</td>
<td>0.8675</td>
<td>0.6987</td>
<td>0.8607</td>
<td>-0.0926</td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>0.5226</td>
<td>0.1529</td>
<td>0.1388</td>
<td>0.1631</td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0.8374</td>
<td>0.7506</td>
<td>0.7846</td>
<td>-0.1234</td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0.8527</td>
<td>0.5756</td>
<td>0.8253</td>
<td>0.0194</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Musc-rig</th>
<th>Nerv-beh</th>
<th>Phys-res</th>
<th>Scream</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscular Rigidity</td>
<td>1.0000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>0.4258</td>
<td>1.0000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>0.5561</td>
<td>0.4904</td>
<td>1.0000</td>
<td></td>
</tr>
<tr>
<td>Scream</td>
<td>0.4968</td>
<td>0.5123</td>
<td>0.9456</td>
<td>1.0000</td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>0.4928</td>
<td>0.1027</td>
<td>0.4840</td>
<td>0.4577</td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0.4752</td>
<td>0.5920</td>
<td>0.8229</td>
<td>0.8426</td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0.6423</td>
<td>0.3981</td>
<td>0.8834</td>
<td>0.8648</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Ver-fear</th>
<th>Ver-pain</th>
<th>Verb-res</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal Fear</td>
<td>1.0000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>0.2723</td>
<td>1.0000</td>
<td></td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>0.5725</td>
<td>0.7141</td>
<td>1.0000</td>
</tr>
</tbody>
</table>

Table 4.  
Correlation matrix of individual items
Item-total statistics for the calculation of Cronbach’s alpha from all eleven items of the OSBDa are presented below in Table 5:

<table>
<thead>
<tr>
<th>Scale</th>
<th>Scale if Item Deleted Mean</th>
<th>Scale if Item Deleted Variance</th>
<th>Corrected Item-Total Correlation</th>
<th>Squared Multiple Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>5.5882</td>
<td>43.6435</td>
<td>0.9137</td>
<td>0.8810</td>
<td>0.9040</td>
</tr>
<tr>
<td>Emot-sup</td>
<td>5.5588</td>
<td>48.8601</td>
<td>0.7493</td>
<td>0.8098</td>
<td>0.9133</td>
</tr>
<tr>
<td>Flail</td>
<td>6.1471</td>
<td>52.8565</td>
<td>0.8418</td>
<td>0.9456</td>
<td>0.9150</td>
</tr>
<tr>
<td>Inf-seek</td>
<td>6.2059</td>
<td>59.9866</td>
<td>-0.0424</td>
<td>0.2303</td>
<td>0.9387</td>
</tr>
<tr>
<td>Musc-rig</td>
<td>5.7059</td>
<td>50.5169</td>
<td>0.6105</td>
<td>0.5784</td>
<td>0.9201</td>
</tr>
<tr>
<td>Nerv-beh</td>
<td>5.2941</td>
<td>49.0018</td>
<td>0.5879</td>
<td>0.6444</td>
<td>0.9233</td>
</tr>
<tr>
<td>Phys-res</td>
<td>5.7353</td>
<td>46.5642</td>
<td>0.8948</td>
<td>0.9273</td>
<td>0.9056</td>
</tr>
<tr>
<td>Scream</td>
<td>5.7353</td>
<td>45.8369</td>
<td>0.8946</td>
<td>0.9264</td>
<td>0.9052</td>
</tr>
<tr>
<td>Ver-fear</td>
<td>6.2059</td>
<td>55.3806</td>
<td>0.4471</td>
<td>0.8183</td>
<td>0.9256</td>
</tr>
<tr>
<td>Ver-pain</td>
<td>5.7059</td>
<td>48.8806</td>
<td>0.8380</td>
<td>0.8233</td>
<td>0.9096</td>
</tr>
<tr>
<td>Verb-res</td>
<td>5.9412</td>
<td>47.5722</td>
<td>0.8649</td>
<td>0.9247</td>
<td>0.9075</td>
</tr>
</tbody>
</table>

Alpha = 0.9231

Table 5
Reliability Analysis - Cronbach's Alpha. N (cases)=34, N (items)=11.

This value of alpha, 0.9231, indicates that the internal consistency of the scale with all eleven items is particularly favourable. As it stands, therefore, the OSBDa may be considered a reliable instrument. However, it can be seen from Table 5 that removal of individual items Information Seeking, Nervous Behaviour, or Verbal Fear would each result in an increase in the value of alpha for the resulting scale, that is, the scale becomes more reliable. When recalculating reliability for a scale consisting only of the eight remaining items, the value of alpha increases to 0.9492, as can be seen from Table 6 overleaf. However, once again a further item may be removed to increase alpha - on this occasion Muscular Rigidity. This pattern of increasingly deconstructing the scale continues, slowly increasing alpha until there are only four items left - Cry, Physical Restraint, Scream, and Verbal Resistance - and the value of alpha is 0.9638. Sometimes a scale will self-destruct in this way, particularly when it is trying to approximate a multifaceted construct such as distress, and this can be because the test of reliability is unconcerned with the construct which the scale is designed to measure. For example, one may imagine this scale degenerating until there is only one item left, perhaps Cry, and alpha may be demonstrably large. However, at this stage the scale as

...continued on page 205
Table 6

Cumulative effect of removing all suggested items from OSBDa.

For each data table, those items for which alpha would increase if deleted are indicated by a hash (#) next to the “Alpha if item deleted” value.

1. **Alpha for the scale with all eleven items.**

<table>
<thead>
<tr>
<th>Statistics for</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>6.3824</td>
<td>59.9403</td>
<td>7.7421</td>
<td>11</td>
</tr>
</tbody>
</table>

**Item-total Statistics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>if Item</th>
<th>Item- Alpha if Item Deleted</th>
<th>Total Correlation if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRY</td>
<td>5.5882</td>
<td>43.6435</td>
<td>.9137</td>
<td>.9040</td>
<td></td>
</tr>
<tr>
<td>PHYS RES</td>
<td>5.7353</td>
<td>46.5642</td>
<td>.8948</td>
<td>.9056</td>
<td></td>
</tr>
<tr>
<td>SCREAM</td>
<td>5.7353</td>
<td>45.8369</td>
<td>.8946</td>
<td>.9052</td>
<td></td>
</tr>
<tr>
<td>VERB RES</td>
<td>5.9412</td>
<td>47.5722</td>
<td>.8649</td>
<td>.9075</td>
<td></td>
</tr>
<tr>
<td>EMOT SUP</td>
<td>5.5588</td>
<td>48.8601</td>
<td>.7493</td>
<td>.9133</td>
<td></td>
</tr>
<tr>
<td>FLAIL</td>
<td>6.1471</td>
<td>52.8565</td>
<td>.8418</td>
<td>.9150</td>
<td></td>
</tr>
<tr>
<td>INF SEEK</td>
<td>6.2059</td>
<td>59.9866</td>
<td>-.0424</td>
<td>.9387#</td>
<td></td>
</tr>
<tr>
<td>MUSE RIG</td>
<td>5.7059</td>
<td>50.5169</td>
<td>.6105</td>
<td>.9201</td>
<td></td>
</tr>
<tr>
<td>NERV BEH</td>
<td>5.2941</td>
<td>49.0018</td>
<td>.5879</td>
<td>.9233#</td>
<td></td>
</tr>
<tr>
<td>VER FEAR</td>
<td>6.2059</td>
<td>55.3806</td>
<td>.4471</td>
<td>.9256#</td>
<td></td>
</tr>
<tr>
<td>VER PAIN</td>
<td>5.7059</td>
<td>48.8806</td>
<td>.8380</td>
<td>.9096</td>
<td></td>
</tr>
</tbody>
</table>

**Reliability Coefficients**

<table>
<thead>
<tr>
<th>N of Cases</th>
<th>34.0</th>
<th>N of Items</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha</td>
<td>.9231</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. **Alpha for the scale with Inf_seek, Nerv_beh and Ver_fear deleted.**

<table>
<thead>
<tr>
<th>Statistics for</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>4.9412</td>
<td>44.6025</td>
<td>6.6785</td>
<td>8</td>
</tr>
</tbody>
</table>

**Item-total Statistics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>if Item</th>
<th>Item- Alpha if Item Deleted</th>
<th>Total Correlation if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRY</td>
<td>4.1471</td>
<td>30.6747</td>
<td>.9154</td>
<td>.9363</td>
<td></td>
</tr>
<tr>
<td>PHYS RES</td>
<td>4.2941</td>
<td>32.8806</td>
<td>.9223</td>
<td>.9348</td>
<td></td>
</tr>
<tr>
<td>SCREAM</td>
<td>4.2941</td>
<td>32.2745</td>
<td>.9201</td>
<td>.9348</td>
<td></td>
</tr>
<tr>
<td>VERB RES</td>
<td>4.5000</td>
<td>33.8333</td>
<td>.8823</td>
<td>.9378</td>
<td></td>
</tr>
<tr>
<td>EMOT SUP</td>
<td>4.1176</td>
<td>35.3797</td>
<td>.7193</td>
<td>.9484</td>
<td></td>
</tr>
</tbody>
</table>
### FLAIL 4.7059 38.2745 .8789 .9456
### MUSC RIG 4.2647 36.9278 .5666 .9580#
### VER PAIN 4.2647 34.9278 .8579 .9400

Reliability Coefficients

| N of Cases | 34.0 | N of Items | 8 |
|-------------|------|------------|
| Alpha | .9492 |

3. **Alpha for the scale with (Inf_seek, Nerv_beh and Ver_fear) and Musc_rig deleted.**

