

CURRENT TOPIC

Surviving chronic physical illness: psychosocial outcome in adult life

Julia Gledhill, Luiza Rangel, Elena Garralda

Recent advances in physical treatments have changed the implications of receiving a diagnosis of chronic physical illness in childhood. Individuals with disorders such as diabetes, cystic fibrosis, renal failure, and cancer, who may previously have had a limited life expectancy are now surviving into adulthood.

During childhood, chronic physical illness confers an increased risk of emotional and behavioural disorders,¹ although the majority of children and families successfully adapt to the diagnosis. The increased likelihood of psychiatric disorder during childhood does not seem to be specific to the diagnostic category beyond those involving brain dysfunction,^{2,3} but reflects the difficulties inherent in living with a chronic illness.

Children at greater risk are those with more severe physical disorder,⁴ and perhaps those with illnesses carrying a greater degree of life threat.⁵ The risk also varies with the stage of the illness. Adjustment disorders (emotional and/or behavioural symptoms clearly linked in onset to a stressful event and time limited in manifestation) are probably the most frequent psychiatric sequelae and are particularly common at the time of initial diagnosis and after changes in treatment have occurred. For example, psychological problems were reported in almost 60% of children at the time of starting dialysis. One year later, after stabilisation of their physical condition, the prevalence of disturbance was reduced to 21%.⁶ Similarly, 36% of 8-13 year olds with newly diagnosed insulin dependent diabetes mellitus developed an adjustment disorder (most commonly dominated by depressive symptoms) within the first three months of diagnosis; 50% had recovered within two months.⁷

While interest is frequently focused on the *physical* outcome of this group of children as they progress through adolescence into adult life, much less attention has been given to *psychosocial* outcome. How are they functioning emotionally and socially after their discharge from paediatric care?

This article aims to critically discuss some of the literature about the psychosocial outcome of adult survivors of chronic physical illness. It is not an exhaustive review and we have focused on some of the more severe chronic disorders. In doing so, discussion of the impact of more common conditions such as asthma and epilepsy has not been included. A

combination of Medline and manual search strategies has been used to select studies for discussion which illustrate the range of methodologies that have been employed in the investigation of this area. We have only included work which has used objective indicators of psychosocial outcome. We have also drawn on some reviews of the literature where available, particularly when discussing the impact of cancer.

We will firstly present a general discussion of some of the methodological considerations which arise when investigating this area. We will go on to focus on specific studies, critically examining the findings and methodological limitations. Conclusions that may be derived from the current literature will be summarised and we will consider possible strategies for further research in this area.

What do we mean by adulthood?

Research in this area has given most attention to early adulthood, particularly focusing on individuals in their early 20s (at the end of adolescence), while fewer studies have followed up people into their 30s and beyond. This may be attributed to the fact that interest in psychosocial sequelae is relatively recent, reflecting the considerable improvements in survival and physical health consequent on advances in paediatric care over recent years. It is important to ascertain whether the increased survival is associated with a good enough quality of life in psychosocial as well as in physical terms. The implications of illness in these two age groups (20s and early 30s as compared to 30s and beyond) might be expected to be very different. The younger adults are in a state of psychosocial transition, negotiating the move from dependence to independence and being faced with adult decisions about relationships and work. Older adults are likely to have more established patterns of functioning in these areas. In addition, new physical complications may arise with older age and this may also impact on psychosocial functioning. It is therefore difficult to generalise the findings of studies in this area from one age group to another.

What is meant by psychosocial outcome?

This may be divided into psychiatric and social outcome. Psychiatric morbidity indicates the presence of significant psychological symptoms or psychopathology. This is defined as the

Academic Unit of
Child and Adolescent
Psychiatry, Imperial
College School of
Medicine (St Mary's),
Norfolk Place, London
W2 1PG, UK
J Gledhill
L Rangel
E Garralda

Correspondence to:
Dr Gledhill. email:
j.gledhill@ic.ac.uk

Accepted 5 April 2000

presence of handicapping abnormalities of emotions, behaviour, and relationships. It means that any psychological symptoms present are so pronounced that they cause handicap or impede personal and social functioning. Another psychological marker used in some studies is self esteem. This is generally thought of as an individual's assessment of their own self worth with regard to attained qualities and performance in relation to those that they desire. This is usually measured by questionnaire. Although lowered self esteem is a key symptom of some psychiatric disorders such as depression, its associations with other disorders are not well established. Its main interest from a psychopathological perspective may lie in the fact that low self esteem may be a vulnerability factor for the later development of psychiatric disorder.⁸

The measures included in the quantification of social outcome differ between studies. They include educational attainment, occupational status, marital status, social relationships, and place of residence (within or outside the parental home).

