Adherence to Physiotherapy and Quality of Life for Adults and Adolescents with Cystic Fibrosis

Summary There is indisputable evidence of the positive affects of empowering patients through education in order to improve adherence to treatment and health outcomes. Considerable work has been reported on how adults learn and this can be used as a framework by physiotherapists. It is important that the increasing treatment burden for people with cystic fibrosis is effectively evaluated to ensure that therapeutic levels of treatment are established through evidence-based research to encourage maximum patient adherence and develop professionalisation.

With increasing age, care becomes more complex, presenting patients with the dilemma of adhering to time-consuming treatments which have a considerable impact on their quality of life. Poor adherence to physiotherapy has been reported in several studies in spite of its recognised benefit in reducing lung damage and increasing exercise tolerance. There is little research on the impact of physiotherapy on quality of life and the need when planning treatment to understand patients’ health beliefs and locus of control, or of the possible variations in adherence throughout the course of the disease. Cross-sectional studies have focused on the reasons why physiotherapy is not done.

Recently adherence has been defined and recognised as rarely perfect. If no discernible improvement in quality of life is evident then adherence to physiotherapy is unlikely to continue, irrespective of advice.

Until recently, the lack of validated cystic fibrosis specific questionnaires meant that few studies have been conducted to establish the impact of the disease and its treatment on patients’ quality of life. This review highlights the need for physiotherapists to undertake longitudinal studies on individually tailored evidence-based treatment, accommodating patients’ health beliefs in order to improve adherence to physiotherapy and potentially their quality of life.

Introduction
The role of a physiotherapist in the treatment and management of people with cystic fibrosis is that of educator, clinician, researcher and manager. Physiotherapy has been defined by the Chartered Society of Physiotherapy as a health profession which emphasises the use of physical approaches in prevention and treatment of disease and disability (CSP, 1991).

Cystic fibrosis is a complex multi-system disorder presenting many challenges. It is the most common life-threatening recessively inherited genetic disease of caucasian populations, with a carrier rate of 1!25 and an incidence of 1 in 2,400 live births (CFT, 1997). There are approximately 7,500 people with cystic fibrosis in the United Kingdom. The median survival time has improved dramatically and average life expectancy is at least 40 years for children born in the 1990s (Elborn et al, 1991). Among people with cystic fibrosis there is a wide range of clinical presentation and severity. The majority present in early childhood with respiratory tract infections, intestinal malabsorption and failure to thrive (RCP, 1996). Advances in the management and care of people with cystic fibrosis have led to the majority surviving into adulthood. This improved survival has been attributed to earlier diagnosis, multidisciplinary specialist regional centre care and more effective methods of treatment (CFT, 2001; Robinson, 2001).

Physiotherapy is time consuming and
one of the least liked aspects of treatment (Davids and Henley, 1990). Pryor and Webber (1998) have stated that physiotherapy regimens have been developed in different parts of the world 'to provide a means of treatment that does not require assistance and thereby improves patient compliance'. The aim of physiotherapy is to teach patients how to self-manage their condition through airway clearance techniques, posture correction and exercise in order to lead as normal and as healthy a life as possible. This is a daily task and at times onerous. Among adults and adolescents with cystic fibrosis non-compliance can be a serious problem that minimises the benefits of good medical care (Fong et al, 1990).

Very little has been written about the developing multi-dimensional role of physiotherapists in relation to patients with chronic disease and their families. Dekelche (1995) states that there is indisputable evidence of the positive effects of patient teaching and education in the knowledge of the disease and its treatment, health behaviour, adherence and health outcomes. In the education field much work has been carried out into how adults learn and this can be used as a framework from a physiotherapy perspective. Vinette Cross (1996) in her study explores the concept of introducing learning contracts into physiotherapy clinical education as 'an example of the humanistic orientation of self-directed learning'. Learning contracts have been a well-established tool in many areas of education. Both Brookfield (1986) and Knowles (1990) saw learning contracts as a key principle in the enhancement of self-directed learning. These concepts can be equally applied to patient and professional education.