<table>
<thead>
<tr>
<th>Statistics for</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>4.2647</td>
<td>36.9278</td>
<td>6.0768</td>
<td>7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item-total Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Deleted</td>
</tr>
<tr>
<td>---------</td>
</tr>
<tr>
<td>CRY</td>
</tr>
<tr>
<td>PHYS RES</td>
</tr>
<tr>
<td>SCREAM</td>
</tr>
<tr>
<td>VERB_RES</td>
</tr>
</tbody>
</table>

Reliability Coefficients

| N of Cases | 34.0 | N of Items | 7 |
|-------------|------|------------|
| Alpha | .9580 |

4. **Alpha for the scale with (Inf_seek, Nerv_beh and Ver_fear), (Musc_rig) and Emot_sup deleted.**

<table>
<thead>
<tr>
<th>Statistics for</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>3.4412</td>
<td>28.3752</td>
<td>5.3268</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item-total Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Deleted</td>
</tr>
<tr>
<td>---------</td>
</tr>
<tr>
<td>CRY</td>
</tr>
<tr>
<td>PHYS RES</td>
</tr>
<tr>
<td>SCREAM</td>
</tr>
<tr>
<td>VERB_RES</td>
</tr>
<tr>
<td>FLAIL</td>
</tr>
</tbody>
</table>
### Reliability Coefficients

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>VER_PAIN</td>
<td>2.7647</td>
<td>20.7914</td>
<td>.8508</td>
<td>.9556</td>
</tr>
</tbody>
</table>

- **N of Cases = 34.0**
- **Alpha = .9603**

#### 5. Alpha for the scale with (Inf_seeK, Nerv_beh and Ver_fear), (Musc_rig), (Emot_sup) and Flail deleted.

**Statistics for**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>3.2059</td>
<td>23.3806</td>
<td>4.8353</td>
<td>5</td>
</tr>
</tbody>
</table>

**Item-total Statistics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>Item- Deleted</th>
<th>Corrected Deleted</th>
<th>Alpha Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRY</td>
<td>2.4118</td>
<td>13.6435</td>
<td>.9097</td>
<td>.9562</td>
<td></td>
</tr>
<tr>
<td>PHYS_RES</td>
<td>2.5588</td>
<td>14.9813</td>
<td>.9420</td>
<td>.9473</td>
<td></td>
</tr>
<tr>
<td>SCREAM</td>
<td>2.5588</td>
<td>14.5570</td>
<td>.9407</td>
<td>.9471</td>
<td></td>
</tr>
<tr>
<td>VERB_RES</td>
<td>2.7647</td>
<td>15.7611</td>
<td>.8793</td>
<td>.9577</td>
<td></td>
</tr>
<tr>
<td>VER_PAIN</td>
<td>2.5294</td>
<td>16.5597</td>
<td>.8466</td>
<td>.9638#</td>
<td></td>
</tr>
</tbody>
</table>

- **Reliability Coefficients**
  - **N of Cases = 34.0**
  - **Alpha = .9634**

#### 6. Alpha for the scale with (Inf_seeK, Nerv_beh and Ver_fear), (Musc_rig), (Emot_sup), (Flail) and Ver_pain deleted.

**Statistics for**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>Std Dev</th>
<th>N of Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE</td>
<td>2.5294</td>
<td>16.5597</td>
<td>4.0694</td>
<td>4</td>
</tr>
</tbody>
</table>

**Item-total Statistics**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Variance</th>
<th>Item- Deleted</th>
<th>Corrected Deleted</th>
<th>Alpha Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>CRY</td>
<td>1.7353</td>
<td>8.6248</td>
<td>.8938</td>
<td>.9629</td>
<td></td>
</tr>
<tr>
<td>PHYS_RES</td>
<td>1.8824</td>
<td>9.6221</td>
<td>.9425</td>
<td>.9440</td>
<td></td>
</tr>
<tr>
<td>SCREAM</td>
<td>1.8824</td>
<td>9.3131</td>
<td>.9334</td>
<td>.9454</td>
<td></td>
</tr>
<tr>
<td>VERB_RES</td>
<td>2.0882</td>
<td>10.1435</td>
<td>.8992</td>
<td>.9574</td>
<td></td>
</tr>
</tbody>
</table>

- **Reliability Coefficients**
  - **N of Cases = 34.0**
  - **Alpha = .9638**
it remains can no longer be said to be reliably measuring distress - it is better described as measuring tearfulness. Therefore, further tests of validity should be made for each stage of the deconstruction of the scale in order to monitor for perceived changes in its focus. Those correlational analyses of the validity of the OSBDa described above, at the beginning of this section, were repeated at each stage of the deconstruction of the scale for increasing alpha, in order that any changes may be documented. A summary of this exercise is presented overleaf in Table 7.

The first observation to note is that neither the child's trait anxiety or anticipated pain correlate with OSBDa total scores at any stage of the decomposition, contrary to the findings of Jay et al (1983). Of interest is the observed variation in correlation with the child's state anxiety, which is highly significant for the full scale ($p=0.001$) but which becomes increasingly less significant as items are systematically removed. However, the scale at its most impoverished (consisting only of four items) still correlates at the $p=0.011$ level ($r=0.6319$), suggesting that the construct it measures overlaps with that of the STAIC state scale by approximately 40% ($r^2$). The full scale coincides, however, by approximately 54%. With the deletion of Information seeking, Nervous behaviour, and Verbal fear, the resulting scale changes from correlating well with experienced pain ($p<0.05$) to not associating with it to a significant extent ($p=0.123$, $r=0.4938$). This suggests that these three items tap to some extent the experience of pain component of distress, although one may not have predicted this relationship from the items themselves, apparently having a more apprehensive focus. The relationship becomes increasingly poorer with the further stages of decomposition and, while the level of significance appears to reach a turning point at step 3, this is because the correlation becomes inverse at this stage and continues with an increasingly negative correlation coefficient at each stage. It is of note that when Verbal Pain is deleted at step 6, the relationship with experienced pain as measured by the Pain Thermometer jumps significantly further into the negative domain.

The relationship between the Visual Analogue Scale of distress taken by the nurse and the OSBDa total scores remains highly significant throughout the process of decomposition, becoming only very slightly (and nonsignificantly) weaker. This suggests that the items deleted up to and including step 6 do not contribute significantly to the detection of those components of distress measured by the nurse VAS. However, as noted above, the inclusion of these items improves correlation with the STAIC state scale. Thus, there are features of the child's response to the situation which are separately measured by the VAS and the STAIC; The items deleted from the OSBDa up to and including step 6 can be considered as indices of those features measured by the STAIC, while the items remaining at step 6 robustly index those features of the response measured by the VAS.
Table 7

Cumulative effect on validity measures of removing all items suggested by calculating Cronbach’s Alpha

“Step_2”, “Step_3” etc refer to the stages of removing items from the scale described in Figure 11. A key to the cumulative deletion of items is presented below this table. Each column of the table represents the correlation coefficients for each validity measure with the total score from the scale at that stage of decomposition. Each cell contains correlation coefficient r, number of cases n, and 2-tailed significance p.

<table>
<thead>
<tr>
<th></th>
<th>OSBDA</th>
<th>STEP_2</th>
<th>STEP_3</th>
<th>STEP_4</th>
<th>STEP_5</th>
<th>STEP_6</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAIC_C1</td>
<td>0.7773</td>
<td>0.7344</td>
<td>0.6711</td>
<td>0.6312</td>
<td>0.6276</td>
<td>0.6319</td>
</tr>
<tr>
<td></td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
</tr>
<tr>
<td></td>
<td>p=0.001</td>
<td>p=0.002</td>
<td>p=0.006</td>
<td>p=0.012</td>
<td>p=0.012</td>
<td>p=0.011</td>
</tr>
<tr>
<td>STAIC_C2</td>
<td>0.1422</td>
<td>0.1381</td>
<td>0.0838</td>
<td>0.0732</td>
<td>0.0691</td>
<td>0.0520</td>
</tr>
<tr>
<td></td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
<td>(15)</td>
</tr>
<tr>
<td></td>
<td>p=0.613</td>
<td>p=0.624</td>
<td>p=0.766</td>
<td>p=0.795</td>
<td>p=0.807</td>
<td>p=0.854</td>
</tr>
<tr>
<td>PAINANTI</td>
<td>0.2619</td>
<td>0.3073</td>
<td>0.3343</td>
<td>0.3346</td>
<td>0.3436</td>
<td>0.3622</td>
</tr>
<tr>
<td></td>
<td>(15)</td>
<td>(14)</td>
<td>(14)</td>
<td>(14)</td>
<td>(14)</td>
<td>(14)</td>
</tr>
<tr>
<td></td>
<td>p=0.366</td>
<td>p=0.285</td>
<td>p=0.243</td>
<td>p=0.242</td>
<td>p=0.229</td>
<td>p=0.203</td>
</tr>
<tr>
<td>PAINEXPE</td>
<td>0.6465</td>
<td>0.4938</td>
<td>0.0955</td>
<td>-0.1313</td>
<td>-0.1313</td>
<td>-0.4317</td>
</tr>
<tr>
<td></td>
<td>p=0.032</td>
<td>p=0.123</td>
<td>p=0.780</td>
<td>p=0.700</td>
<td>p=0.700</td>
<td>p=0.185</td>
</tr>
<tr>
<td>VAS2MID</td>
<td>0.8134</td>
<td>0.7877</td>
<td>0.7580</td>
<td>0.7547</td>
<td>0.7659</td>
<td>0.7556</td>
</tr>
<tr>
<td></td>
<td>(28)</td>
<td>(28)</td>
<td>(28)</td>
<td>(28)</td>
<td>(28)</td>
<td>(28)</td>
</tr>
<tr>
<td></td>
<td>p=0.000</td>
<td>p=0.000</td>
<td>p=0.000</td>
<td>p=0.000</td>
<td>p=0.000</td>
<td>p=0.000</td>
</tr>
</tbody>
</table>

Key:

Step 2. The scale with Inf_seek, Nerv_beh and Ver_fear deleted.
Step 3. The scale with (Inf_seek, Nerv_beh and Ver_fear) and Musc_rig deleted.
Step 4. The scale with (Inf_seek, Nerv_beh and Ver_fear), (Musc_rig) and Emot_sup deleted.
Step 5. The scale with (Inf_seek, Nerv_beh and Ver_fear), (Musc_rig), (Emot_sup) and Flail deleted.
Step 6. The scale with (Inf_seek, Nerv_beh and Ver_fear), (Musc_rig), (Emot_sup), (Flail) and Ver_pain deleted.