How can psychological symptoms best be assessed?

The presence of psychological symptoms can be objectively measured by the use of questionnaires and interviews. The best are those with established psychometric properties showing satisfactory reliability and validity data for the population under study. Questionnaires are a useful means of rapidly obtaining standardised information from small and large samples. However, they are only a measure of "risk for" psychiatric disorder and do not necessarily reflect the true presence or absence of diagnoses or associated functional impairment.

To convincingly assess the presence of significant psychological problems causing impairment, interviews are usually required which enquire in detail about the severity, duration, and handicap caused by any psychological complaints. A number of standardised psychiatric research interviews have been developed. They are more costly and time consuming to administer than questionnaires and require trained research staff to do so. We will indicate when information is derived from questionnaires or from validated research interviews but we regard the latter as providing more robust information about psychopathology.

It is helpful to describe the psychiatric and social adjustment of survivors of chronic illness separately, because although the two may influence each other, they do not always run parallel courses and each are of interest in their own right. However, when assessing social outcome, it is important to differentiate objective from subjective indicators. For example, survivors of illness may be comparable to general population norms on social indicators and yet feel disadvantaged in these areas; the converse may also be true.

An additional consideration when discussing objective social indicators is that there may be geographic and cultural differences of rel-

evance to interpretation of the findings. For example, levels of unemployment and age of marriage may vary in different countries.

Study design

Examining the psychosocial outcome in adulthood for survivors of chronic physical illness would ideally start by assessing psychiatric and social adjustment in children even prior to the inception of their physical illness through birth cohort studies. However, such studies are a large and expensive undertaking and the assessments of psychological and social functioning are by necessity frequently brief and not optimal for quantification of these measures, unless psychosocial outcome is included as a primary objective of the study and appropriate measures incorporated into its design. Large, longitudinal birth cohorts may be useful when studying a mix of the more common and less severe conditions but they are not an efficient way of identifying children with individual severe and rare conditions, who may be expected to be at higher risk for suffering psychosocial sequelae. An additional factor complicating the use of this study design is that physical treatments are continually advancing and by the time the sample reaches adulthood, their developmental experiences may be quite different from those of children currently being diagnosed with the same condition who may have a more optimistic life expectancy and more effective treatment options available.

A more common research strategy is the comparison of adults with a history of childhood chronic illness compared to a control group. Individuals known to tertiary services are frequently identified as the index group. They are likely to represent those more severely affected. Individuals in these studies may be more homogeneous with regard to diagnostic group and the smaller sample size makes the use of interview based measures of psychiatric adjustment more likely.

What about a control group?

In assessing psychosocial outcome, a crucial issue is the choice of control group. Different control groups, for example, general population, siblings will answer different questions. It is important to acknowledge that the experiences of siblings are also likely to have been affected by the illness.

General population or healthy controls are most commonly used as the most important issue is likely to be to what extent psychosocial adjustment differs in adult survivors from that of healthy subjects of comparable age, gender, and social class. Sociodemographic differences between the populations may contribute more to any differences found than the illness experience itself and so it is important to match for as many of these factors as possible.

The comparison of adult outcome between subjects suffering from different diagnoses (without brain involvement) is unlikely to be helpful unless these conditions differ in some specific aspect which is considered likely to lead to different rates of psychopathology.

Table 1 Table outlining diagnoses of index and control groups, age, gender, number of participants, and main outcome measures for some of the studies of non-malignant conditions discussed

