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ABSTRACT

Young people with chronic conditions experience more difficulties with psychological adjustment than healthy young people. A chronic condition is one that persists for longer than 3 months; a clear diagnosis is not required before a problem can be defined as chronic. Various approaches to improve the psychological outcome for young people with chronic conditions have been developed. Several consensus guidelines are included in this document to outline best practice for providing care for young people with chronic conditions. Chapter 1 provides the background information on developing consensus guidelines. Chapter 2 reviews the literature on the basis for the interventions. Conclusions are drawn in chapter 3. Appendix contains "Development of Consensus of Good Practice." (Contains 30 references.) (JDM)

The psychological adjustment of children with chronic conditions

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Clinical approaches to early intervention in child and adolescent mental health

Volume 5

**Clinical approaches to early intervention
in child and adolescent mental health**

Volume 5

Series editors:

**Robert Kosky, Anne O'Hanlon, Graham Martin and Cathy Davis
The University of Adelaide and Flinders University of South Australia**

The psychological
adjustment of
**children
with chronic
conditions**

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The Australian Early Intervention Network for Mental Health in Young People

2000

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The opinions expressed in this document are those of the authors and are not necessarily those of the Commonwealth Department of Health and Aged Care.

This document is designed to provide information to assist decision making and is based on the best information at the time of publication.

This document provides a general guide to appropriate practice, to be followed only subject to the individual professional's judgement in each individual case.

A copy of this book can be downloaded from the AusEinet website:
<http://auseinet.flinders.edu.au>

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Clinical approaches to early intervention in child and adolescent mental health

Series editors:

**Robert Kosky, Anne O'Hanlon, Graham Martin and Cathy Davis
The University of Adelaide and Flinders University of South Australia**

Foreword to series

There are now about three thousand people who form the Australian Early Intervention Network for Mental Health in Young People (AusEinet) developed since 1997. They include carers, consumers, mental health professionals, policy makers, teachers and others who are interested in the new developments in early intervention for the mental health of young people. The members of the network are linked by our website (<http://auseinet.flinders.edu.au>), our journal (AusEinetter), the seminars we held across Australia, the first International Conference held in Adelaide in 1999 and by the set of books and guides we have produced for them. The books have so far included two national stocktakes of prevention and early intervention programs in Australia, a comprehensive account of eight model early intervention projects which were subsidised by AusEinet and a general early intervention literature review. Details of these publications can be obtained from our website.

This current series deals with clinical approaches to early intervention for the mental health of young people. The AusEinet team asked some leading clinical researchers in Australia to review the evidence base for recent clinical approaches to early intervention in their particular fields of interest. Only a few mental health problems could be chosen to start the series. We are aware that there are research groups active in other areas and we hope to access their work at a later date.

We are also aware that few programs in the field have been well evaluated; certainly few reach Level I or II evidence, according to the standards recommended by the National Medical Health and Research Council in Australia (levels of evidence are

discussed in the series volumes). Consequently, we asked groups to consult with clinical experts and consumers to develop a consensus view on the best approach to practice in early intervention in their fields.

The volumes so far created for this series include clinical approaches to attention deficit hyperactivity disorder in preschool aged children, anxiety disorders, conduct problems, the perinatal period, and psychological adjustment to chronic conditions. Details of these volumes are available from the AusEinet website. A guide for delinquency will also become available on our website. The National Health and Medical Research Council (<http://www.health.gov.au/nmhrc>) has produced guidelines on depression in young people aged 13 to 20 years. AusEinet may look at clinical approaches specifically for early intervention in depression in children as well as young people in the future. Guidelines for early psychosis are available through the Early Psychosis Prevention and Intervention Centre (<http://home.vicnet.net.au/~eppic/>).

The clinical approaches recommended by the authors of the volumes in the series are the responsibility of the authors and naturally reflect their particular interests and those of their expert advisors. While the approaches outlined in this series do not necessarily reflect our views, we consider that it is important to open up a forum for information on early intervention for mental health and to allow our network access to some of the most recent scientific and clinical knowledge in the field. We hope that this series will help bridge the gap between research and practice.

The Editors

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Chapter 1

Introduction

Background

The prevalence of chronic childhood illnesses in the population is around 10-15 per cent (Pless & Nolan, 1991). However, some epidemiological studies have found prevalence ranging from six per cent (Rutter & Tizard, 1970) to 30 per cent (Mattsson, 1972). This indicates that one of the problems confronting these types of surveys is the definition of what constitutes 'chronic illness'.