STAIC_C1 State-Trait Anxiety Inventory STATE scale.
STAIC_C2 State-Trait Anxiety Inventory TRAIT scale.
PAINANTI Anticipated Pain from Pain Thermometer.
PAINEXPE Experienced Pain from Pain Thermometer.
VAS2MID Nurses' ratings of distress during the procedure on 10cm Visual Analogue Scale.
In their analysis of the original OSBD, Elliott et al (1987) devised their own criteria for retention or deletion of items, rather than using the criterion of the value of alpha if the item is deleted. Instead, items were deleted if they occurred in less than 10% of the subjects or if they had an item-total correlation coefficient of less than +0.3. Based on these criteria, they deleted Verbal Fear, Nervous Behaviour and Muscular Rigidity and found a value of alpha equal to 0.72. Prior to this deletion, alpha equaled 0.68.

There are two ways in which data from the current study may be compared to these results: by administering the same criteria, or by deleting the same three items. The first method, when applied to the current data set gives rise to the deletion of Information Seeking by virtue of the correlational criterion (as can be seen from the first table in Table 6) and Verbal Fear due to its only being present in 9% of the sample (see Table 8).

<table>
<thead>
<tr>
<th>Item</th>
<th>Percentage Scoring Zero</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry</td>
<td>64.71</td>
</tr>
<tr>
<td>Scream</td>
<td>67.65</td>
</tr>
<tr>
<td>Physical Restraint</td>
<td>64.71</td>
</tr>
<tr>
<td>Verbal Resistance</td>
<td>79.41</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>47.06</td>
</tr>
<tr>
<td>Muscular Rigidity</td>
<td>58.82</td>
</tr>
<tr>
<td>Verbal Fear</td>
<td>91.18</td>
</tr>
<tr>
<td>Verbal Pain</td>
<td>55.88</td>
</tr>
<tr>
<td>Flail</td>
<td>82.35</td>
</tr>
<tr>
<td>Nervous Behaviour</td>
<td>41.18</td>
</tr>
<tr>
<td>Information Seeking</td>
<td>88.24</td>
</tr>
</tbody>
</table>

Table 8
Percentage of scores being zero per item. N=34.

After deletion of these two items from the current scale, the value of alpha increases slightly to 0.9445 and, while none of the non-significant validity measures become significant, the relationship between total distress scores and child state-anxiety, experienced pain, and nurses' VAS ratings of distress all improve (r=0.81, p=0.000; r=0.69, p=0.019; r=0.79, p=0.000 respectively). The second means of comparison is to delete the same items deleted by Elliott et al, and for the current scale this yields an alpha of 0.9271 - a negligible increase from the original 0.9231. Again none of the non-significant validity measures become significant, and this time the relationship between total distress scores and child state-anxiety, experienced pain, and nurses'
VAS ratings of distress all diminish ($r=0.63$, $p=0.011$; $r=0.12$, $p=0.717$; $r=0.78$, $p=0.000$ respectively).

At a more fundamental level, it should be noted that values of alpha quoted for the amended scale OSBDa are all between 0.9271 and 0.9638, while those quoted by Elliott et al (1987) are 0.68 and 0.72. It would appear that the internal consistency of the amended scale is much higher than for the original scale. This will be discussed in the following section (Discussion).

**Factors Associated with Distress**

Measures of association between those variables hypothesised to vary with increased distress were conducted using Pearson’s product moment correlations. As presented later in this section, distraction and preparation were not shown to be related to distress, and so this distinction is not made in the following analyses.

**Anxiety:**

Associations between total OSBDa scores and parent and child state and trait anxiety were calculated\(^1\), and the results are presented in Table 9:

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>S. D.</th>
<th>$r$</th>
<th>2-tailed $p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAI-Y1 (State Scale)</td>
<td>33</td>
<td>33.06</td>
<td>9.01</td>
<td>0.14</td>
<td>0.455</td>
</tr>
<tr>
<td>STAI-Y2 (Trait Scale)</td>
<td>32</td>
<td>37.97</td>
<td>7.30</td>
<td>0.07</td>
<td>0.695</td>
</tr>
<tr>
<td>STAIC-C1 (State scale)</td>
<td>15</td>
<td>33.87</td>
<td>7.00</td>
<td>0.78</td>
<td>0.001**</td>
</tr>
<tr>
<td>STAIC-C2 (Trait scale)</td>
<td>15</td>
<td>37.33</td>
<td>6.62</td>
<td>0.14</td>
<td>0.613</td>
</tr>
</tbody>
</table>

Table 9

Means, standard deviations, correlation coefficients and significance values for anxiety measures with total scores from the OSBDa. ** $p<0.01$.

As may be seen from the above figure, only the state anxiety of the child varies with distress exhibited during the procedure, and that is very significant at the $p=0.001$ level, accounting for 61% of the variance. It is not possible to predict how distressed the child is likely to be from the anxiety of the accompanying parent, or the trait anxiety (the potential for anxiety) of either parent or child. This result is contrary to the

\(^1\) Child state and trait anxiety are here reconsidered as predictors of distress. The dual uses of validity measures and predictor variables are discussed in the Discussion section.
anecdotal report of most nurses and clinic staff that a visibly anxious parent often has a child who becomes distressed during the procedure. It also fails to reproduce the finding of Jay et al (1983) that parental trait anxiety predicted procedural distress (for more stressful medical procedures) although interestingly, Jay et al also did not find a relationship between distress and parental or child state anxiety scores. The non-significant result for parental trait anxiety corresponds also to that found by Frank et al (1995). However, it is of note that Frank et al suggest their result does not replicate that of Jay et al because their sample of parents reported levels of anxiety below that of the normative group, thus restricting the range of scores. The current study, however, shows comparable norms for both state and trait anxiety to those presented by Spielberger et al (1970)\textsuperscript{2}, yet also finds no significant relationship between the variables.

**Locus of Control**

Similar calculations to those made for the anxiety measures were made for both child and parent locus of control measures (NS-LOC and R-LOC respectively):

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>S. D.</th>
<th>r</th>
<th>2-tailed p</th>
</tr>
</thead>
<tbody>
<tr>
<td>R-LOC</td>
<td>33</td>
<td>11.58</td>
<td>3.32</td>
<td>0.29</td>
<td>0.100</td>
</tr>
<tr>
<td>NS-LOC</td>
<td>16</td>
<td>18.13</td>
<td>4.67</td>
<td>-0.02</td>
<td>0.956</td>
</tr>
</tbody>
</table>

*Table 10*

Means, standard deviations, correlation coefficients and significance values for locus of control measures with total scores from the OSBDa.

It is clear from the above figure that neither parental nor child locus of control measures are significantly associated with total scores on the OSBDa. Jay et al (1983) found such a null relationship for stressful medical procedures, and the current results would suggest that the same lack of predictive power would apply for less stressful procedures such as those examined in this study (phlebotomy and administration of general anaesthetic.) Because of the lack of results involving locus of control scales in previous studies, it is not possible to justify the use of a one-tailed test in the examination of these variables - also, as mentioned in the introduction to this chapter, it

\textsuperscript{2} Comparison of means and standard deviations for the current study and the normative sample:

<table>
<thead>
<tr>
<th>Current Study</th>
<th>Mean</th>
<th>S. D.</th>
<th>Normative Sample</th>
<th>Mean</th>
<th>S. D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>STA1-Y1</td>
<td>33.06</td>
<td>9.01</td>
<td>STA1-Y1</td>
<td>m35.71</td>
<td>f35.20</td>
</tr>
<tr>
<td>STA1-Y2</td>
<td>37.97</td>
<td>7.30</td>
<td>STA1-Y2</td>
<td>m34.89</td>
<td>f34.79</td>
</tr>
</tbody>
</table>

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is not easy to hypothesise a particular direction for a potential effect as one may reasonably assert relationships in either direction. However, although unjustified, it may be interesting to note that a small relationship may be found between total OSBDa scores and parental locus of control with a one-tailed test ($r=0.382$, $p=0.017$).

**Anticipated Pain**

From the pain literature examined in the above sections of this chapter, it was hypothesised that a child who anticipated more pain from the procedure would be more distressed than one who expected very little. However, no such relationship was found, as indicated in *Table 11*:

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>S.D.</th>
<th>$r$</th>
<th>1-tailed P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipated Pain</td>
<td>14</td>
<td>42.57</td>
<td>31.92</td>
<td>0.26</td>
<td>0.183</td>
</tr>
</tbody>
</table>

*Table 11*

Mean, standard deviation, correlation coefficient and significance value for anticipated pain measures with total scores from the OSBDa.

Jay et al’s (1983) result for stressful procedures demonstrated a very strong relationship between anticipated pain and total OSBD scores ($r=0.76$, $p<0.0001$) but this is clearly not found here for less stressful experiences with the amended scale.