Study	Index group diagnoses	Control group diagnoses	Number of subjects	Subjects: gender age (years)	No. of controls	Controls: gender age (years)	Main outcome measures used
⁹ Pless <i>et al.</i> , 1989	Heterogeneous	Birth cohort—no chronic illness	467 at start	Boys > girls Last assessed 36	4895 at start	Last assessed 36	*PSE ¹⁰ aged 36, sociodemographic enquiry
⁸ Jacobson <i>et al.</i> , 1997	IDDM	Acute medical problem same year as subject recruited	57	29M, 28F Mean 22.9, SD 2.1	54	36M, 18F Mean 22.9, SD 2	Sociodemographic enquiry, Symptom Checklist (SCL-90), ¹¹ Harter Perceived Competence Scale ¹² *PSE ¹⁰
¹³ Kokkonen and Kokkonen, 1993	Heterogeneous	General pop. controls	407	223M, 184F 18–25	202	99M, 103F	Sociodemographic enquiry
¹⁴ Kokkonen, 1995	Heterogeneous	General pop. controls	487	265M, 222F 22.1 (19–25)	202	99M, 103F	Sociodemographic enquiry
¹⁵ Morton <i>et al.</i> , 1994	Renal disorders (paediatric dialysis and transplant prog.)	Healthy controls (GP registers)	45	21M, 24F Mean 24.8, SD 3.7	48	25M, 23F Mean 24.7, range 17–35	*SADS-L, ¹⁶ Rosenberg Self-esteem Scale ¹⁷
¹⁸ Reynolds <i>et al.</i> , 1993	Renal disorders (as above)	Healthy controls	45	21M, 24F Mean 24.8, range 17–35	48	25M, 23F Mean 25 (4.1)	Sociodemographic enquiry, Stress and Social Support Inventory ¹⁹
²⁰ Pearson <i>et al.</i> , 1991	Cystic fibrosis adults	Cystic fibrosis children	36	20M, 16F 24.8 (16–40)	61	34M, 27F 10.96 (8–15)	EAT, ²¹ STAI-C, ²² CDI, ²³ STAI, ²⁴ ZUNG, ²⁵ SCL-90 ¹¹
²² Blair <i>et al.</i> , 1993	Cystic fibrosis	Anorexia Healthy controls	29	20M, 9F 19.2 (2.7)	(a) 27 (b) 31	(a) 2M, 25F 18.7 (3.2) (b) 8M, 23F 18.2 (2.6)	Structured clinical interview for psychiatric disorder, GHQ ²⁶
²⁸ Walters <i>et al.</i> , 1993	Cystic fibrosis	N/A	866	423M, 397F Median 22, 17–67	N/A	N/A	Sociodemographic enquiry
²⁹ David <i>et al.</i> , 1994	Juvenile arthritis (JCA)	N/A	43	M:F 1:3 Mean 26.7, SD 7.8	N/A	N/A	BDI, ¹⁹ GHQ ²⁷
³¹ Peterson <i>et al.</i> , 1997	Juvenile arthritis	Clinic attenders without JCA	44	13M, 31F Median 33.5, 19–45	102	29M, 73F 33.6 (19–49)	Sociodemographic enquiry
³³ Utens <i>et al.</i> , 1994	Congenital heart disease (surgically corrected)	General population	288	147 M, 141F Mean age 22.7	336	223M, 113F Mean 22.2	Dutch Personality Questionnaire, ³³ sociodemographic enquiry

Sociodemographic information was obtained by self report questionnaire or by interview in different studies.

*Validated psychiatric research interview. All other named psychiatric status measures are self report questionnaires.

IDDM, insulin dependent diabetes mellitus; PSE, Present State Examination; SADS-L, Schedule for Affective Disorders and Schizophrenia, Life-time version; GHQ, General Health Questionnaire; EAT, Eating Attitudes Test; STAI(C), Trait-Anxiety Inventory (for Children); CDI, Child Depression Inventory; ZUNG, Zung Self-Report Depression Inventory; BDI, Beck Depression Inventory.

A different question with regard to psychosocial sequelae is factors within specific conditions which might influence their outcome. These may be biological, for example, severity of illness, persistence of symptoms into adulthood, or psychosocial factors. Assessment of their contribution necessitates within group analyses and this is likely to require large sample sizes.

What do we know of the psychosocial outcome of childhood chronic illness?

Table 1 presents details of some of the studies whose findings will be discussed. This highlights some of the differences in case mix, control groups, size of the study, age at assessment, and the quality of the main outcome measures used.

Studies of heterogeneous diagnostic groups

PSYCHOLOGICAL OUTCOME

A British birth cohort study which included individuals with a wide variety of chronic physical illnesses found that at the age of 26, there were no significantly increased reports of medically treated psychiatric disorders compared to healthy controls,⁹ (6.1% compared to 3.8% for males, and 14.1% compared to 9% for females). These findings were based on self report from the individuals and do not provide objective information about psychiatric disorders which may have been present but unrecognised or for which help was not sought. However, persistent severe and disabling physical ill health in adult life increased the likelihood of later psychiatric difficulties. When the cohort was reassessed at the age of 36, subjects were interviewed using the Present State Examination (PSE),¹⁰ a well validated psychiatric research interview to assess psychiatric symptoms in the preceding month. Overall levels of psychopathology were not increased compared to those without chronic illness but the results revealed that women with chronic physical illness since childhood had greater levels of psychopathology.⁹

