adolescents, and adults have to integrate into “normal” life this huge burden of lifelong daily treatment.

Mealtimes can be psychological battlefields for such families, with eating often reflecting a child’s first experience of power struggles. Difficulties may recur in puberty, an age that may be critical for the further course of the disease; they are often exacerbated by the need for patients to conform to today’s ideal that “thin is beautiful.” Just as treating patients with anorexia nervosa needs more than simply prescribing supplements, efforts to clarify the underlying psychodynamic processes in cystic fibrosis may be critical for success.

In this issue (p 632) Poustie and colleagues present an important, well planned, and carefully conducted randomised multicentre study of oral supplements in cystic fibrosis patients.⁸ Concordance with the intervention was reinforced continuously by staff making regular home visits. Nevertheless, the prescription of extra oral supplements failed to improve the nutritional status of the patients.

The trial was conducted to detect a 10 point difference in centile for body mass index within one year of the intervention, comparing patients receiving dietary advice with patients who were also prescribed oral energy supplements. This means that the trial was powered to detect, for example, a difference in weight gain of 2 kg between two 9 year old girls allocated to the different treatment groups. This was a noble goal, but an over-optimistic end point for a clinical trial in cystic fibrosis.

The authors say that the intervention failed because of inconsistency or inaccuracy in the dietary records and, perhaps, because patients did not take the supplements they were prescribed. In addition, the appropriately used statistical method, intention to treat analysis, may have led to underestimation of the effects of the intervention, but a per protocol analysis was not possible in this trial because adherence to treatment was unknown. Therefore conclusions from the trial must be drawn very carefully.

Treatments for cystic fibrosis are time consuming, generally unpleasant, and potentially anxiety provoking, and this can be particularly problematic when patients are feeling generally healthy. Professionals often have to “sell” such medical options to patients. Powers and colleagues have reported how they successfully influenced the behavioural aspects of nutrition in children with cystic fibrosis by using a multidisciplinary approach.⁹ The “intention to feed” is certainly not enough.

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What sort of evidence do we need in primary care?

General practitioners need evidence from and about the patients they see

Research p 635

In this week’s *BMJ* (p 635), Mant and colleagues raise again the question of whether large scale randomised controlled trials provide evidence relevant to primary care.¹ In a cross sectional study they question whether the UK national clinical guidelines for stroke are applicable to primary care patients. These guidelines, largely based on the PROGRESS trial,¹ recommend a target blood pressure of 140/85 mm Hg, with further lowering beyond this target desirable through use of a thiazide diuretic and an angiotensin converting enzyme inhibitor.²

Mant and colleagues critiqued the applicability of these guidelines to primary care patients by comparing the characteristics of patients in English general practice who had confirmed stroke with participants in the PROGRESS trial. They concluded that these populations were not sufficiently similar to warrant

widespread use of the guidelines. Patients with stroke in English primary care were generally older, equally comprised men and women, and had had their cerebral events less recently than the trial participants. They may not necessarily benefit from the relatively aggressive treatment recommended in the national guidelines. Given that most chronic stroke patients are managed by general practitioners, Mant and colleagues are calling for more appropriate research to provide evidence applicable to primary care.³

Primary care has specific needs for research. This setting is contextually complex, with patients who present with a broad range of signs and symptoms. Therefore, practitioners need research evidence for the whole range of diagnostic, prognostic, interventional, and phenomenological questions that emanate from this contextual complexity.³ Well documented gaps in

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the evidence limit the quality of patients' care. Some evidence is simply lacking—for example, on the aetiology of upper respiratory tract infections, and on the reasons for variation in health seeking behaviours between people who have the same symptoms. Even when there is relevant evidence, it is not always implemented.⁴

For evidence to be implemented in primary care it must be accessible as well as relevant.⁵ The sheer volume of published studies documenting medical and clinical research means it is impossible for busy clinicians to read, let alone digest, sufficient material to keep up to date. Clinical guidelines can provide clinicians with concise, evidence based recommendations to enable the delivery of high quality and well researched care for their patients.⁶ However, the guidelines must be regularly updated,⁵ and they should evaluate the methodological rigour of included studies and be clear about both the application and the limitations of the recommendations.⁷

With good clinical guidelines, clinicians can confidently use research evidence as a basis for their individualised decision making with patients, while also considering patients' personal histories and preferences. Mant and colleagues indicate that these criteria are not met by the UK clinical guidelines for stroke, thus undermining the applicability of the recommendations.²

The PROGRESS trial not only had a different patient profile than that seen in primary care but yielded results that are open to interpretation. In particular, the cause of the substantial reduction in stroke risk seen in the trial (relative risk reduction 43%, 95% confidence interval 30 to 54) is unclear: is it due to the use of a thiazide diuretic and angiotensin converting enzyme inhibitor in combination or alone, or simply due to the lowered blood pressure?⁸ Really useful guidelines would help clinicians to interpret these findings, rather than just uncritically basing clinical recommendations on them.

Evidence from randomised controlled trials is only a portion of the real knowledge that is needed in primary care. Such trials provide vital information about the effectiveness of interventions in selected populations of

patients. However, general practitioners require evidence about how an individual patient will respond to an intervention. Active involvement of patients in decisions about their health care can improve health outcomes. For instance, patients with breast cancer have less anxiety and depression if treated by doctors who involve them in the decision making, and patients with diabetes achieve better blood sugar control if involved in discussions about their management.⁹

Mant and colleagues call for further research in the primary care population to determine the efficacy and appropriateness for individual patients of intensive lowering of blood pressure.² Their call is well justified and should be heeded.

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Grieving the death of a child

Health professionals need to be particularly sensitive to the needs of parents

The death of a child brings profound distress and intense grief to the family, challenging all those involved in caring for the family through such times. That such grief can lead to suicide is known, but two cases in this week's *BMJ* show a particular hazard after a child has died at home: in both cases mothers committed suicide with drugs prescribed for the palliative care of their children (p 647).¹

There is substantial evidence from comparative and longitudinal studies that the grief of parents following the loss of a child is more intense and prolonged than that of other losses.²⁻³ Parental vulnerability includes a heightened risk of suicide, especially in the first month, as shown in a nested case-control study of Danish longitudinal registers.⁴ Population based follow-up studies also show that anxiety and

depression may last four to nine years after the loss of a child from cancer.⁵

When a child dies suddenly—for instance, through suicide, homicide, violence, or accidental death—parental grief may become complicated by post-traumatic stress reactions arising from the nature of these circumstances, so that the parent has to deal with the interplay of both trauma and grief.⁶

The challenges that arise when a death is prolonged are different. Caring for a child with chronic fatal disease such as cancer may involve intense and prolonged treatments; the sustaining of hope; the denial of the potential for death as the parent fights for the child's survival in a protracted battle with the disease. Anticipatory grieving as the probability of death becomes more real may lead parents to feel guilt about giving in to such a

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