**Distraction and Preparation**

A simple analysis of variance of OSBDa total distress scores by distraction and preparation was conducted to investigate whether these strategies could be associated with levels of distress during the procedures. These results are presented in *Table 12* overleaf:
As can be seen from the above table, there is no detectable association between total OSBDa scores and either distraction during the procedure, preparation in advance of the procedure, or the interaction of both. This result does not reproduce that of Schwartz et al (1983) who found that children involved in related play therapy (similar to the preparative procedure in the current study) were less upset than those in the control group. However, the variable nature of play specialist preparative techniques makes it very difficult to generalise across those techniques.

As seen in Table 12, there are no significant effects of distraction and preparation on OSBDa total distress scores.

Note regarding nil results:

It should be noted that the sample size for this study is rather small, especially for those analyses involving self-report of the child. As a result of this it is possible that small yet significant relationships could be identified between those variables which are shown above to not be associated. For a further discussion of this see the section entitled "Limitations and Future Directions" in the Discussion section below.
Discussion

Validity Measures - Differences between the two scales

It is encouraging to note that the amended form of the Observation Scale of Behavioural Distress correlates so strongly ($p=0.000$) with nurses' thumbnail observations of the severity of the child's distress, particularly when the notion of distress is (deliberately) not defined to any extent on that measure (the visual analogue scale, VAS.) This suggests that the concept of distress indexed by the OSBDa, and elaborated in the introduction to this chapter, corresponds very strongly with whatever it is that a nurse means when using the term "distress". Equally, of course, one may conclude that nurses’ use of the word can be taken to refer to those features used to represent distress by the OSBDa. Thus, in Table 5 on page 201 of this volume, from the item-total correlation values for each item, one may make informed inferences about nurses’ tacit definition of distress; that it involves crying, physical restraint and screaming, for example, and to a lesser extent emotional support and nervous behaviour. (The question of how representative the three nurses involved in the current study are of the general nursing population is, of course, an entirely separate issue.)

The total distress scores of the OSBDa are also quite strongly related to the experience of pain during the procedure ($p<0.05$), although, being a correlational study, it is impossible to draw conclusions as to the causal direction of this relationship. It may be ventured that, as proposed by Black and Chapman (1976) above (p172, this volume) the relationship between total distress scores and experienced pain is due to the inseparability of the concepts distress and pain, perhaps that pain is a significant component of distress and therefore changes in that variable necessarily yield changes in total distress (by definition). If this explanation is accepted, then the value of $r^2(0.42)$ for the relationship between experienced pain and total distress derived from Table 2 (p195, this volume) reflects the proportion of the concept “distress” occupied by pain (strictly pain experience.) However, this interpretation of the figure should not be taken as absolute since distress, and its potential component concepts of pain and anxiety, overlap quite considerably as described in the introduction to this chapter. To be an accurate representation, the strict concept measured by the pain thermometer for experienced pain would need to be analysed and the effects of each component of the concept partialled out. Equally, of course, we may propose from this relationship that increased pain resulting from a procedure such as cannula introduction leads to increased distress manifested by the child. This feels intuitively true, and perhaps few would argue that it is absolutely false, but unfortunately it does not shed any light on the other causal explanations proposed here - they are not mutually exclusive. The intuitive feel of this explanation does not enlighten the hypothesis that increased pain is
or is not increased distress - proposed above. A further causal explanation, and one which it is important to consider, is that children who were old enough to complete the pain thermometer (that is, eight years old and above) and who exhibited increased levels of distress during the procedure may have been particularly self-conscious when asked by somebody who had witnessed the distress how much the procedure hurt. For example, a child who had expended considerable energy protesting about the procedure, screaming, crying, flailing limbs and so on, would perhaps be unlikely to report that in actual fact the procedure wasn't nearly as painful as he or she had expected. It is plausible to imagine that some face may be saved by asserting that the procedure was very painful, and therefore the response to it was justified in some way. The competing motivations of respondents should always be considered in this way, however it may be observed that the mean value of experienced pain is considerably lower on a similarly anchored scale (the pain thermometer) than that for anticipated pain (Table 2, p195) suggesting that children significantly overestimate the pain they are likely to experience during the introduction of a cannula. From the current study this is perhaps the result most of interest to apprehensive paediatric outpatients.

The OSBDa has also been shown in the previous section to correlate very strongly with the state-anxiety of the child, lending support to the notion that distress consists more significantly of situation specific anxiety than of more pervasive anxiety proneness (trait-anxiety did not correlate with OSBDa total distress scores - see below.) A complicating issue, however, is that out of practical necessity all scales and questionnaires completed by parents and children were completed in the waiting area, prior to being called into the clinic room. Thus, the state-anxiety of both parties was measured while waiting for the procedure to occur, while distress was measured during the procedure itself. To be an ideal test of the validity of the scale, the state-anxiety of the child would need to be measured during the actual procedure, which is absurd for a forty-item self-report measure. An assumption made in the current study, therefore, is that state-anxiety measured during waiting-time meaningfully reflects that likely to be obtained were it measured during the procedure itself. It is argued that the situation specific to this anxiety is the imminent procedure, although that procedure may at the time be an unknown quantity to the child, and so the anxiety being indexed by the STAIC state scale pertains to that imminent procedure. Given the discrepancy between mean values for anticipated and actual pain highlighted in the previous paragraph, it is argued that, even during the procedure, that which gives rise to the anxiety may better be understood as beliefs about the procedure (accurate or otherwise) rather than the procedure itself.

Alongside the measure of experienced pain, the other two measures of the validity of the OSBDa which form replications of those carried out by Jay et al (1983) are those of anticipated pain, by way of the pain thermometer, and the trait-anxiety of the child.
Neither of these two variables were found to be significantly related to the OSBDa total scores, while Jay et al found powerful relationships between their original OSBD total distress scores and these two validity measures \((p<0.0001, \text{ and } p<0.001 \text{ respectively})\). From Jay et al’s result, and from the literature discussed throughout the introduction to this chapter, it was hypothesised that increased anticipated pain would correlate strongly with OSBDa total distress scores; particularly as Katz et al (1981) point out that their distress measure the PBRS correlates much more highly with a self-report measure of fear than one of pain, suggesting that anticipated pain would be more strongly related to distress than experienced pain (if one supposes that anticipation, apprehension and fear are different degrees or colours of a similar construct.) A possible reason for the results of the current study and that of Jay et al differing in respect of the anticipated pain measure is that the procedures undergone in the two studies are dramatically different, as are the experiences of the children regarding those procedures. Jay et al studied children undergoing Bone-Marrow Aspiration (BMA), while the current study examined the considerably less threatening insertion of a cannula for a blood test or general anaesthetic, and skin-test. The mean number of previous BMA’s experienced by Jay et al’s sample was 13.1 and the purpose of the procedure is to determine the presence or absence of cancer cells. Although previous hospital experience was not recorded in the current study, the degree of experience with the procedure, it is argued, cannot compare to that of the BMA patients. For the latter group, anticipated pain may be much better informed by past experience, and the level of anticipated pain will therefore be more accurate and much higher as the procedure is, unfortunately, considerably painful. It could be that accurate anticipation of a very painful procedure and nervous guesswork about an unfamiliar procedure are quite different concepts, and that labelling both “anticipated pain” is therefore quite misleading.

The current study did not find a significant relationship between the trait-anxiety of the child and total distress scores of the OSBDa, and it is difficult to informedly make suggestions as to why this should be the case. There can be few explanations regarding the effect of the differing procedures since trait-anxiety is explicitly defined as being a stable feature of anxiety proneness, and the effect of repeated traumatic medical procedures on the trait anxiety of children with cancer is not known to this author. In order to give rise to a detectable effect, the effect of such an experience on anxiety-proneness would have to be to enhance in some way its relationship with distress during the procedure - that is, simply giving rise to higher or lower overall levels of trait anxiety would not lead in itself to a detectable effect. It is difficult to see how this enhancement of an effect would operate, although it is certainly not unreasonable to suggest that the trait-anxiety of the BMA children differs in some way to those
participating in the current study.  

A further possible explanation regarding this discrepancy in results involves the difference between the measures used. The measure of trait-anxiety was similar across the two studies, but the OSBDa of course differs slightly from the OSBD, and it is possible that this difference gives rise to the two results - again this may happen in two ways, either the OSBD enhances the relationship, or the OSBDa masks it somehow. The differences between the two scales, however, are quite small and the largest difference (that of abandoning the scoring weights and time-sampling administration) has been shown to make very little difference to the validity of the scale (Elliott et al., 1987) - that is, it continues to index the same construct. The only other amendment which distinguishes the OSBDa is that of scoring each item on a four-point Likert scale and it is possible, though it is proposed unlikely, that this system masks the effect.

Ultimately, one may conclude that although both scales are asserted to be valid measures of behavioural distress, it is inescapable that despite the overlap between the two sets of validity measures, there are also associations which are not common between the two scales: The OSBD can be said to measure distress as validated by children's trait anxiety scores and children's anticipated and experienced pain, while the OSBDa shows significant associations with the validity measures of experienced pain (only), nurses' judgments of distress (by VAS) and the child's state-anxiety (discussed above.) If the two scales measure precisely the same construct, one would expect the validity measures to correspond - thus, when they do not one may either look for reasons such as those outlined above or conclude that the scales measure slightly different constructs. From the nature of the amendments made in the creation of the OSBDa, however, it is difficult to argue that it is these changes which give rise to a difference in the construct measured.