A Finnish cross sectional study compared a large sample of young adults aged 18–25 drawn from a university teaching hospital who had a history of childhood chronic physical illness, with general population controls without a history of childhood chronic illness. The physical illness group included individuals with asthma, diabetes, epilepsy, growth hormone deficiency, motor handicaps, rheumatoid arthritis, and congenital heart disease, of varying degrees of severity. Assessment of psychiatric disorder was made using the Present State Examination.¹⁰ The prevalence of psychiatric disorder was found to be similar (20%) in both the ill and healthy groups. However, more severe psychiatric disorders were especially likely to be found in women with more severe physical illness.¹³

SOCIAL OUTCOME

Further examination of these samples suggests slightly impaired academic and employment achievements for young adults with chronic physical illness in childhood. By the time individuals had reached 19–25 years, significantly

more cases (23%) compared to 11% of the control group had no vocational education and they were less likely to be in permanent employment (44% of patients compared to 50% of controls).¹⁴ There is evidence that by the age of 36, unemployment is significantly higher in men (13.3% as compared to 5.9%) but not women with a history of chronic illness in childhood, when compared to individuals of the same gender without this illness history.⁹ The difference was only found for men from families employed in manual work and attributable to the presence of serious illness between the ages of 21 and 25.⁹ By the age of 36, there was a significant excess of single men and single women compared to healthy controls (30.6% compared to 9.8% for men and 19.1% compared to 4.7% for women). This difference was also accounted for by those with persistent health problems between the ages of 21 and 25.⁹

Studies focusing on a specific disorder

DIABETES

Psychological outcome

A cohort study of children diagnosed with diabetes mellitus between the ages of 9 and 16, found no difference in psychological outcome 10 years later between these individuals and a cohort matched for age who had experienced an acute medical problem in childhood. However, the main outcome measure for psychiatric disorder at 10 year follow up was the Symptom Checklist,¹¹ a questionnaire measure of psychological distress with regard to different domains including somatisation, depression, anxiety, and obsessive-compulsive symptoms. The instrument is not sufficiently sensitive to detect all cases of psychiatric disorder. This study does indicate that in early adulthood, 10 years after the initial diagnosis, individuals with diabetes mellitus have lower self esteem than a comparable cohort without chronic illness. It is possible that this may act as a predisposing factor for psychiatric disorders such as depression later in adulthood.⁸

Social outcome

In early adulthood, there was no difference between individuals with diabetes mellitus compared to the control group (with a history of an acute medical problem in childhood) with regard to educational achievement or past and current employment. This study suggests that diabetes may have protective effects on health related behaviours with evidence of less frequent drug use and fewer criminal convictions as compared to the control group.⁸ This finding could be explained by reporting bias in the absence of collateral information, for example, individuals with diabetes mellitus may be less likely to admit to cigarette smoking because of their awareness of its association with cardiovascular risk and likely health advice to abstain.

CHRONIC RENAL FAILURE

Psychological outcome

It is possible that the psychological functioning of individuals with chronic renal disease may

be better in early adulthood than in childhood. Young adults with chronic renal failure (successfully transplanted or receiving dialysis) reported more psychiatric disturbance than healthy controls before but not after the age of 17.¹⁵ Adult lifetime psychiatric disorder of any type was slightly more common in young adults with chronic renal failure (43%) than in an age and sex matched control group (33%). Similar results were found with regard to the presence of more severe psychiatric co-morbidity (present in seven of 45 (15%) adults with renal failure and 10% of controls). There was a trend for more severe depressive disorders in the renal group. The study also showed that renal patients had significantly lower self esteem than their healthy controls and this was especially so for individuals with physical health problems starting early in childhood which have a substantial effect on educational achievement.

This study used a structured psychiatric interview (the Lifetime Schedule for Affective Disorders and Schizophrenia¹⁶) as the main outcome measure. Operationally defined research diagnostic criteria were used to make psychiatric diagnoses. However, when considering these results, it is important to bear in mind that a number of children will not have survived until adulthood and they may have been the group most severely affected, both physically and psychologically.

Social outcome

Young adult survivors of a paediatric dialysis and transplant programme have a lower level of educational attainment (35% left school without any qualifications compared to 10% of controls). While 66% of the renal group were in some kind of employment, 53% of patients compared to 75% of the controls were working full time. Unemployment was linked to an earlier age at onset of the renal disorder.