In the first case, most severe illnesses are clear-cut and have widely agreed upon patterns of disturbed function and easily determined signs. However, it is characteristic of many chronic conditions that there are periods when function is normal or near normal and signs are minimal or absent. When this occurs, it is difficult to talk about illness. A generic term which is often used is 'disorder'. Unfortunately, this usually has the same connotation as illness, although the latter is generally restricted to medical discourse. In an attempt to get around these semantic confusions, some surveys have preferred the use of the term 'problem'. While this does not signify a medical condition, and this may be an advantage, it tends to stretch the boundaries of what might be considered to be the subject of concern. For example, problems might include many forms of behaviour which have nothing to do with disturbed function but owe their origin to extrinsic environmental factors.

In the second case, the terms illness and disorder are sometimes found by consumers to be stigmatising. While in general these terms are used without such intention on the part of professionals, it is true that sometimes people who have a particular illness can become known by the name of that illness e.g. a person who has epilepsy may be called an 'epileptic' and so on.

The members of the expert advisory panel have considered these issues and are of the opinion that it would be preferable to use the neutral term 'condition' as a generic indicator of illness and disorder. We have tried to follow this approach throughout this document.

There are a number of definitions of 'chronic'. For example, in the Isle of Wight study, children were considered to have a chronic problem when there was a 'persisting or recurrent handicap of some kind [which] lasts for at least one year' (Rutter et al., 1970). The National Health Interview Survey conducted in Britain considered that chronic conditions included all problems lasting longer than three months (Pless & Stein, 1996). This seems a reasonable definition to use when the natural history of the disorder involved is likely to be persistent and we have adopted this use of the term 'chronic' in this discussion.

Young people with chronic conditions and their families experience more difficulties with psychological adjustment than healthy young people. The Australian Survey of Disability, 1993 (Australian Bureau of Statistics, 1998), indicated that 7% of Australian children had a disability. For 6% of Australian children, their disability restricted their ability to perform the tasks associated with daily living. Of the children with a disability, primary disabilities were of a physical nature in 76% of cases and were primarily mental problems in 24% of cases. Asthma and other respiratory diseases made up 34% of the physical conditions, with disorders of the ear and mastoid processes, nervous system, speech and other disabilities making up the balance. Reliable rates of 'recent' illnesses for young people in the Australian population who were under 25 years of age have been provided for asthma (23%) and eczema/dermatitis (10%) by the Australian Bureau of Statistics (1995). Thus, these are common conditions and are ones which are likely to lead to chronic problems.

An important question is how often do psychological problems occur among young people with chronic physical illnesses. Secondary emotional problems among

children with chronic disorders have been reported to be significantly greater than among healthy children (Pless & Stein, 1996). The Ontario Child Health Survey estimated the increased risk for psychiatric disorders for those with chronic conditions to be two times higher and for those with chronic conditions and an accompanying disability, to be over three times higher, than for healthy children (Cadman et al., 1987).

Traditionally, classification of chronic conditions has been attempted on the basis of aetiology (disease), their illness characteristics or their severity. There are, however, other ways of looking at these conditions. Pless and Perrin (1985) and Davis (1993) have each highlighted the failure of categorical diagnostic approaches to reliably predict psychological outcomes in young people and their parents. Those advocating a non-categorical, or generic approach (Pless & Pinkerton, 1975; Stein & Jessop, 1982) suggest that it is the natural history of the disease and its severity, and not its particular characteristics, that matter most in the risk of psychological maladjustment.

When studying the potential psychological effects of chronic conditions, most research has used models based on the pathology of disease. Bradford (1997) preferred a paradigm that conceptualised chronic conditions as influences creating particular stresses and strains on individuals. Families reacted to these with a range of adverse responses and coping behaviours. Re-appraisals of theories of adjustment suggested four key factors that can influence psychological adjustment to chronic conditions. These were: family patterns of interaction, doctor-patient communication, ward and health care environments and individual beliefs about health (Bradford, 1997).

Various approaches to improve the psychological outcomes for young people with chronic conditions have been developed. These include the type of care offered, the training and qualifications of the people providing the care, the location in which services are delivered and the timing of service delivery. Most of these

models of intervention were based on identifying someone as a therapist whose goal was to offer therapy, counselling, or non-specific support to the young person or family. Although Bradford (1997) has suggested an intervention approach that focuses more on improving an individual's resilience, there has not yet been any research to support benefits from this approach. Generally, it can be said that there has been very little investigation of the intervention programs which are commonly utilised. For this and other methodological reasons, evidence in favour of the effectiveness of the various interventions remains very tentative at this stage.