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1 The increase of an effect by the BMA procedure is discussed here, rather than the masking of an effect by the procedures in the current study because the former is considered to be the extraordinary case.
The Structure and Reliability of the OSBDA

Reliability:

From the study reported in section 3 iii) above it may be argued that the scale demonstrates high inter-rater reliability, although the following important points should be considered: The index of inter-rater reliability cited in the above study comprises a Spearman’s rank order correlation coefficient \( r_s = 0.92 \) which is particularly favourable. However, from a calculation of rater agreement based on Cohen’s Kappa which takes the value of overall agreement (the proportion of obtained data points which demonstrate complete agreement between the two raters - 59.62%) and corrects for chance agreement, the index of inter-rater reliability is shown to be only 49%. This value is significantly less favourable. This reflects a discrepancy in the ways in which the two approaches measure inter-rater reliability - Kappa measures, as stated, the (corrected) proportion of scores upon which the raters agree; thus for example, a child for whom a total distress score of six is obtained by both raters will provide a point of agreement, whereas if one rater scored the child as six, and the other five, this is considered disagreement. The magnitude of the discrepancy in scores is not considered in the calculation. Spearman’s rank order correlation however, being a measure of the strength of the relationship between the scores of the two raters, does consider the inter-rater degree of disagreement, which would lead to a more favourable value for inter-rater reliability. However, another feature of Spearman’s rank order correlation is that, as implied, it is concerned with the ranked order of the data-points, and not with the actual values of each point. Thus it would be possible for one rater to consistently over or under-score the other, for example by always adding or subtracting a constant to or from the total distress scores - and the correlational agreement, by Spearman, would be 100% \( r_s = 1.00 \). This has not been accounted for in the previous study, as it may be by investigating the mean total distress scores for each rater, although random allocation of each rater pair to the categories of ‘rater 1’ and ‘rater 2’ would account for the effect to some extent (see section 3 iii). Nevertheless, the discrepancy between values for total agreement, corrected agreement, and Spearman’s rank order correlation coefficient should be seriously considered here.

The initial value of alpha obtained for all eleven scale items (0.9231) indicates that the reliability of the OSBDA is particularly favourable, and thus the scale may be considered to be highly internally consistent. It has been noted above (results section) that this already high index of internal consistency may be further increased by deletion of the items Information Seeking, Nervous Behaviour and Verbal Fear, and that such item deletion may be continued until only four items remain. As this process is carried out, by definition the value of alpha increases from 0.9231 in the first instance to 0.9638 for
the diminished four-item scale, however, as has been demonstrated above, the
correlational measures of the validity of the scale correspondingly decrease. It is argued
here that while this exercise only increases the reliability of the scale very slightly from
a starting point of being already very favourable, it correspondingly has a larger, more
significantly detrimental, effect on the validity measures: The significance of the child’s
state-anxiety correlation falls by a factor of ten, and experienced pain becomes non-
significant; only the nurses’ VAS ratings of distress remain comparably significant and
even then the value of $r$ falls slightly. Although comparing the relative merits of distinct
scales such as validity versus reliability will always remain a moot point, it is
nevertheless the case that a reliable scale which measures nothing is worthless - and so
validity conceptually precedes reliability. Since reliability is high for the eleven-item
OSBDa it is suggested that the scale has more experimental worth in its eleven-item
form than with items removed from it at any stage in the decomposition outlined in the
above results section.

It is suggested that for scales designed to measure multifaceted constructs such as
distress, this tendency to self-destruct for an increasing value of alpha is perhaps more
likely. This would be because the construct under examination may be considered an
umbrella term for a number of more fundamental variables such as, for example, pain,
anxiety, apprehension and so on, and it is possible to increase reliability by erroneously
focussing on smaller and smaller numbers of these fundamental variables. As described
in the previous section (Results) one may imagine deconstructing the OSBDa right
down to the single item Cry, which would very reliably index tearfulness but no longer be
a useful measure of distress. It would therefore be more beneficial to utilise a more
considered means of item-deletion than straightforward increase of alpha in short-
sighted stages.

In their analysis of the original OSBD, Elliott et al (1987) outline their rationale for item
deletion, described above (p206), and although they do not make any suggestion as to
why this rationale is more appropriate than any other (for example regarding the item-
total correlation criterion) it does nevertheless yield an improved alpha and increased
validity when applied to the current scale OSBDa. The items deleted in line with these
criteria are Information Seeking and Verbal Fear, which are the two items which
correlate least well with the total distress scores - indeed Information Seeking has a
small negative correlation. It is therefore suggested that the remaining nine-item scale,
consisting Cry, Scream, Physical Restraint, Verbal Resistance, Emotional Support,
Muscular Rigidity, Verbal Pain, Flail and Nervous Behaviour is the most valid and
reliable version of the scale for indexing situation-specific behavioural distress. It is
surprising that items as strictly defined as Information Seeking should yield a negative
(albeit tiny) correlation with total distress scores. This lack of a relationship suggests
that Information Seeking as a behaviour may also vary with other factors uncontrolled
in the study, for example educational background or expectation of the child of health professionals and the effect of these other variables masks the expected effect of distress in isolation. Indeed, in their analysis of the Procedure Behavioural Rating Scale (PBRS) Katz et al (1980) note that children who expressed inquisitiveness about the procedure demonstrated fewer anxiety behaviours than those who did not, suggesting that Information Seeking may better be described as a coping behaviour that one of distress. It would not be justified to assert that rates coping behaviour necessarily covary with levels of distress and therefore rates of distress behaviours. When choosing items for such a scale, it is clearly important therefore to consider the variety of other variables which are likely to impact upon those items.

**Structure - Multidimensional Scaling:**

In order to further explore the amended distress scale OSBDa, a multidimensional scaling analysis was applied to the data obtained from each participant (n=34) for each of the eleven items of the scale. This approach to the analysis of the underlying structure of the scale was chosen because the sample size was not large enough to support a formal factor analysis. As pointed out in the previous section (p196, Results) the best fitting model of the items of the complete OSBDa is the two-dimensional representation presented in Figure 2, page 197. Because the model is Euclidean the solution presented is invariant under both rotation, translation and rescaling of the axes (Coxon, 1982) and it is not until the axes are rotated and translated slightly that some structure begins to emerge. Figure 6 overleaf presents this translated solution (no scale is presented as the interpretation is purely qualitative.)
Figure 6 presents the same two-dimensional space as that found in Figure 2 in the previous section, the difference being that the axes have been translated to the right of the figure slightly, and they have been rotated approximately 30 degrees anticlockwise. This transformation eases interpretation of the distribution of points.

It is argued here that the distribution may be understood as lying primarily along Dimension 1, and that that dimension represents a continuum of behaviours from coping behaviours on the left, to stress behaviours on the right - stress behaviour and coping behaviour are considered as opposite ends of a continuum of behaviours, consistent with the definitions of Lazarus & Folkman (1984) and Sarafino (1990). This interpretation is prompted by the observation above that information seeking may be considered a means of coping with a stressful situation, and rather an adaptive one, while crying, screaming and nervous behaviour (although potentially successful means by which the situation may be addressed) are better understood as direct expressions of distress than conscious efforts to cope. For example, from the operational definitions of each item (see appendix), asking questions about what is happening, gritting teeth/clenched fists/white knuckles, saying "I'm afraid" and so on are conscious efforts to ameliorate the stressful nature of the situation; verbal resistance (does not follow instructions) and verbal pain (says "Ow!", "Ouch!") etc can be seen as less sophisticated reactions to the situation but which have some intent, while crying and screaming may be straightforward intentionless reactions to the stressful procedure. This interpretation is not to say, however, that the OSBDa erroneously measures coping behaviours as well as distress behaviours as it is simplistic to think of these categories as mutually exclusive. It would be more accurate to say that manifestation of distress comprises a variety of behaviours which include unintended reactions to distress, pain and anxiety and deliberate attempts to ameliorate the stressful nature of the situation. As illustration to this point it may be observed that the order of points along this principal dimension bear no relation to the order of items in terms of item-total correlation in Table 5 - thus distress as indexed by the OSBDa samples a breadth of behaviours along this dimension rather uniformly, rather than loading particularly heavily at either end. The erroneous item here is that of Information Seeking, which has been shown above to share no variance with total distress scores and therefore lies at the extreme coping end of the figure.

Interpretation of the second dimension in Figure 6 is more difficult to make. However observation of the distribution of items along this dimension suggests that it can be taken to represent the degree to which the behaviour is overt or emphatic. Thus, to the lower end of the figure (Nervous Behaviour, Muscular Rigidity) the behaviours are more subtle expressions of distress, while at the upper end (Scream, Verbal Fear etc) the behaviours are more intense or urgent. This is of less theoretical interest than the primary axis described above, but from this second dimension it may be claimed that
the OSBDa is sensitive to both overt and subtle expressions of distress.

It is certainly notable that this model of OSBDa items reflects the decomposition of the scale for increasing alpha (as presented in Table 6.) As a reminder, the order of deletion of items, step-by-step was as follows:

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>Step 5</th>
<th>Step 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>No items</td>
<td>Inf_seek</td>
<td>Musc_rig</td>
<td>Emot_sup</td>
<td>Flail</td>
<td>Ver_pain</td>
</tr>
<tr>
<td>deleted</td>
<td>Nerv_beh</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ver_fear</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 13
Order of deletion of items for increasing alpha (summary.)

At the final stage of this decomposition, the remaining items are Cry, Physical Restraint, Scream and Verbal Resistance and it can be seen that these cluster closely together near the top of the figure. By imagining the items being replaced in reverse order (step 6, step 5 etc) it may be observed from Figure 6 that the items occur in the model at increasing distance from this original cluster. Measured from an imaginary point in the centre of this cluster of four items, the order of item deletion for increasing alpha may be reliably predicted from distance away from the cluster, that is items which lie further away are deleted before more proximal items. Therefore the representation may also be understood as a radial model of the contribution to the internal consistency of the scale. Step 1 of this deletion removes Information Seeking, Verbal Fear and Nervous Behaviour from the analysis; These items do not lie in similar areas of the model and this supports the assertion that neither of the two dimensions represent distress versus no distress, rather they represent dimensions of distress.