Renal patients were also found to be less socially mature than their controls. Significantly more were living with their parents (68% compared with 29% of controls), more were single (76% of patients and 65% of controls), and less were married (20% of renal patients compared to 31% of controls). There was evidence of a gender difference with regard to marital status; 46% of the female renal patients were married compared to none of the men. This contrasted with the community control group where equal numbers of men and women were married. Fewer renal patients had children. An early age of illness onset and persistent physical health problems were associated with a poorer social outcome. Despite these findings, renal patients did not report more stress with regard to these domains than the control group. The only areas in which the renal patients were found to experience significantly increased stress was with regard to marriage and co-habitation as assessed by objective indicators. Almost one third felt highly stressed about the physical aspects of their relationship. By contrast, being single between 18 and 35 years was not reported as a source of stress for survivors of childhood chronic renal failure.¹⁸

It is possible that this delay in social maturation is an adaptive process for individuals with a history of chronic illness in childhood. General population age standards may not be directly applicable to these groups of individuals whose social maturation may be delayed rather than impaired. However, continuing follow up of such cohorts is important in order to clarify this issue.

CYSTIC FIBROSIS

Psychological outcome

The life expectancy of children with cystic fibrosis was very limited until relatively recently and the opportunity to examine psychological adjustment in the adult age group is thus a relatively recent development. The available studies are limited by the use of questionnaires to assess psychological symptoms and by the lack of healthy control groups. Some studies have reported lack of clinically significant anxiety in adults with cystic fibrosis,³⁴ while others have reported more emotional symptoms in females than males though generally normal self concept.³⁵ One study examined psychiatric symptomatology in children aged 8–15 and adults aged 16–40 with cystic fibrosis, using self report questionnaires. Eating related symptoms (resisting food, using food as a control) were more frequent in the children, whereas symptoms of anxiety and depression were more prevalent in the adult group.²⁰ However, older patients did not show any greater degree of global emotional disturbance than younger patients and a relationship between psychiatric symptomatology and illness severity (older patients were more severely ill) was not shown. The authors suggest that cognitive developmental stage may account for differences in emotional symptoms with age, with children expressing psychological distress more indirectly than adults.

A further small study included a comparison of cystic fibrosis sufferers aged between 14 and 24 living in the family home with healthy peers of similar age (frequently selected by the index families) using self report questionnaires. It found no difference in terms of psychological health with regard to symptoms of anorexia nervosa and symptoms on the General Health Questionnaire, a well validated screen for psychiatric disorder.²⁶

Social outcome

Impaired educational attainment for individuals with cystic fibrosis is reflected in the achievement of fewer formal qualifications on school leaving at 16 (15%) compared to the general population (11%). This is related to increased disease severity and lower social class. As formal qualifications enhance subsequent employment independent of disease severity, the need for flexibility in the education of those suffering health problems while studying for exams may be important. Over 50% of the 1052 adult cystic fibrosis sufferers surveyed were in paid employment which is significantly less than the 69% for the general population. There is evidence that adults with cystic fibrosis have difficulty achieving independence, with

only one third of those surveyed married or co-habiting and a higher proportion of individuals living in the parental home (52%), compared to the general population (11%). However, the proportion of responders achieving independence from their parents increases with age (82% of those under 20, 15% of those over 30, and none over 40 were living with their parents), suggesting that independence might be delayed rather than prevented by this chronic illness.²⁸

JUVENILE RHEUMATOID ARTHRITIS

Psychological outcome

A British study using self report questionnaires as its outcome measure revealed a 21% prevalence of depression in early adulthood. This increased with the degree of disability. Poorer psychological outcome (both depression and an anxious preoccupation with the disease) was related to greater physical disability and the presence of active disease.²⁹ This study did not have a control group.

Social outcome

An American study which compared slightly older adults with juvenile chronic arthritis (mean 33.5 years) with an age matched control group of paediatric clinic attenders without this diagnosis found no differences between the two groups with regard to educational attainment, annual income, marital status, and pregnancy outcomes. Unemployment was increased in the index group (30% compared to 13%), but in only three cases was this attributed by individuals to their rheumatoid arthritis.³¹

SURGICALLY CORRECTED CONGENITAL HEART DISEASE

Psychological outcome

A Dutch study compared emotional functioning in adult life for individuals with a surgically corrected congenital heart defect during childhood with general population controls.³² The Dutch Personality Questionnaire³³ revealed that the former patient group had a better outcome with regard to hostility, neurotic symptoms, and self esteem. This self report instrument yields a measure of emotional adjustment, but no attempt was made to screen for psychiatric disorder such as depression or anxiety.