Patient education, adherence to treatment and its impact on quality of life and health status has been a feature of the increasing professionalisation of physiotherapy where patients are seen more as partners in the planning of their treatment. Richardson (1999) considers that: 'Taking responsibility for professionalisation must be perceived as integral to being a physiotherapist and the spur to continuing professional development over the professional life span.'

Most research work on professional effectiveness and development has been carried out by nurses although it can, in principle, be related to physiotherapy. However, this imbalance is being addressed and a growing interest can be seen in the physiotherapy literature. Cystic fibrosis provides an ideal example of the developing professional role of physiotherapists.

**Cystic Fibrosis**

**History**

The study of cystic fibrosis provides a fascinating insight into the advances in medicine (Super, 1992). Busch (1986) noted in his study into the history of cystic fibrosis that, in the 19th century, references were made in the medical literature to 'the child that tastes salty when kissed who will die in the first year of life'. However, it was not until 1938 that Dorothy Anderson described the disease accurately and comprehensively. By the 1960s the estimated median survival time for children born with cystic fibrosis was less than five years. Death resulted from persistent chest infections, and malnutrition as a result of poor fat absorption was also a significant contributing factor.

Towards the end of the 1980s the median life expectancy of patients with cystic fibrosis had advanced to the mid 20s. By 1985 Tsui had discovered the cystic fibrosis gene, the first heart/lung transplant was carried out on a cystic fibrosis patient, and advances in inhaled antibiotics (Hodson et al, 1984) led to a reduction in respiratory infections. These clinical milestones led to an increase in longevity and improved quality of life. However, according to Conway et al (1996) the complexity and time-consuming nature of daily drug and physiotherapy regimens needed by adult patients discourage adherence to prescribed treatments. In addition, patients with diabetes require insulin and those with poor nutrition need supplements or enteral feeding. Dodd and Webb (2000) emphasised that as the treatment burden increases, the patients' lifestyle becomes more complex. Cystic fibrosis treatment is expensive; non-adherence can waste resources, reduce quality of life and lead to increased hospital admissions.

Demanding treatment programmes challenge both patients and professionals, particularly as there is no recognised cure for cystic fibrosis. More recent
studies have combined natural and social science models where objective treatment outcomes are evaluated with quality of life measures to discover the impact of the disease and its treatment on individuals and consequently the professional role of physiotherapists.

Humanity
The 'humanity of cystic fibrosis' has been described by Barbero (1996) with an apt quote from Robert Louis Stevenson: 'Life is often about playing well with half a deck of cards'. Barbero (1996) also states that 'as care givers we can keep faith with our patients, and as science progresses we can give them hope; and, above all, we can ensure that all that we do is done with charity'. While advances had been made in the natural sciences resulting in patients living into their mid 40s and beyond, greater understanding of human nature and insights into the 'real world' as experienced by patients is required in order to improve adherence. More empirical studies have been undertaken, taking into account both qualitative and quantitative data, in order to provide a greater understanding of the disease from the patients' perspective.

By the late 20th century, international law recognised the increasing significance of individuals with the drafting of the United Nations Universal Declaration of Human Rights (1948), the World Health Organisation Alma-Ata Declaration for Primary Health Care (1978) and the diverse medical/humanitarian aspects of the United Nations with the formation of the United Nations Office for the Coordination of Humanitarian Affairs in 1992. This humanitarian perspective can be applied to cystic fibrosis where greater emphasis is now being given to the impact the disease has on the individual and consequently the professional role of physiotherapists.

Physiotherapy
In modern times science is highly esteemed (Chalmers, 1982). However, the physiotherapy profession has been disadvantaged by its historical background of a lack of research and failure to recognise the significance of epistemology. This imbalance is being corrected with the promotion of the concept of the 'practitioner-scientist' (Robertson, 1996). Previously, emphasis has been given to 'belief' in treatment. As Newham (1997) states: 'Belief is inevitable and often valuable, but it must not be confused with knowledge, which can only be gained through scientific inquiry.'