As described in the introduction to this study, Ambuel et al (1992), in their factor analysis of their COMFORT scale identified two main factors: Behavioural distress and Physiologic Distress. While the OSBDa explicitly set out to measure behavioural distress, it is reassuring that a similar distinction cannot be made from this model of the current data-set. Similarly it is not possible, from this representation to derive axes of pain or anxiety (although it is pointed out that such a distinction is notoriously difficult, as alluded to in the introduction.) However, this lends credence to the suggestion that these two concepts are intertwined in their contribution to distress.
Factors Associated with Distress

Anxiety:

From those measures of anxiety examined in the current study - the State-Trait Anxiety Inventory and the State-Trait Anxiety Inventory for Children (Spielberger et al, 1970 & 1973, respectively) indexing the state and trait anxiety of both parents and children just prior to moderately stressful paediatric procedures - it is surprising that only the state anxiety of the child has been shown to covary with distress manifested during the procedure. This variable, however does account for 61% of the variance in behavioural distress. As mentioned in the previous Results section, this relationship contrasts with the findings of Jay et al (1983) who found no significant relationship between distress measured on the original OSBD and the state anxiety of the child, which is perhaps surprising given the conceptual proximity of distress and anxiety - particularly anxiety which pertains to a specific situation. It is of course unreasonable to assume that constructs which appear to lie close to one another conceptually necessarily will share variance, however one may make a strong case for this hypothesis. Thus, the identification of a relationship between the child’s state-anxiety and total distress score on the OSBDA but not between trait-anxiety and distress can be asserted to support the model of situation-specificity and anxiety presented in Figure 1 in the introduction to this study. Although the elements of this model - distress, state-anxiety and trait-anxiety are not intended to represent different degrees of a similar construct, it would nevertheless be expected that the corresponding amounts of situation-specificity inherent in distress and state-anxiety would lead to a stronger relationship between these two, than with distress and trait-anxiety, which do not share this feature to the same extent.

In this instance, the above anxiety variables are being considered as potential predictors of distress - that is, it is proposed that attention to the levels of such anxiety in paediatric outpatients and their parents could, with knowledge of their relationships with distress, be used to more effectively target distress-prone children with interventions designed to minimise this distress (which are manifold - Schwartz et al, 1983). The state anxiety of the child has of course been asserted as an index of the validity of the OSBDA in the preceding sections of this discussion, but it is argued that it may also be considered as a means of prediction for the distress exhibited during the procedure. This may appear somewhat contradictory, but the assertion is based on the assumption that the situation to which the state-anxiety is specific is more the upcoming procedure than the actual experience of the waiting area. The experience of waiting may admittedly contribute to some extent to the anxiety in and of itself, but the very exercise of trying to distinguish the contributions to state-anxiety of the waiting experience and
the imminent procedure suggests that the procedure may account for the greater proportion of the variance. A combination of this and the conceptual inseparability of distress and anxiety supports the use of state-anxiety as a validity index of the OSBDa. However, the fact that the state anxiety in the waiting area is apparent before the child enters the clinic room also enables it to be used as a means of predicting the distress exhibited in the clinic. This point could also be considered as follows: the state-anxiety measure indexes the already apparent apprehensive components of the distress exhibited by the child. It is simplistic to think of the distress in the clinic room as a separable constellation of behaviours, although distress is directly measured in this study during a discreet time period in the clinic; it is perhaps better understood as beginning to be manifested in the waiting area and may continue as the child leaves the clinic as well. Thus the state-anxiety of the child represents the early stages of distress provoked by the imminent procedure, rather than being a distinct variable which predicts changes in another (distress.)

The lack of a detectable relationship between total OSBDa scores and the trait-anxiety of the child has been described above in the discussion on validity. It would be redundant to reiterate those observations here, although of course many of those observations will apply.

During the collection of data, many nurses, paediatricians, and indeed parents voiced their opinions that the anxiety of the parent was instrumental in determining the distress exhibited by the child during the procedure, and the relationship between maternal anxiety and child distress is more formally echoed in the literature (Jay et al, 1983; Robins, Robins & Rawson, 1973). However, as demonstrated above, this is not found in the current study: neither the trait- nor state-anxiety of the accompanying parent are shown to covary with the distress of the child during the procedure, while Jay et al (1983) are able to show a relationship between parental trait anxiety and the behavioural distress of the child. The main difference between the current study and that of Jay et al's has been cited above as the differing medical procedures experienced by participating children and so this would be the first area to consider in determining reasons for the discrepancy in the results. If this were to provide an explanation, either extremely stressful medical procedures promote a relationship, or some feature of moderately stressful procedures conceals or inhibits this effect. These are perhaps two sides of the same coin. As pointed out in the above remarks concerning the validity of the scale in which hypotheses are proposed for the lack of an observable relationship between distress and the child's trait-anxiety, trait-anxiety is formally a stable construct less susceptible to changes in the environment than state-anxiety. It could perhaps be argued that for those experiences which fall into the realm of normal/everyday experience, trait-anxiety indeed remains stable - however, maybe repeatedly being involved in the extremely stressful invasion of one's child (bone marrow aspiration)
does indeed impact upon levels or variability of parental trait-anxiety. Although arguing for the opposite discrepancy in effect findings, it may also be argued, though, that the effect of a very stressful procedure would mask the perhaps more subtle effects of parental trait anxiety, such that for moderately stressful procedures the effect would become more apparent. This argument is presented on the grounds that it feels more intuitively probable, however as pointed out it is unsupported by the results.

**Locus of Control and Anticipated Pain:**

Just as found by Jay et al (1983) for stressful procedures, no relationship is found in the current study between parental or child locus of control and the behavioural distress of the child during less stressful procedures. Again, one might perhaps expect that as the powerful effect of a very stressful procedure is taken away, more subtle effects of locus of control would become apparent, but this is not shown to be the case. All of the technological reasons hypothesised to explain the null effects above (that is those pertaining to the OSBDa as an instrument, or to the nature of the procedure) obviously apply to these results as well. Thus, no effect may have been detected because changes in distress related to locus of control are not picked up by the OSBDa. However, this part of the study was intended to largely replicate the investigations of Jay et al (1983) for less stressful medical procedures, and on this question the results concur - neither the current study, nor that of Jay et al find covariance between behavioural distress and parental or child locus of control. In the abstract to their study of routine medical examinations, Bachanas and Roberts (1995) assert a relationship between the health locus of control of the child and behavioural responses during the procedure, based on the findings of Hackworth and McMahon (1991) that children’s attitudes towards health care were associated with health locus of control, and the assumption that attitudes towards health care are associated with periprocedural behavioural responses. However, in their results section this relationship is not actually shown to be the case. Overall, therefore, it may be concluded that no relationship between locus of control and behavioural distress exists to be measured.

Similar to the state-anxiety of the child, the degree of anticipated pain is also considered here as a potential predictor variable, as well as an index of validity. However, no relationship was found between the amount of pain anticipated by the child and the amount of distress exhibited during the procedure, which is in direct contrast to Jay et al’s (1983) findings of a moderate relationship between distress and experienced pain, and a very strong relationship between distress and anticipated pain. The amount of pain anticipated pre-procedurally by the child cannot therefore be used to target which children are more likely to become distressed. This reversal of Jay et al’s results would support the hypothesis that the original OSBD and the amended form OSBDa index
slightly different features of distress, as alluded to in the discussion regarding the validity measures above. The focus of the amended form would appear to be the specific situation, loading heavily upon state-anxiety and anticipated pain, while the original OSBD appears to focus upon trait-anxiety and the anticipation of pain - being perhaps slightly distinct from the actual situation.

Limitations and Future Directions:

It is important at this stage to draw attention to the limitations of this study, and thereby to propose areas for reconsideration or further research. Perhaps the main consideration to be made is that of sample size which, as a result of certain practical constraints, is unfortunately limited. The entire data-set consists of 34 parent-child pairs, and of these 15 children are old enough to complete the NS-LOC, STAIC and Pain Thermometers; these low participant numbers give rise to certain shortcomings: Firstly, a reduced sample size such as this increases the probability of making Type II errors, that is, concluding that there is no relationship between variable pairs, when in fact there may be. This is particularly pertinent given the results above of non-significant relationships between total OSBDa scores and STAIC (Trait scale), STAI (State and Trait scales), Anticipated Pain, R-LOC and NS-LOC. It is possible that the sample size is too small to enable the detection of significant associations between these variables, and this masking effect is especially likely if the relationships are small.

Secondly, in accordance with previous studies of similar variables, assumptions have been made in the current study regarding the (normal) distribution of the data. These assumptions may be questioned, however, and the current results should be considered in the light of this. Similarly, the subject numbers in this study rule out the use of more sophisticated statistical analyses. For example, with increased subject numbers, the relationships between factors proposed to affect the distress of children could more thoroughly have been examined using a stepwise multiple regression analysis. Similarly the factor structure of the OSBDa could have been derived from a formal, quantitative, factor analysis rather than using multidimensional scaling to derive further hypotheses about the structure of the scale.

As a result of the restrictions on available statistical analyses due to sample size, it has not been possible to control for the effects of age on the distribution of scores within the OSBDa. Although the original OSBD has been designed to be applicable for people aged between 2 and 20 years of age, it is possible that younger children will demonstrate a different pattern of scores across the items than would an older adolescent. It could be argued that such differences in distributions of item scores would affect the item analysis conducted above. This has not been controlled for in this
study.

As a result of these limitations, it is suggested that further research may usefully focus on these shortcomings, by recruiting a larger number of participants and further exploring the data with a more sophisticated analysis.