Development of consensus guidelines

These consensus guidelines have been developed to outline good practice for providing care for young people with chronic conditions and their families. They do not represent the sole means of intervention. We hope instead that these guidelines, combined with professional judgement, will promote psychological adjustment in young people with chronic conditions, their families and other carers. Practitioners should access information and guidelines on specific conditions, the impact of developmental stages (e.g. transition of care) and the impact of stages of disease progression (e.g. bereavement care) as appropriate.

The consensus guidelines were developed by a process of reviewing the literature and consulting with care providers and consumers. They incorporate the opinions of experts from around Australia who are working with children and young people of various ages with a range of chronic conditions. The experts work with young people and their families in a variety of disciplines (e.g. doctors, nursing staff, mental health workers, teachers) and settings (e.g. rural, metropolitan, hospital, community). Young adults with chronic conditions and the parents of children and young people with chronic conditions have also been consulted.

These consensus guidelines were produced in 1999. It is recommended that they be reviewed every three to five years in order to encompass advances in clinical practice, research and the evaluation of guideline outcomes (National Health and Medical Research Council, 1999).

In the interest of brevity, we have used the term 'young people' to cover infants, children, adolescents and young adults. A condition is defined as 'chronic' if it is persistent or recurring and continues for longer than three months. A clear diagnosis is not a requirement before a problem can be defined as chronic.

Users of the consensus guidelines may include all those involved in the care of young people with chronic conditions. This includes the young people themselves, their parents and siblings, as well as professionals such as clinicians, teachers and other members of the education system. The guidelines will also be useful for the care of young people with chronic conditions and developmental disorders which have associated psychological problems (such as depression in a young person with eating disorder).

The consensus guidelines are also targeted towards organisations such as developmental disability services, institutions and alternate care providers, adult settings which provide care for young people and the research community. We also hope that professional bodies, health administrators, government departments and politicians will find the guidelines useful to ensure adequate training for professionals and to inform service provision.

A description of the guideline development process is contained in Appendix 1. In brief, the process involved the following steps:

1. The Expert Advisory Panel was formed;
2. A systematic review of the intervention literature was completed;
3. A questionnaire for obtaining consensus was designed and mailed;

4. Data from the questionnaire were analysed;
5. The consensus guidelines were developed.

The studies identified in the literature review were rated using the Levels of Evidence ratings outlined in the National Health and Medical Research Council's (1999) guidelines on developing guidelines:

- | | |
|-------------|--|
| Level I | evidence obtained from a systematic review of all relevant randomised controlled trials. |
| Level II | evidence obtained from at least one properly designed randomised controlled trial. |
| Level III-1 | evidence obtained from well designed pseudo-randomised controlled trials (alternate allocation or another method). |
| Level III-2 | evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group. |
| Level III-3 | evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group. |
| Level IV | evidence obtained from case series, either post-test or pre-test and post-test. |

To inform recommendations for practice, evidence needs to prove the effectiveness of potential intervention strategies. As such, good meta-analyses of randomised controlled trials (Level I evidence), individual randomised controlled trials (Level II evidence) or pseudo-randomised controlled trials (Level III-1 evidence) are required. In the absence of such high quality intervention evidence, evidence from case-control or cohort studies (Level III-2) can be used to suggest possible intervention strategies.

To date, there has been little high quality evidence (Levels I and II) of the effectiveness of different intervention strategies. In the absence of high quality evidence, consultation with experts in the field and establishment of consensus among them, is one way to move towards consensus guidelines. We have adopted this strategy in developing the guidelines.

Chapter 2

The basis for interventions

Review of the literature

The Medline databases for the years 1976 to 1999 were searched using the MeSH heading terms: 'adaptation, psychological', 'chronic disease' and the search was limited to humans aged from birth to adulthood. To ensure that articles of importance were not missed using this search strategy, separate searches were also undertaken using more specific condition lists and more specific outcomes. Three articles appeared using these more specific searches that were not found by the MeSH heading search. Studies were included if they were of the following designs: clinical trial, controlled clinical trial, randomised clinical trial, multi-centre study, meta-analysis, or focused on practice guidelines. Each paper was reviewed by two independent assessors for type of randomisation process, nature of analyses and clinical relevance of outcomes. Review of the reference lists of articles found by the search did not detect any other relevant articles. Studies which did not establish sufficient pre-test similarity between experimental and control groups were excluded. Table 1 summarises the findings of the systematic literature review.