Social outcome

The majority of the patient sample (84%) were studying or in employment. Younger patients were less likely than the control group to be living outside the parental home (91% of patients, 80% of controls aged 18–20; 49% compared to 35% at 21–24 years; and 18% compared to 6% at 25–35).³²

CANCER

Psychological outcome

Five year survival rates for childhood cancer have increased from 26% for those treated between 1962 and 1970, to 65% for children treated between 1986 and 1988.³⁶ Survival into adulthood carries with it the threat of possible recurrence, an increased risk of secondary

malignancies, and reduced fertility. More recently, attention has begun to focus on the associated psychological and social sequelae of surviving childhood cancer.³⁹

A recent review suggests that many children treated for cancer in childhood are by adulthood, indistinguishable from the general population with regard to psychosocial outcome.³⁷ However, studies have varied widely in the spectrum of diagnoses included, failing to take into account differences in severity of the cancer, its treatment, or initial prognosis. They include a wide variation in the age at diagnosis, the source of information, for example, the survivor themselves, parent, medical team, and with regard to the measures used. In addition, the sample sizes have been small in many of the studies.³⁷ Many studies have included depression as an outcome measure and found this not to be increased in young adult survivors compared to peers or healthy siblings. Similarly, no consistent evidence of impaired self esteem or increased anxiety has emerged from studies to date.³⁸

Impaired cognitive functioning, specifically, reduced IQ and memory deficits have been well documented as sequelae of cancer treatment with chemotherapy and radiotherapy. Specific areas of neuropsychological functioning such as attention may be similarly affected; such declines may continue long after the end of treatment.^{39 40}

Social outcome

Survivors treated for central nervous system tumours are at greater risk of compromised academic achievement. In other cases, there is no consistent evidence that survivors are less successful academically when compared to healthy controls. While there is no consistent evidence to suggest that employment is compromised, earlier studies have reported discrimination in the workplace, particularly the armed forces.⁴¹ Others have found that rates of female employment are below that expected from population norms.⁴² In addition, fewer survivors are married when compared to the general population (39% of men and 44% of women at a mean age of follow up of 26.6 years). This contrasts with proportions in the general population of 53% and 59% respectively.⁴²

Conclusions

In trying to reach conclusions from the available literature, its inherent methodological difficulties must be taken into consideration; these include heterogeneous samples, variable outcome measures, and differing control groups. However, despite this, there is considerable agreement with regard to many of the findings. This consistency is maintained for studies with both large and small sample sizes, across individuals with different conditions, and in different countries. Furthermore, the results of studies using well validated psychiatric interviews such as the Present State Examination and the Schedule for Affective Disorders and Schizophrenia are similar to those of studies using questionnaire based measures in

showing that psychiatric outcome is not severely compromised in the majority of adult survivors (without brain involvement) when compared with healthy or general population controls. Some studies have indicated that persistent physical health problems in adulthood may be related to the presence of greater or more severe psychiatric disorder and others have suggested that psychiatric outcome may be better for men than for women. However, when interpreting these findings, consideration needs to be given to the fact that studies on some specific conditions may be carried out in units which pay special attention to psychosocial aspects of physical disorders. Outcomes may be less optimistic among units or individuals who do not participate in these studies. Adult outcome may also be related to the quality of paediatric care and psychosocial support.

The evidence regarding social outcome—objective indicators of educational attainment, employment, and the development of independence—suggests that there is mild impairment when compared to the general population. Persistent severe illness in adulthood seems to be related to poorer outcome in these domains. However, these findings do not take into consideration more subjective indicators which suggest that the experience of chronic illness may change an individual's views about what is important in life.⁴⁰ Lesser academic achievement, lower employment, and delayed independence may be achieved by an alteration in an individual's personal life goals and might represent part of an adaptive process. In particular, studies have interpreted the delay in social maturation in this way. Studies which follow up individuals into later adulthood will be important in clarifying this to see whether this group eventually catches up developmentally.

The study of psychosocial outcome in adults with chronic illness since childhood is not easy, both because of the heterogeneity of physical disease severity, the rapid progression of physical treatments, and the many other factors—in the individual, his/her family, and their social environment—which may predispose to psychosocial difficulties. To adequately account for these factors, large study samples are needed. Some of the studies discussed have had small sample sizes and it is possible that this may account for negative results in these cases.

Further research in this area might helpfully focus efforts on the acquisition of larger samples, not just from more specialised units (who may be more sensitive to psychological difficulties), which is reflected in a more optimistic psychosocial prognosis. Despite this possibility the evidence shows similar results in a sample drawn from a Finnish teaching hospital and from a British birth cohort study.^{9 13} While the majority of children with chronic illness are not compromised in adult life with regard to these domains, future research might usefully focus on identifying those most likely to develop difficulties. This might involve further exploration of the role of adjustment disorder and low self esteem in childhood,

persistence and severity of physical illness, school attendance, and family factors which may affect adult outcome. This may lead on to the evaluation of interventions aimed at reducing this risk.

