CURRENT TOPIC

Paediatric patients' distress and coping during medical treatment: a self report measure

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Research on distress and coping provides theoretical and practical information on treatment. Cognitive and behavioural coping with illness itself or a specific treatment affect adjustment in the hospital setting.¹⁻⁴

Assessment of coping in children with serious and chronic illness is useful for a variety of reasons. Most paediatric patients are psychologically healthy and, therefore, traditional measures of psychopathology are inappropriate. In this and the accompanying paper,⁵ two instruments will be reviewed; both are designed for physically ill, but mentally healthy, children. Assessing distress and coping over time and in different situations will lead to hypotheses about distress and coping—hypotheses that can be tested in treatment or clinical research programmes. Encouraging clinicians to explore children's coping will improve the care of children, especially those with a long term illness.

In the past, many different self report measures were applied (Tobin *et al*, 1984, unpublished; Patterson and McCubbin, 1983, unpublished).⁶⁻⁸ It is suggested that widespread use of the same instrument would allow distress and coping data to be compared more convincingly. Systematic administration and uncomplicated, yet thorough, analyses would lead to establishing a solid research base from which the effects of coping could be explored. The strengths and weaknesses of different coping strategies could then be demonstrated.

Definition of distress and of coping

Lazarus refers to "distress" as a reaction to stress with emotional overtones.⁹ Coping is also a reaction to stress. Lazarus and Folkman define "coping" as "constantly changing cognitive and behavioural efforts to manage the specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person".¹⁰ Thus, in Lazarus' view, distress is an emotional reaction whereas coping always involves efforts to deal with the stress. This definition also suggests that coping strategies used by the individual may vary across types of stressor and over time.

A self report measure

Coping in children can be assessed through a brief and easy to use checklist. Checklists provide valuable information and are relatively objective. Furthermore, their data are suited to quantitative analysis and can be compared

within and between individuals. Nonetheless, two drawbacks should be borne in mind. First, the completion of a checklist requires a degree of verbal competence for children to understand the questions put to them and to be able to verbalise their thoughts. Second, because of the confined structure of a checklist and its demands on cognitive maturity, detailed descriptive information is invariably lost along the way.

To date, the only assessment tool specifically designed to investigate distress and coping in paediatric patients is the "Kidcope checklist".^{7 11 12} The purpose of our paper is to describe Kidcope and suggest ways in which it can be used. The construction of this measure was based on Lazarus and Folkman's classic definition of coping, and it assesses variations in the frequency and type of coping strategies used by children.¹⁰

The Kidcope checklist is suitable for use by clinicians and researchers as part of an individual or group assessment. "Kidcope for younger children" has been used with children as young as 5 years of age (U Pretzlik and P Hindley, the VIth European Conference on Developmental Psychology, Germany, Bonn, 1993) and as old as 13, and "Kidcope for older children" with age groups from 13 to 16 years. Both have been shown to be reliable and valid instruments.^{7 12 13} Kidcope's uniqueness is that it was designed for paediatric patients and is based on a theoretical framework. Kidcope invites children to report a personal problem (the stressor) within a specific situation (the setting), and then to describe their efforts at coping with that problem (coping strategies).

Administration

There are two ways of completing the Kidcope checklist. The clinician can present the child with a stressor—for example: "Can you remember when you had a blood test . . .?". Alternatively, the child will be asked to choose a personal stressor recently encountered. In the second instance, the process of completing Kidcope will require a child to identify and describe his or her "personal" stressor. The child's personal choice will be constrained by the interviewer who might ask him or her to recall a problem "during inpatient treatment" or "a visit to the outpatient department". Thus, in the first method the choice of the actual stressor is made by the interviewer,

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whereas using the second method the choice is made by the patient. The child describes the stressor and, while remaining focused on it, he or she completes the set of questions during a one to one interview.

The checklist is made up of four main parts: the stressor within a setting, the distress felt by the child in relation to that stressor, the child's way of coping with the stressor, and the helpfulness of that coping strategy. It can be repeated across settings and/or over time.