There has been some evidence to indicate that *family therapy* may be effective in helping families of children with chronic conditions (Gustafson et al., 1986; Lask & Matthew, 1979). However, these studies have mostly suffered from small sample sizes and have generally focused on physical outcomes, rather than on the psychosocial adjustment of the children and/or parents. One study used parental outcomes to evaluate the effectiveness of marital therapy but the impact on the child's adjustment is unknown (Walker et al., 1996).

To date, research has concentrated on the effectiveness of certain types of *service delivery models* which have generally combined different elements of care. For example, Nolan et al. (1987) studied phone counselling and face-to-face counselling with an emphasis on reducing the financial burden for families. The authors found no evidence for effectiveness.

Table 1: Review of evidence

Author	Study design	Sample size	Problems of study group	Intervention	Statistically significant outcomes	Comments
Gustafsson et al. (1986)	Randomised controlled trial	Study = 9 Control = 8	Severe asthma	Family therapy	Reduction in β -2-agonist doses in children with asthma	Diverse groups in terms of age and condition duration; baseline differences between groups not explored; univariate analyses only
Lask & Matthew (1979)	Randomised controls	Study = 18 Control = 11	Moderate to severe asthma	Family psychotherapy	Study group better than controls on thoracic gas volume (TGV) and dry wheeze in children with asthma	Blinding not possible; univariate analyses only
Nolan et al. (1987)	Randomised controlled trial	Study = 154 Control = 169	Chronic physical disorders	Social work support and counselling	No significant differences between cases and controls other than on hostility (cases improved)	Used blinding; used ANCOVA for analysis; used standardised measures of children's adjustment; researchers compensated for 'aura' of extra attention from the hospital.
Pless & Satterwhite (1972)	Case-control trial	Study = 55 Control = 42	Dermatological, neurosurgical, respiratory and other chronic disorders	Supportive counselling, practical advice and assistance by trained non-professionals	60 per cent of those in a counselled group showed improvement in their psychological status compared with only 41 per cent of controls	Blinding used; used standardised measures of children's adjustment; most impact was on the low risk group
Pless et al. (1994)	Randomised controlled trial	Study = 163 Control = 145	Chronic physical disorders	McGill Model of Nursing	Psychosocial adjustment of cases was better than controls	Unknown if blinding used; used ANCOVA; used standardised measures of children's adjustment

Roberts et al. (1995)	Randomised controlled trial	Problem solving = 98 Phone calls = 100 Controls = 95	Chronic illness and problems with adjustment	Problem solving & supportive phone calls	<p>Psycho-social adjustment improved in:</p> <ul style="list-style-type: none"> ■ problem-solving group for those who had mainly used avoidance for coping ■ phone call group for those who mainly used problem-solving 	Blinding: not used; studied adults aged 44 - 48 yrs but results may also be relevant to young people living on their own; used ANCOVA
Smyth et al. (1999)	Randomised controlled trial	Study = 71 Controls = 41	Asthma and rheumatoid arthritis	Writing about stressful events	<p>Lung function improved in asthma group; disease activity improvements in rheumatoid arthritis group; no change in controls</p>	Used blinding; used ANCOVA; took baseline levels of disease into account; calculated treatment effect size (d = 0.68 in study sample and 0.47 in healthy sample)
Stein & Jessop (1984)	Randomised controlled trial	Standard care = 104 Paediatric Home Care program = 105	Chronic physical illness	Standard care provided by hospital; home care program focused on child & family, advocacy, health education & support	Children's psycho-social adjustment was better in home care group than in standard care group; 6 months after intake	Used ANCOVA; did not use blinding
Walker et al. (1996)	Randomised controlled trial	Study = 16 Control = 16	Parent couples of chronically ill children	Emotionally Focused Marital Therapy	At 5 month follow-up, marital adjustment of study group was better than for controls.	Used MANOVA; did not use blinding; calculated treatment effect size (1.28 at 5-month follow-up); did not report impact on child with chronic illness

Pless and Satterwhite (1972) used non-professional workers who were trained to act as *child and family advocates* and counsellors. These workers explained the nature of the child's illness to the family, coordinated support services, gave advice about behavioural and educational difficulties and gave practical support and counselling to mothers. Pless et al. (1994) evaluated the McGill Model of Nursing, which blended advocacy and liaison work, and found it to have some benefits. Stein and Jessop (1984) compared standard home care with a more specialised form of home care and reported that the specialised care was more useful. However, generalisation from these studies suffers from inconsistent inclusion/exclusion criteria, lack of replication of results and lack of clarification about which elements of the service were of key importance.