Increasing emphasis needs to be placed on the practical application of physiotherapy based on sound scientific knowledge and evidence-based practice. An example of this is the Clinical Guidelines for the Physiotherapy Management of Cystic Fibrosis (2002) developed by the Association of Chartered Physiotherapists in Cystic Fibrosis, in a move towards evidence-based practice.

In scientific studies the gold standard is the randomised control trial. However, this has proved problematical for physiotherapists. Prassad and van der Schans reviewed physiotherapy studies for the Cochrane Institute (2000) and found that due to the lack of randomised control trials many of the studies did not stand up to scientific scrutiny and were therefore excluded. Valid and reliable measurement tools need to be developed to evaluate physiotherapy effectively.

Developing Role of Physiotherapists
Physiotherapy has become an accepted part of life for patients with cystic fibrosis (Webber and Pryor, 1993). Physiotherapists provide an ongoing education programme to ensure maximum fitness, effectiveness and efficiency of treatment. They function as teachers/practitioners and have been described as professionals whose occupational commitment involves them in both the practice of their branch of skills and in teaching carers about their role (Jarvis and Gibson, 1985). They also need to teach postgrad-uate healthcare professionals, medical and nursing staff.

Treatment
In the 1960s, when virtually all patients were children, physiotherapy was carried out in special schools where the children were educated. Their lifestyle was limited and treatment regimens were uncomplicated, requiring little in the way of patient education programmes.

By the 1980s treatment became more complex with the introduction of intravenous and nebulised drugs administered at home (Dodd and Webb, 2000). Physiotherapy became more dynamic with increasing emphasis on exercise, and a greater range of airway
clearance methods, including the active cycle of breathing techniques, were more actively promoted for cystic fibrosis patients.

By the 1990s home-based treatment for some patients extended from day into night. Overnight feeding was initiated, insulin and dietary control were required for those with diabetes, evident in 75% of the adult population aged 30 and over (Betts, 1998). From a physiotherapy perspective recently there has been a greater awareness of musculoskeletal and incontinence issues. Treatment has become more complex and time consuming. Abbott et al (1996) suggested that partial or non-adherence to treatment might be the product of patients striking a balance between treatment regimens and their quality of life.

Little attention however has been paid among physiotherapists as to how adults learn. A greater awareness of patient education needs to be encouraged as part of increasing professionalisation and to ensure that physiotherapy is as effective as possible.

Evidence-based Practice
It is important that the increasing burden of treatment is evaluated effectively to ensure that physiotherapy is evidence-based. Bithell (2000) has described evidence-based practice as the integration of ‘clinical judgement with both quantitative and qualitative evidence seeming at present to be of most relevance to physiotherapy. It represents a radical shift away from the traditional paradigm of knowledge based on the “expert’s” authority and clinical experience towards a new understanding’. It is essential to establish therapeutic levels of treatment which will bring about a clinical improvement or prevent deterioration in order to improve patient adherence. Patient-centred treatments represent a paradigm shift away from professionally driven agenda towards a more balanced partnership.

Patients as Partners
Empowerment of patients is encouraged in recent government policy (NHSE, 1999) and the Chartered Society of Physiotherapy which emphasises in its Core Standards of Physiotherapy Practice (2000: 8.1) that patients should be ‘fully involved in any decision-making process during treatment planning’. The National Health Service Executive (1999) emphasises the patient partnership strategy to promote patients’ involvement in their own healthcare by functioning as active partners with professionals. This can be seen as a means of empowering patients.

Giving patients knowledge and empowering them implies that they are better equipped to participate in their own healthcare. Giving patients knowledge also implies learning for which patient education strategies need to be developed. Willingness and ability to learn has been the topic of much educational research. The emphasis on evidence-based practice, through research, for the benefit of patients and subsequent improved clinical effectiveness results in the increasing development of the profession (Richardson, 1999). The development of education strategies will encourage patients to direct their own care.

Adherence
With the increasing longevity of people with cystic fibrosis greater attention has been paid not just to the treatment itself but how much of the recommended treatment is actively practised by patients. In the 1970s few lived to adolescence (Czajkowski and Koocher, 1987). Most treatments were carried out by parents, whose intentions would predominate. However, by the mid 1980s 50% of cystic fibrosis patients were surviving to 20 or more years and 35% were older than 30 years (Matthews and Drotar, 1984). Improved care and greater quality of life coincided with an explosion of knowledge in both the natural and social sciences. Patients were living longer but an ever-increasing demand was placed upon them to undertake time-consuming and complex treatments.