THE DISTRESS MEASUREMENT

Once the child has recalled a stressor the perceived level of distress is rated. Three questions are put to the child: "Did that time make you feel (a) nervous/anxious, (b) sad/unhappy, or (c) cross/angry?". These questions are answered on a Likert-type scale with: not at all (1), a little (2), somewhat (3), a lot (4), or very much (5). The ratings are added together and generate the self reported distress score. Graded colour coded response strips make these questions and their answers visual to the child. On the orange scale, the child indicates how nervous or anxious, on the blue scale how sad or unhappy, and on the red scale how cross or angry he or she felt.

THE COPING MEASUREMENT

The child rates each of the statements (table 1) according to whether or not he or she used this particular coping strategy. The 10 coping strategies are measured via a simple "yes" or "no" to 15 statements. After replying that he or she did use/did not use a coping strategy, the child is asked how helpful he or she perceived it to be. On a graded green strip the child points to: not at all (1), a little (2), or a lot (3).

A child may cope in one way with a specific medical procedure—for example, getting a parent to hold a hand during the blood test, but might have an alternative way of coping when told that his or her medical condition is deteriorating—for example, by withdrawing from the parent.

Use in practice

Administering the structured Kidcope might lead a child to identify an effective coping strategy—for example, describing the experience of an intravenous injection during which he or she found it helpful to ask for additional information or, alternatively, describing the

experience of a blood test and finding that being distracted had helped. Reflection on previous successful experience has the advantage that young patients can take credit for their ability to cope with a difficult situation. This in turn enhances their positive feelings of self management—these newly discovered feelings can lead to fundamental changes in coping in certain settings. Positive feelings of self management should be built on because they might lead ill children to understand better a potentially stressful situation, and lead them to increased independence.

One important task for researchers is to find out which coping strategies are adaptive for the different types of disease related stressors encountered by paediatric patients. It is appropriate to assist children to make distinctions between a global stressor (the illness) and a specific stressor (an injection), and between changeable aspects (playing a game to alleviate boredom on the ward) and unchangeable aspects (having to take foul tasting medicine). Although children cannot do anything about the illness as a whole, if a stressor is reduced to manageable proportions—from the general to the specific and personal—they are likely to devise and apply helpful coping strategies to deal with it.

The Kidcope checklist is suitable for children and young people; they also enjoy completing it. A note of caution however, Kidcope is not a comprehensive clinical assessment of distress and coping. Results should be supplemented with open ended interviews whenever possible and/or direct observations³ to obtain in depth assessment of children's ways of dealing with the medical setting.

Use in research

Assessing distress and coping through self report methods such as Kidcope provides the researcher with a glimpse of the child's inner world.

Whether a coping strategy is maladaptive or adaptive is discernable through systematic research on different populations using identical research tools. Although a practical advantage, Kidcope's brevity could be criticised scientifically for the limited number of distress and coping statements that make up the instrument. At first, one might argue that the checklist should be extended to add breadth and depth to find out about children's emotional reactions to their way of coping. Because coping varies over time and setting, it is useful to apply Kidcope as a repeated measure.^{13 14} To achieve optimum results, a child should be asked to complete the checklist for different situations. However, extending the one to one interview might cause the paediatric patients' attention to wander. Children with a long term illness might be interviewed as "important events" unfold—such as the child's first night in hospital, his or her first night back on the second visit to the hospital, and so on. The choice of the stressor by the child demonstrates what is felt to be stressful, in similar situations repeated over time. Results from

Table 1 The Kidcope checklist: 15 statements generate 10 coping strategies¹²

Coping strategy	The child is asked: "Did you . . ."
Distraction	Try to forget it? Do something like watch telly or play to forget it?
Social withdrawal	Stay on your own? Keep quiet about the problem?
Cognitive restructuring	Try to see the good side of things?
Self criticism	Blame yourself for causing the problem?
Blaming others	Blame someone else for causing the problem?
Problem solving	Try to sort out the problem by thinking of answers? Try to sort it out by doing something or talking to someone about it?
Emotional regulation	Shout, scream, or get angry? Try to calm yourself down?
Wishful thinking	Wish the problem had never happened? Wish you could make things different?
Social support	Try to feel better by spending time with others like family or friends?
Resignation	Do nothing because the problem could not be sorted anyway?

such investigations using the brief Kidcope will add to the understanding of the coping process in different contexts and over time.

Although distress and coping are important constructs to assist clinicians and researchers understand the adaptation to illness and treatment by paediatric patients, the limited amount of empirical literature on the topic highlights the gap between theory and reported research findings.

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