Roberts et al. (1995) compared *supportive telephone calls* with *problem-solving counselling*. They found that problem-solving was effective in people who normally would infrequently use it for coping and who, instead, tended to use avoidance as a means of coping. Supportive telephone calls were helpful to those who already used problem-solving as a means of coping. The participants in this study were adults. Smyth et al. (1999) explored the usefulness of *writing about the most stressful experiences* as a means of alleviating physical symptoms. Again the subjects were adults.

Problems with appropriateness of outcomes, the age groups studied and methodological concerns in the studies described above, mean that guidelines cannot yet be based entirely on these findings.

Consensus views

These consensus views were based on current practice in the field and were subject to review by various stakeholders, including consumers (see Appendix 1 for respondent list). The members of the Expert Advisory Panel reviewed the process in

the light of their own opinions. The following represent the consensus views about interventions for better mental health of young people with chronic conditions.

Not all responses to chronic conditions are pathological. Chronic conditions in young people can have a substantial impact upon their lives and the lives of their families. It is important to recognise that many emotional responses are *healthy ways* of adapting to the extraordinary experiences of a chronic condition. However, when the way a person is dealing with the chronic condition begins to interfere with their daily functioning, it is clear that coping style can be less helpful or maladaptive.

It is too often overlooked that *parents and siblings* of young people with chronic conditions can experience stress, accompanied by a variety of emotions and psychological difficulties. Intervention for psychological difficulties in parents and siblings may be both necessary in its own right or to help the psychological adjustment of the young person with the condition.

It is important to *empower* health care consumers and carers by giving them information and the opportunity to make choices about treatment and their sources of support. These choices will have to be made according to the particular cultural world familiar and comfortable to the young persons and their carers. To ensure good communication with families, professionals need to communicate well with each other and to be clear of their own and each other's purpose in the overall management plan.

Young people with chronic conditions and their families may experience stressful events which, combined with the stress of living with a chronic condition, place them at greater risk of later psychological problems. Not all young people will be exposed to all the *risk factors* listed below, but awareness of them is important for families and professionals who are working with young people living with chronic conditions. These risk factors include:

- Prolonged ambiguity about the diagnosis or the prognosis;
- Confused messages from the management team;
- The impact of stressful life events (eg starting school, abuse);
- Difficult peer relationships;
- Problems relating to physical appearance;
- Lack of resources such as respite care, parental care, or access to financial support.

Not all young people with chronic conditions will show signs of distress or psychological problems. However, we have noted some *warning signs* below which we consider may indicate that a young person is having problems. Awareness of these warning signs may alert families and professionals to seek extra help to assess their relevance.

There may be problems at school, including lack of school attendance for over three months, deterioration in school performance or withdrawal from social interactions.

There may be problems with understanding the condition: the young person may not understand what is happening to them, or may believe the condition is a punishment. The young person may feel that he or she has no control over the situation and has given up hope. The young person may not acknowledge that s/he has the illness and may not accept help. The parents may not acknowledge that the young person is ill. There may be poor attendance at consultations or the parents may not agree on the management of the young person's condition.

The consensus view was that one of the best ways to intervene to prevent poor psychological adjustment would be to provide *practical assistance to carers*, usually the family. It is important to empower health care consumers and carers by giving them the opportunity to make choices about their sources of support and, wherever possible, for the professionals and management team to validate these choices. Practical support could be provided by a number of different agencies and could include financial support, transport services, respite care, environmental modifications

and home visits. Another source of early intervention is to help the parents with their management techniques. This could be achieved by teaching pain management techniques and educating family members about what to do in case of an emergency.

Practical assistance can also be provided to *schools*, so that early identification of problems can be made by the teachers. This means educating school staff about the nature of the chronic conditions and what they might be expected to encounter with the affected young person. Teachers need to know what to do in case of a medical emergency and how best to facilitate constructive peer relations. Peers at school may need to know about the condition as well.

Assessments of young people with chronic conditions serve many functions, including monitoring the progress of the illness and the disabilities and the early identification of problems. One of the aims of assessment is to guide intervention strategies. Consequently, psychosocial functioning should form part of the assessments of a young person with a chronic condition and their family. It goes without saying that assessments should be done sensitively and humanely and with professional dignity.