Conclusions

In the introduction to this study, the construct of distress is examined along with its component features of anxiety and pain. It is found to be a particularly difficult construct to formally define, largely because its component parts are equally elusive, but also because many terms are used throughout the literature to describe behaviours and reactions which resemble distress and all of these terms are used interchangeably. Many studies assert relationships between, for example, distress, anxiety, and pain, but it is interesting to note that different authors have defined each in terms of the others in a variety of combinations. This study has set out to examine these definitions and to propose another, though perhaps more considered, formal definition.

This having been done, the study has further examined – along with the previous study in this portfolio – an amended form of a well-grounded measure of behavioural distress. This measure has been shown to be satisfactorily valid in terms of a number of parallel measures, most particularly the judgments of clinic nurses, but also the state-anxiety of the child prior to the procedure and the amount of pain experienced at the time. The internal consistency of the amended scale has been shown to be particularly satisfactory, and an item analysis and multidimensional scaling procedure have further explored the constitution of this instrument. Together, these results suggest interesting differences between the actual foci of the amended scale and the original OSBD – indicating perhaps that the amended scale focuses more at the situation-specific end of a distress continuum, while the original OSBD is concerned with perhaps more characterological distress. However, these hypotheses have to stand up to the objection that both scales consist of the same items, the only difference being subtle changes in the way those items are treated numerically.

The amended scale OSBDa has then been used to examine potential relationships between behavioural distress and a number of variables proposed to predict changes in that distress. This part of the study was designed as a replication of a study by Jay et al (1983) concerned with very stressful medical procedures in order to examine whether a similar pattern of results was achieved when examining only moderately stressful medical procedures. A very different pattern emerged, however, and because of the unexpected differences between the two distress measures, it is impossible to say
whether the results are due to the different procedures, or the differences between the scales. However, it can be concluded that the state-anxiety of the child while waiting is a good predictor of the distress likely to be manifest during the procedure. A number of other potential predictor variables - namely the trait anxiety of the child, the trait anxiety of the parent and the amount of pain anticipated by the child were found not to covary with distress in this study, although other studies have found positive results in these areas. However, the null results regarding parental and child locus of control are also supported in the literature, and so it may be concluded that distress may not be predicted from these variables.

Finally, all of the above results should be considered in the light of the limitations of the study outlined above. As such, these results should be understood as indicators of further research, rather than as asserted truths regarding the variables.
References


FACTORS AFFECTING THE DISTRESS OF CHILDREN IN HOSPITAL AND THE SATISFACTION OF THEIR PARENTS

Following our meeting on 13 June 1997 with Dr Wilson and a letter from Mr Peebles dated 12 June saying he would be happy for you to collect data on Dental Department patients, I am now pleased to confirm approval of your study.

Yours sincerely

Dr G K Knowles
Chairman
Local Research Ethics Committee
Consent Form

*** The parent/carer should complete this sheet himself/herself ***

Factors affecting the distress of children in hospital and the satisfaction of parents.

Investigator: J A Cromwell, Trainee Clinical Psychologist, University of Surrey

Supervisors: Dr R Wilson, Consultant Paediatrician, and S Waugh, Chartered Clinical Psychologist

You are being asked to take part in a study examining factors which may affect the amount of upset experienced by children when they come to hospital. It has been shown that children who are less upset actually experience less pain than more upset children undergoing the same procedure. If we can identify things which influence how upset children are, we would therefore be able to help them experience less pain than they would otherwise. The study also clarifies the usefulness of a measure of distress in children, and examines how those factors may affect how satisfied parents are with the service they received.

In order to address these questions, you will be asked to complete three questionnaires. If your child is 8 years old or over, he or she will be asked to complete two questionnaires of a similar type, and will be asked to colour in two pictures of thermometers at different times during the visit. None of these questionnaires take very long to complete and certainly should not prolong the amount of time spent in hospital.

There is a Parent Information Sheet available which explains the study in more detail, and you are free to ask any questions of the person giving you the questionnaires.

If you agree to take part in the study, please complete the following pieces of information.
(Other than this consent form, all questionnaires completed and observational measures made are completely anonymous.)

I (print name): ________________________________________________

hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I confirm that my child has had the study explained to him/her and has given verbal consent. I also understand that I may withdraw from the investigation at any stage without giving a reason for doing so and that this will in no way affect the care received as a patient.

Signed: ____________________________ Date: __________________

Witness: ____________________________ Date: __________________
Factors affecting the distress of children in hospital and the satisfaction of parents.

Parent Information Sheet

It is sometimes all too clear that children can become upset during visits to the hospital. Often this seems to be quite unrelated to the severity of the procedure which the child experiences during the hospital visit, suggesting that there are many other aspects to the overall hospital visit which determine the amount of upset the child encounters. Apart from being an important aspect of the hospital experience to try and reduce, it is known that the amount of upset affects the amount of pain experienced by each child. That is, children who are less upset report feeling less pain than those who are more upset. This demonstrates that if we can help children to be less upset in hospital we will make their visit a happier one, and reduce any pain that may be experienced.

You are being asked to participate in a study which aims to achieve a number of things: The first is to identify a suitable way of identifying how upset children can become during hospital procedures. We are looking at a particular way in which a member of staff observes the child during the procedure and records on paper how frequent certain behaviours were. In this way it can be shown how upset particular children are. Your child will be observed by somebody during his or her particular procedure, and may not even notice this taking place. The way in which this particular recording chart is completed will enable us to show how effectively and reliably it records distress.

The second question we hope to address is the main one: We wish to discover how much other factors affect the distress of children. These other factors are the child's usual levels of anxiety, the parent's levels of anxiety, how much both people feel in control of the situation, and how much the child expects the procedure to hurt. We will also look at how much the upset of the child affects the amount of pain experienced. We hope to understand these factors by asking you and your child (if he or she is 8 years old or over) to complete a small number of questionnaires - you will be asked to complete two and children 8 years or over will also be asked to complete two. These children will also be asked to colour in two thermometers at different times during the visit. During the visit, a nurse will be observing your child to see if he or she is upset about something. During the procedure, somebody will observe your child with the special recording chart to see if he or she becomes upset. Children less than 8 years old will not be asked to do anything.

We are also interested to find out how these aspects of the hospital visit affect how much people are satisfied or dissatisfied with the service. We will therefore ask you before you leave to complete a third questionnaire (of eight questions) to give us some idea of this.

No information will be recorded which will enable you or your child to be identified. All questionnaires are anonymous. Index numbers on the questionnaires will enable us to join them together at the end, but it will not be possible to identify you from this information.

When everybody's answers to the questions have been looked at, we will be able to use them to identify which children are more or less likely to become upset in the future. It will then be possible to more effectively target those children in order to help them to feel less upset. The recording chart used to measure distress will also be able to be used by others in future studies looking at distress in similar situations. The satisfaction questionnaire results will make it possible to identify how different people vary in how much they are satisfied with the service which will enable more appropriate audits to be made of this and similar services. Finally all results will be presented to the doctors at Kingston Hospital.

If you have any questions, please do not hesitate to ask the person who gave you this form.

Signed by the person in charge of the project: ______________________ Date: ______________________
R-LOC Questionnaire

This is a questionnaire to find out the way in which certain important events affect different people. Each item consists of a pair of alternatives lettered a or b. Please select the one statement of each pair (and only one) which you most strongly believe to be the case as far as you are concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. This is a measure of personal belief: obviously there are no right or wrong answers.

Please answer these items carefully but do not spend too much time on any one item. Be sure to find an answer for every choice. Write a or b in the box next to each item to indicate your response. In some instances you may discover that you believe both statements or neither one. In such cases, be sure to select the one you more strongly believe to be the case as far as you're concerned. Also try to respond to each item independently when making your choice; Do not be influenced by your previous choices. There are just 29 questions.

1. a Children get into trouble because their parents punish them too much.  
   b The trouble with most children nowadays is that their parents are too easy with them.

2. a Many of the unhappy things in people's lives are partly due to bad luck.  
   b People's misfortunes result from the mistakes they make.

3. a One of the major reasons we have wars is because people don't take enough interest in politics.  
   b There will always be wars, no matter how hard people try to prevent them.

4. a In the long run people get the respect they deserve in this world.  
   b Unfortunately, an individual's worth often passes unrecognised no matter how hard he tries.

5. a The idea that teachers are unfair to students is nonsense.  
   b Most students don't realise the extent to which their grades are influenced by accidental happenings.

6. a Without the right breaks, one cannot be an effective leader.  
   b Capable people who fail to become leaders have not taken advantage of their opportunities.

7. a No matter how hard you try, some people just don't like you.  
   b People who can't get others to like them don't understand how to get along with others.

Please turn this sheet over and continue.
8. a Heredity plays the major role in determining one's personality.  
b It is your experiences in life which determine what you are like.

9. a I have often found that what is going to happen will happen.  
b Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10. a In the case of the well-prepared student there is rarely if ever such a thing as an unfair test.  
b Many times exam questions tend to be so unrelated to course work that studying is really useless.

11. a Becoming a success is a matter of hard work, luck has little or nothing to do with it.  
b Getting a good job depends mainly on being in the right place at the right time.

12. a The average citizen can have an influence in government decisions.  
b This world is run by the few people in power, and there is not much the little guy can do about it.

13. a When I make plans, I am almost certain that I can make them work.  
b It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

14. a There are certain people who are just no good.  
b There is some good in everybody.

15. a In my case, getting what I want has little or nothing to do with luck.  
b Many times we might just as well decide what to do by flipping a coin.

16. a Who gets to be the boss often depends on who was lucky enough to be in the right place first.  
b Getting people to do the right thing depends upon ability, luck has little or nothing to do with it.

17. a As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.  
b By taking an active part in political and social affairs, the people can control world events.

Please turn over and continue.
18. a Most people don't realize the extent to which their lives are controlled by accidental happenings.
   b There is really no such thing as "luck".