There is a need for well designed studies in this field, as life expectancy for these children continues to increase. At present, there is no consistent evidence that psychosocial functioning is severely compromised, but it is likely that chronic physical illness has a differential impact on different individuals. Understanding this more thoroughly is likely to be important, not only in terms of quantifying the impact of chronic illness but also in facilitating the targeting of therapeutic interventions.

- 1 Eiser C. Psychological effects of chronic disease. *J Child Psychol Psychiatry* 1990;**31**:85-98.
- 2 Rutter M, Tizard J, Whitmore K. *Education, health and behaviour*. London: Longman, 1970.
- 3 Breslau N. Psychiatric disorder in children with physical disabilities. *J Am Acad Child Psychiatry* 1985;**24**:87-94.
- 4 Garralda ME, Jameson RA, Reynolds JM, Postlethwaite RJ. Psychiatric adjustment in children with physical illness. *Br J Hosp Med* 1988;**52**:230-4.
- 5 Howarth RV. The psychiatry of terminal illness in children. *Proc R Soc Med* 1972;**65**:1039-40.
- 6 Wass VJ, Barratt TM, Howarth RV, *et al*. Home dialysis in children. *Lancet* 1977;**1**:242-6.
- 7 Kovacs M, Feinberg TL, Paulauskas S, Finkelstein R, Pollock M, Crouse-Novak. Initial coping responses and psychosocial characteristics of children with insulin-dependent diabetes mellitus. *J Pediatr* 1985;**106**:827-34.
- 8 Jacobson AM, Hauser ST, Willett JB, Wolfsdorf JJ, Dvorak R, Herman L, De Groot M. Psychological adjustment to IDDM: 10-year follow-up of an onset cohort of child and adolescent patients. *Diabetes Care* 1997;**20**:811-18.
- 9 Pless IB, Cripps HA, Davies JMC, Wadsworth MEJ. Chronic physical illness in childhood: psychological and social effects in adolescence and adult life. *Dev Med Child Neurol* 1989;**31**:746-55.
- 10 Wing JK, Cooper JE, Sartorius N. *The measurement and classification of psychiatric symptoms*. New York: Cambridge University Press, 1974.
- 11 Derogatis LR. *SCL-90 administration, scoring and procedures manual-I*. Baltimore, MD: John Hopkins University Press, 1983.
- 12 Harter S. *Manual for the Self-perception Profile for Children*. Denver: University of Denver, 1985.
- 13 Kokkonen J, Kokkonen E-R. Prevalence of mental disorders in young adults with chronic physical diseases since childhood as identified by the Present State Examination and the CATEGO program. *Acta Psychiatr Scand* 1993;**87**:239-43.
- 14 Kokkonen J. The social effects in adult life of chronic physical illness since childhood. *Eur J Pediatr* 1995;**154**:676-81.
- 15 Morton MJS, Reynolds JM, Garralda ME, Postlethwaite RJ, Goh D. Psychiatric adjustment in end-stage renal disease: a follow-up study of former paediatric patients. *J Psychosom Res* 1994;**38**:293-303.
- 16 Endicott J, Spitzer RL. A diagnostic interview: the Schedule for Affective Disorders and Schizophrenia. *Arch Gen Psychiatry* 1978;**35**:837-44.
- 17 Rosenberg M. *Society and the adolescent self image*. Princeton: Princeton University Press, 1965.
- 18 Reynolds JM, Morton MJS, Garralda ME, Postlethwaite RJ, Goh D. Psychosocial adjustment of adult survivors of a paediatric dialysis and transplant programme. *Arch Dis Child* 1993;**68**:104-10.
- 19 Bailey D, Garralda ME. The use of the social stress and support interview in families with deviant children; methodological issues. *Soc Psychiatry* 1987;**22**:209-15.
- 20 Pearson DA, Pumariega AJ, Seilheimer DK. The development of psychiatric symptomatology in patients with cystic fibrosis. *J Am Acad Child Adolesc Psychiatry* 1991;**30**:290-7.
- 21 Garner DM, Garfinkel PE. The Eating Attitudes Test: an index of the symptoms of anorexia nervosa. *Psychol Med* 1979;**9**:273-9.
- 22 Spielberger CD. *Preliminary manual for the State-Trait Inventory for Children*. Palo Alto, CA: Consulting Psychologists Press, 1973.
- 23 Kovacs M. The Children's Depression Inventory (CDI). *Psychopharmacol Bull* 1985;**21**:995-8.
- 24 Spielberger CD. *Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press, 1970.
- 25 Zung WWK. A self-rating depression scale. *Arch Gen Psychiatry* 1965;**12**:63-70.
- 26 Blair C, Cull A, Freeman CP. Psychosocial functioning of young adults with cystic fibrosis and their families. *Thorax* 1994;**49**:798-802.
- 27 Goldberg D. *The user's guide to the GHQ*. Slough: NFER Publications, 1987.
- 28 Walters S, Britton J, Hodson ME. Demographic and social characteristics of adults with cystic fibrosis in the United Kingdom. *BMJ* 1993;**306**:549-52.
- 29 David J, Cooper C, Hickey L, Lloyd J, Doré C, McCullough C, Woo P. The functional and psychological outcomes of juvenile chronic arthritis in young adulthood. *Br J Rheumatol* 1994;**33**:876-81.
- 30 Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry* 1961;**4**:561-71.
- 31 Peterson LS, Mason T, Nelson AM, O'Fallon WM, Gabriel SE. Psychosocial outcomes and health status of adults who have had juvenile rheumatoid arthritis. A controlled, population-based study. *Arthritis Rheum* 1997;**40**:2235-40.
- 32 Utens EMWJ, Verhulst FC, Erdman RAM, *et al*. Psychosocial functioning of young adults after surgical correction for congenital heart disease in childhood: a follow-up study. *J Psychosom Res* 1994;**38**:745-58.
- 33 Luteijn F, Starren J, Van Dijk H. *Manual for the Dutch Personality Questionnaire. Handleiding bij de NPV*. Lisse, NL: Swets and Zeitlinger BV, 1975.
- 34 Strauss GD, Wellisch DK. Psychological assessment of adults with cystic fibrosis. *Int J Psychiatry Med* 1980;**10**:265-72.
- 35 Cowen L, Corey M, Simmons R, *et al*. Growing older with cystic fibrosis: psychologic adjustment of patients more than 16 years old. *Psychosom Med* 1984;**46**:363-76.
- 36 Robertson CM, Hawkins MM, Kingston J. Late deaths and survival after childhood cancer: implications for cure. *BMJ* 1994;**309**:162-6.
- 37 Eiser C. Practitioner review: long-term consequences of childhood cancer. *J Child Psychol Psychiatry* 1998;**19**:621-33.
- 38 Eiser C, Havermans T. Long term social adjustment after treatment for childhood cancer. *Arch Dis Child* 1994;**70**:66-70.
- 39 Meadows AT, Gallagher JA, Bunin GR. Late effects of early childhood cancer therapy. *Br J Cancer* 1992;**66**:592-5.
- 40 Cousens P, Waters B, Said J, Stevens M. Cognitive effects of cranial irradiation in leukaemia; a survey and meta-analysis. *J Child Psychol Psychiatry* 1988;**29**:839-52.
- 41 Teta MJ, DelPo MK, Kasl SV. Psychosocial consequences of childhood and adolescent cancer survival. *J Chronic Dis* 1986;**39**:751-9.
- 42 Green DM, Zevon MA, Hall B. Achievement of life-goals by adult survivors of modern treatment for childhood cancer. *Cancer* 1991;**67**:206-13.