Young people suffering from chronic conditions should be involved in choosing who will assess them. Clinicians from different disciplines and other professionals, such as teachers, should contribute to the assessment. The key issue is that everyone knows who is principally involved in coordinating and summarising the information and who has the clinical responsibility for the overview of the management.

Formal psycho-social assessment should be carried out at various intervals such as when parents identify problems, when teachers observe warning signs and when problems are identified by the management team. Assessments may also be needed during psycho-social transition phases such as those associated with entering school, changing residences or with puberty. For these assessments it is necessary

to take into account the young person's progress at school, their on going peer relationships and their ability to handle the practical aspects of their daily living as well as their general mental state. Family interactions should also be assessed.

It is important to avoid *labelling* or otherwise stigmatising young people who are living with chronic conditions. For example, young people should be referred to as having a given condition, not as being that condition (e.g. having diabetes, not being a "diabetic").

Good, clear, jargon-free *communication* between professionals and families can do much to alleviate the stress associated with the disruptions created by frequent visits to hospitals and health professionals. The course of the condition should be explained to the family, including potential shortened life span. However, this needs to be done sensitively and with respect to the family and their stage of acceptance of the condition. The potential complications of the condition should be explained to the family before they occur. Care providers should continually check with young people and families to see that they understand what is being communicated. To ensure good communication with families, professionals need to communicate well with each other and understand their own roles and the roles of others. Depending on resources, parents may join with teams in discussions or decision making.

Parents should be provided with written copies of instructions regarding treatment regimes, regardless of whether these instructions have already been verbally communicated. Where possible, young people with the chronic conditions, should be encouraged to ask questions of the doctors, nurses and other clinicians who look after their health needs. Parents can be encouraged to advocate for their child, especially when the child is an infant or preschooler.

People need to be provided with contact details for obtaining information or advice outside appointment times. As close as possible to the time of diagnosis of the

young person's chronic condition, parents should be provided with a resource list, including contact details for support and self-help associations. Parents, and children when they are old enough, should be aware of complaints procedures in hospitals and in non-government agencies, such as Health Consumers' Councils. They may also need to know of the protection offered through statutory bodies, such as Guardianship Boards.

It is usually preferable that young people with chronic conditions should get their treatment needs met in a community setting rather than a hospital. Primary health care of the young person should be provided by the general medical practitioner. Other health care professionals should keep the general practitioner informed about the young person's condition and treatment.

While *intervention* may need to focus on ongoing problems or crises, it also needs to be a source of ongoing support, monitoring and empowerment. Interventions need to be provided where appropriately indicated. Young people need to be offered a choice of age appropriate interventions. Not all forms of intervention will suit all individuals. The types of interventions which can be offered to young people include praise and encouragement of their positive behaviours, and individual and group therapies. Issues common to all young people, not just those with chronic conditions, need to be addressed in intervention programs. These include personal issues such as self-esteem and control over one's own life and relationship issues such as relationships with family members and peers.

Parenting in itself may be a challenge. However, parenting a young person with a chronic disorder can sometimes be more difficult than expected. It is easy for the task of caring to inadvertently fall on one parent, often the mother. Both parents, where appropriate, should be encouraged to be involved in care. Special difficulties may arise if siblings also have a chronic condition. The way in which parents discipline children with a chronic condition and set limits on their behaviour, may need to be

discussed with them from time to time. Parents and families need to be offered a choice of appropriately indicated interventions. Some interventions which may be appropriate for parents are: individual counselling or supportive therapy, facilitated group support and information seminars.

Chronic medical conditions often involve *hospitalisation*. The Australian Council on Healthcare Standards and the Association for the Welfare of Child Health (1998) have produced guidelines specifically for the care of hospitalised children and adolescents. Their recommendations include the following:

- Ward staff at all levels and in all the roles (domestic, nursing, medical etc), should create a warm caring environment and give reassurance to the young person. The young person should visit the ward prior to hospitalisation and nurses should explain to him/her the administrative and medical procedures.
- Staff can assist the young person to take responsibility for aspects of their treatment regimen, at an age appropriate level. They can provide reassurance that help is available to assist the young person to cope. The staff can encourage young people to plan for the future.
- Hospitals should facilitate frequent visiting by family and friends. A parent should be present when anaesthesia is induced. On occasions, having the parent stay in the same room as the young person may allay anxiety in both parties.
- During adolescence, the transition from paediatric hospital care to adult hospital services may become an important issue and may be challenging for the staff, the young person and their family. One clinician should maintain ongoing contact with the young person during the transition of care.

All carers of young people with chronic conditions, including health professionals, need to have access to an appropriate level of care and support for themselves.