19. a One should always be willing to admit mistakes.
   b It is usually best to cover up one's mistakes.

20. a It is hard to know whether or not a person really likes you.
   b How many friends you have depends upon how nice a person you are.

21. a In the long run, the bad things that happen to us are balanced by the good ones.
   b Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.

22. a With enough effort we can wipe out political corruption.
   b It is difficult for people to have much control over the things politicians do in office.

23. a Sometimes I can't understand how teachers arrive at the grades they give.
   b There is a direct connection between how hard I study and the grades I get.

24. a A good leader expects people to decide for themselves what they should do.
   b A good leader makes it clear to everybody what their jobs are.

25. a Many times I feel that I have little influence over the things that happen to me.
   b It is impossible for me to believe that chance or luck plays an important role in my life.

26. a People are lonely because they don't try to be friendly.
   b There's not much use in trying too hard to please people. If they like you, they like you.

27. a There is too much emphasis on athletics in high school.
   b Team sports are an excellent way to build character.

28. a What happens to me is my own doing.
   b Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a Most of the time I can't understand why politicians behave the way they do.
   b In the long run the people are responsible for bad government on a national as well as on a local level.
This is not a test. Please read these questions and say no or yes to each one by ticking (✓) in the square which says yes or the square which says no.

1. Do you believe that most problems will solve themselves if you just don't fool with them? ___________ Yes □ No □
2. Do you believe that you can stop yourself from catching a cold? ___________ Yes □ No □
3. Are some kids just born lucky? ___________ Yes □ No □
4. Most of the time do you feel that doing well at school means a lot to you? ___________ Yes □ No □
5. Are you often blamed for things that just aren't your fault? ___________ Yes □ No □
6. Do you believe that if someone works hard enough he or she can pass any subject? ___________ Yes □ No □
7. Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway? ___________ Yes □ No □
8. Do you feel that if things start out well in the morning that it's going to be a good day no matter what you do? ___________ Yes □ No □
9. Do you feel that most of the time parents listen to what their children have to say? ___________ Yes □ No □
10. Do you believe that wishing can make good things happen? ___________ Yes □ No □
11. When you get punished does it usually seem it's for no good reason at all? ___________ Yes □ No □
12. Most of the time do you find it hard to change a friend's mind? ___________ Yes □ No □
13. Do you think that cheering helps a team to win more than luck? ___________ Yes □ No □
14. Do you feel that it's nearly impossible to change your parents' mind about anything? ___________ Yes □ No □

Please turn over and continue.
15. Do you believe that your parents should allow you to make most of your own decisions? ■ Yes □ No

16. Do you feel that when you do something wrong there's very little you can do to make it right? ■ Yes □ No

17. Do you believe that most kids are just born good at sports? ■ Yes □ No

18. Are most of the other kids your age stronger than you are? ■ Yes □ No

19. Do you feel that one of the best ways to handle most problems is just not to think about them? ■ Yes □ No

20. Do you feel that you have a lot of choice in deciding who your friends are? ■ Yes □ No

21. If you find a four-leaf clover do you believe that it might bring you good luck? ■ Yes □ No

22. Do you often feel that whether you do your homework has much to do with doing well at school? ■ Yes □ No

23. Do you feel that when a kid your age decides to hit you, there's not much you can do to stop him or her? ■ Yes □ No

24. Have you ever had a good luck charm? ■ Yes □ No

25. Do you believe that whether or not people like you depends on how you act? ■ Yes □ No

26. Will your parents usually help you if you ask them to? ■ Yes □ No

27. Have you felt that when people were mean to you it was usually for no reason at all? ■ Yes □ No

28. Most of the time, do you feel that you can change what might happen tomorrow by what you do today? ■ Yes □ No

29. Do you believe that when bad things are going to happen they just are going to happen no matter what you do to stop them? ■ Yes □ No

30. Do you think that kids can get their own way if they just keep trying? ■ Yes □ No

Please turn over and continue.
31. Most of the time do you find it useless to try to get your own way at home? □ Yes □ No

32. Do you feel that when good things happen they happen because of hard work? □ Yes □ No

33. Do you feel that when somebody your age wants to be your enemy there's not much you can do to change matters? □ Yes □ No

34. Do you feel that it's easy to get friends to do what you want them to do? □ Yes □ No

35. Do you usually feel that you have little to say about what you get to eat at home? □ Yes □ No

36. Do you feel that when someone doesn't like you there's little you can do about it? □ Yes □ No

37. Do you usually feel that it's almost useless to try in school because most other children are just plain smarter than you are? □ Yes □ No

38. Are you the kind of person who believes that planning ahead makes things turn out better? □ Yes □ No

39. Most of the time, do you feel that you have little to say about what your family decides to do? □ Yes □ No

40. Do you think that it's better to be smart than to be lucky? □ Yes □ No

Thank you very much for helping with this questionnaire.
SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R.L. Gorsuch, R. Lushene, P.R. Vagg, and G.A. Jacobs

STAI Form Y-1

Name: ___________________________ Date: ________ S ______
Age: ________ Sex: M _____ F _____ T _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1. I feel calm .......................................................... 0 0 0 0
2. I feel secure ......................................................... 0 0 0 0
3. I am tense .......................................................... 0 0 0 0
4. I feel strained ....................................................... 0 0 0 0
5. I feel at ease .................................................. .... 0 0 0 0
6. I feel upset ......................................................... 0 0 0 0
7. I am presently worrying over possible misfortunes ......................... 0 0 0 0
8. I feel satisfied ....................................................... 0 0 0 0
9. I feel frightened ..................................................... 0 0 0 0
10. I feel comfortable .................................................... 0 0 0 0
11. I feel self-confident .................................................. 0 0 0 0
12. I feel nervous ....................................................... 0 0 0 0
13. I am jittery .......................................................... 0 0 0 0
14. I feel indecisive ...................................................... 0 0 0 0
15. I am relaxed ........................................................ .0 0 0 0
16. I feel content ........................................................ 0 0 0 0
17. I am worried ........................................................ 0 0 0 0
18. I feel confused ...................................................... 0 0 0 0
19. I feel steady ........................................................ 0 0 0 0
20. I feel pleasant ....................................................... 0 0 0 0

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HOW-I-FEEL QUESTIONNAIRE

Developed by C. D. Spielberger, C. D. Edwards, J. Montuori and R. Lushene

STAIC Form C-1

Name: _________________________________________ Age: _______ Date: __________

DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide how you feel right now. Then put an X in the box in front of the word or phrase which best describes how you feel. There are no right or wrong answers. Do not spend too much time on any one statement. Remember, find the word or phrase which best describes how you feel right now, at this very moment.

1. I feel ........ □ very calm □ calm □ not calm
2. I feel ........ □ very upset □ upset □ not upset
3. I feel ........ □ very pleasant □ pleasant □ not pleasant
4. I feel ........ □ very nervous □ nervous □ not nervous
5. I feel ........ □ very jittery □ jittery □ not jittery
6. I feel ........ □ very rested □ rested □ not rested
7. I feel ........ □ very scared □ scared □ not scared
8. I feel ........ □ very relaxed □ relaxed □ not relaxed
9. I feel ........ □ very worried □ worried □ not worried
10. I feel ........ □ very satisfied □ satisfied □ not satisfied
11. I feel ........ □ very frightened □ frightened □ not frightened
12. I feel ........ □ very happy □ happy □ not happy
13. I feel ........ □ very sure □ sure □ not sure
14. I feel ........ □ very good □ good □ not good
15. I feel ........ □ very troubled □ troubled □ not troubled
16. I feel ........ □ very bothered □ bothered □ not bothered
17. I feel ........ □ very nice □ nice □ not nice
18. I feel ........ □ very terrified □ terrified □ not terrified
19. I feel ........ □ very mixed-up □ mixed-up □ not mixed-up
20. I feel ........ □ very cheerful □ cheerful □ not cheerful

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Will hurt lots and lots

Please colour in this thermometer so that it shows how much you expect the treatment to hurt today. For example, if you expect it to hurt a bit, but not much, you would only colour it a little way up. If you expect it to hurt a lot, you would colour it right up to the top.

Won't hurt

Hurt lots and lots

Please colour in this thermometer so that it shows how much your treatment actually hurt today. For example, if it hurt a bit, but not much, you would only colour it a little way up. If it hurt a lot, you would colour it right up to the top.

Didn't hurt
Arrival

Please indicate the amount of distress exhibited by the child 
*at the moment* by making a single mark on this line.

No distress  Extreme distress

During procedure

Please indicate the amount of distress exhibited by the child 
*at the moment* by making a single mark on this line.

No distress  Extreme distress

Before leaving

Please indicate the amount of distress exhibited by the child 
*at the moment* by making a single mark on this line.

No distress  Extreme distress
## Observation Scale of Behavioural Distress

*Observe the child for the duration of the procedure and then rate the child on each of the following behavioural items:*

<table>
<thead>
<tr>
<th>Behavioural Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Rather a lot</th>
<th>All the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cry (Has tears in eyes or running down face.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Scream (No tears, but somewhat raised voice.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Physical Restraint (Has to be held down due to lack of cooperation.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Verbal Resistance (Does not follow instructions.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Requests Emotional Support (Seeks reassurance either verbally or non-verbally.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Muscular Rigidity (Any of the following: Clenched fists, white knuckles, eyes clenched shut, body stiffness, gritted teeth.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Verbal Fear (Says “I’m afraid”, “I’m scared” etc.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Verbal Pain (Says “Ow!”, “Ouch!”, “Oooh!” etc.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Flail (Random-seeming movement of limbs with intention to make aggressive contact.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Nervous Behaviour (Physically holds on to nurse or other adult.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Information Seeking (Asks questions about what’s happening.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>