Surviving chronic physical illness: psychosocial outcome in adult life

Julia Gledhill, Luiza Rangel and Elena Garraalda

Arch Dis Child 2000 83: 104-110
doi: 10.1136/adc.83.2.104

Updated information and services can be found at:
<http://adc.bmj.com/content/83/2/104>

- These include:*
- References** This article cites 30 articles, 7 of which you can access for free at:
<http://adc.bmj.com/content/83/2/104#BIBL>
- Email alerting service** Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.
-

Topic Collections

Articles on similar topics can be found in the following collections

- [Child and adolescent psychiatry \(paediatrics\)](#) (683)
- [Child health](#) (3922)
- [Oncology](#) (777)
- [Adolescent health](#) (329)
- [Stroke](#) (227)
- [Adjustment disorders](#) (1)
- [Asthma](#) (369)
- [Cystic fibrosis](#) (182)
- [Diabetes](#) (339)
- [Epilepsy and seizures](#) (391)
- [Immunology \(including allergy\)](#) (2018)
- [Metabolic disorders](#) (761)
- [Mood disorders \(including depression\)](#) (39)
- [Pancreas and biliary tract](#) (269)
- [Renal medicine](#) (273)
- [Urology](#) (446)

Notes

To request permissions go to:
<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:
<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:
<http://group.bmj.com/subscribe/>