Professionals need to be aware of the warning signs of *'burnout'* in themselves and in others. Hospital staff may need to be offered debriefings at regular intervals and after catastrophic incidents, such as deaths. Some of these issues have been dealt with in other reports (Ashby, Kosky, Laver & Sims, 1991).

Education of clinicians about the psychological problems relating to chronic conditions is clearly essential. However, the extent to which this occurs within medical, nursing and other curricula is possibly variable. This issue could be addressed through a national approach to mental health curriculum (Deakin Human Services, 1999).

Chapter 3

Conclusion

There are a number of issues that we would wish to emphasise. First, there are risk factors which are avoidable. These include prolonged ambiguity about the diagnosis and poor communication to the carers about the illness. Stressful life events can precipitate, maintain or worsen a condition. Sometimes these can be as simple as starting school and on other occasions as serious as abuse by carers. The condition may produce oddities of appearance which can affect peer relationships.

Second, professionals and carers need to be alert to warning signs of distress. These can include deterioration in school or social settings, a tendency to blame the self and a developing sense of helplessness and hopelessness, a denial of problems and poor compliance with treatment. The range of psychological problems which can develop is non-specific and includes depression, anxiety, eating disorders, conduct disorders, oppositional behaviour, suicide threats and sleep disturbances.

Third, parents and siblings can become exhausted and develop problems of their own. Again, these are non-specific, but anger and depression are commonly reported.

Fourth, we consider that it is important to provide practical assistance to families who have children with a chronic condition. This includes support with finances, transport, documentation, recreation and respite care. It may also include educating family members about what to do in the case of an emergency. Where the young person is at school, practical and educational assistance may need to be provided to teachers and peers.

Fifth, assessments are an integral part of management. A number of professionals may undertake assessment. We consider that the young person should have a say

in determining which professional has the major responsibility for coordinating assessments and management. At a practical level, this is most likely to be the family doctor. Assessments may need to be undertaken on both a regular and a periodic basis.

Sixth, communication between professionals and the young person and between professionals and carers needs to be very clear. It may be helpful to provide written information and instructions as conversations can easily be misconstrued or forgotten over time. It is particularly important that the complications of the condition or the risks of treatment should be explained clearly. Parents often want to know about the causes of the condition. During management, it may be helpful for the carers and the young person to join team discussions and participate in decision making. A particular problem may arise when children need to obtain help from adult health services. The professionals who are caring for the child need to ensure that the child's developmental needs are appropriately met. It is easy to overlook the needs of siblings and they should, wherever possible, be included in the network of communication.

Finally, with respect to our review of the effectiveness of early interventions, so far there are encouraging findings relating to the use of family therapy, supportive counselling of parents and children and of use of protocols such as the McGill Model of Nursing. There is also some evidence that relatively simple and cost-effective interventions such as telephone support services can be useful. Some creative methods of intervention, such as asking young people to write about the stress they experience with their condition, may be helpful. Focusing attention on the parents' marital relationship may also be a useful supportive intervention. Finally, there is one randomised controlled study that suggests that psychological adjustment for young people with chronic conditions is better when their needs are met as far as possible in the home setting.

Our review of the literature showed that a firm scientific base for developing interventions has not yet been established. Currently, good clinical practice is based on a consensus view developed by experts in the field. More research is needed to discriminate which practices are effective and, in particular, which interventions can be reliably expected to help young people with chronic medical disorders. Because enduring conditions carry high risks of psychological problems, it will be essential to identify interventions which can be made at an early stage.

Resource list

Community health centres

Should you wish to speak with a mental health professional please contact your local Community Health Centre for advice or a referral. It is a free service provided by each State Government.

Association for the Welfare of Child Health (AWCH)

AWCH provides information and referrals to support agencies.

National office: PO Box 113
WESTMEAD NSW 2145
Telephone: 1800 244 396 or (02) 9633 1988

AWCH library: Located in the grounds of the
Paramatta campus of the
University of Western Sydney
PO Box 10
KINGSWOOD NSW 2747
Telephone: (02) 9685 9317

The Australian Guide to Consumer Health Information

This is a database of support groups, services, general information and publications related to an extensive range of conditions and contexts. It is regularly updated and can be purchased for \$45 (as at July 1999) from:

HealthLink Directories
Westmead Hospital
WESTMEAD NSW 2145
Telephone: (02) 9845 7307

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A p p e n d i x 1

D e v e l o p m e n t o f c o n s e n s u s g u i d e s t o g o o d p r a c t i c e

The members of the Expert Advisory Panel were selected to represent different professional disciplines, different working environments, Aboriginal people and consumers. Practical considerations, such as their willingness and availability to attend the scheduled meetings, also influenced working party membership.

Members of the Expert Advisory Panel were mailed information about the guideline development process and key issues to be addressed. In addition, each member was mailed a background summary of the literature about the psychological adjustment of young people with chronic conditions. The summary had been developed from the background literature review.

The committee was divided into two groups and each group was invited to attend one half day meeting. Two separate meetings were held to maximise group functioning and to provide more opportunity for attendance.

The committee refined the brief by clarifying the title of the guidelines, the definition of 'chronic condition' and deciding on the scope of the guidelines. Key issues (e.g. that the guidelines should be practical and focus on training) with regard to the content and the nature of the guidelines were also decided by the committee. The committee discussed the types of intervention strategies known or suspected to promote psychological adjustment in young people with chronic conditions, their families and other carers.

Exclusions

Practices and interventions more appropriately dealt with in condition specific guidelines are not included. Issues of chronic pain and death and dying have not been addressed specifically. Consensus guidelines already exist for palliative care of children and these take into account ethical, medical, family, social and spiritual aspects of children's care (Association for Children with Life-Threatening or Terminal Conditions and their Families & Royal College of Paediatrics and Child Health, 1997; World Health Organisation, 1998).

Objectives

- To develop a consensus guide to good practice which addresses potential risk factors, warning signs, psychological difficulties, assessment, communication, intervention, hospitalisation, transition of services and education and training in young people, parents and siblings and professionals.
- To make the consensus guidelines practical and relevant to professionals and consumers.
- To make the consensus guidelines user-friendly and readily applicable to day to day management in both hospital and community settings.
- To develop an understanding of areas which would benefit from further research.
- To develop a standard for good practice relevant to evidence and consensus in 1999, which can form a sound basis for further development of subsequent guidelines which will be adapted depending on evaluation, research and feedback from consumers and professionals.

Questionnaire design and mail-out

The questionnaire was developed to seek consensus about important issues and interventions which emerged from literature review and advisory committee discussions, but for which there was little evidence of importance or effectiveness. This covered the topics of potential risk factors, warning signs, psychological difficulties, assessment, communication, hospitalisation, transition of services and education and training. The individuals to which the questionnaire items applied included young people, parents and siblings and professionals. The questionnaire was revised by the advisory committee and then sent to 218 professionals and consumers to establish consensus in areas where evidence was not available. Respondents were encouraged to confer with colleagues when completing the questionnaire.

Analyses

Questionnaire respondents were asked to rate how strongly they agreed that each item should be included in the guidelines. The rating system was a 9-point Likert scale with scores of 1-3 indicating disagreement, 4-6 equivocal opinion and 7-9 agreement. Ninety-seven questionnaires were returned. Of these, 95 were completed. The median score of each question item was reviewed and χ^2 analysis completed for each item to ensure that the distribution of responses for each question was not uniform. This was similar to the methods used by Kahn and colleagues (Frances et al., 1996; Kahn et al., 1997) and Jacoby and Brodie (1996). Items with a median of 7, 8 or 9 were included in the guidelines, provided that χ^2 indicated that responses differed significantly from those obtained by chance and that items with a median of 7 had a distribution clearly skewed towards scores of 8 and 9. Significance level was set at 0.05.

Table A1. Questionnaire Respondents

Professional Groups	Number mailed (% of total mailed)	Number respondents	Percentage response (by group)
Nurses	26 (12)	10	38
Physiotherapists	8 (4)	6	75
Occupational therapists	6 (3)	2	33
Dietitians	2 (1)	1	50
Music therapists	3 (1)	3	100
Social workers	10 (5)	7	70
Paediatricians & physicians	39 (18)	18	47
Trainee paediatricians	13 (6)	7	54
Psychologists	11 (5)	11	100
Psychiatrists	26 (12)	11	42
Aboriginal health officers	12 (5)	1	8
Chaplains	3 (1)	1	33
Parents	11 (5)	5	45
Young adults	14 (6)	3	21
Support association workers	2 (1)	3	150
General practitioners	12 (5)	2	17
Speech pathologists	1 (1)	1	100
Principals of hospital schools	3 (1)	2	67
Genetics counsellors	12 (5)	2	17
Patients' representatives	2 (1)	0	0
Respite carers/teachers	2 (1)	1	50
Total	218	97	





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