Compliance
In the 80s the social sciences studies in cystic fibrosis began to develop with greater attention paid to quality of life and health status, and what the disease meant to the patients themselves. The terms ‘compliance’ and ‘adherence’ were often used interchangeably in the medical literature. The term ‘compliance’ has been defined as the disposition to follow a
prescribed regimen or specific instructions, as those of a physician to a patient (Churchill's Medical Dictionary, 1989). Compliance, defined as the degree of patient adherence to medical advice and treatment regimens, may be an important factor in successful management of the disease (Abbott et al, 1994). Huss et al (1997) outlined the negative connotation of the word. Compliance implies a passivity assumed by patients. In moving away from this passivity the term 'adherence' began to be used.

Adherence has been defined as the act or quality of sticking to something (Dorland's Medical Dictionary, 2000). This connotation is more positive, implying a voluntary active role for patients and collaboration in management. It is more a negotiated arrangement with a desired effect of agreement by both sides with the aim being to encourage greater adherence and potentially an improvement in the patients' quality of life. If they cannot detect any improvement they are unlikely to continue treatment, in spite of physiotherapists' or doctors' advice (Abbott et al, 1997). There is no conclusive link between poor treatment adherence and progression of the disease, but it would be logical to assume that it would be clinically detrimental (Abbott et al, 1994). Studies by Davids and Henley (1990), Abbott et al (1994), Conway et al (1996) and Walters (2001) state that adherence to physiotherapy treatment in cystic fibrosis patients is 50-75%.

In the 1990s studies began to be carried out into adherence and quality of life. A pilot study conducted by Carr et al (1996) proposed that the majority of patients held positive beliefs about physiotherapy and exercise and the benefits they obtained from them. However, the opinions of non-responders (46%) could not be accounted for and consequently the results could be biased. Further investigations would be needed to establish whether patients with strong positive health beliefs about physiotherapy had a strong internal locus of control in their overall health (Carr et al, 1996).

By the late 1990s Lask (1997) recognised that total adherence was abnormal and unrealistic. He emphasised that it was naïve to assume that adherence can ever be complete and recommended that reasonable degrees of adherence were acceptable, otherwise conflict and tension resulted which would ultimately be detrimental to the relationship between the health carers and the patient.

'Concordance', described by Mullen (1997) as the 'frank exchange of information, negotiation and a spirit of cooperation' requires a non-judgemental approach from professionals to implement such a cultural change in the patient/professional relationship. This is particularly true in view of the considerable burden of complex treatment for people with cystic fibrosis. Although controversial, there is some evidence that cystic fibrosis patients do adhere reasonably well to the enormous demands made on them.

Abbott et al (1995) examined the relationship between the medical and paramedical staffs' views of whether patients were adhering to treatment, the patients' own self-reported adherence levels, and those of carers, parents or friends. The presenting of prescriptions was one of the measures used to indicate adherence to treatment. This information was then compared with the physicians' impressions. However, the validity of prescription fulfilment as an outcome measure could be questioned; although collected, medication might not always be put to use.

The studies carried out have been cross-sectional in time and as yet no longitudinal studies have been conducted giving recognition to the possible variation in adherence throughout disease progression and the impact this would have on the patients' quality of life.

Quality of Life

Health Status

The terms 'quality of life' and 'health status' are often used interchangeably. Quality of life in this study will be considered in terms of the broader impact that disease has on patients' lives and from patients' perspectives, while health status will be considered in terms of a more functional concept of doing/not doing something. This framework is defined from a clinician's perspective. In cystic fibrosis the majority of studies have been undertaken from a quality of life perspective and this will be the terminology used.

In the 1980s psychologists and psychiatrists first started to become involved
with patients who had cystic fibrosis and
greater attention was given to individuals.
The initial work was conducted on
children and their families. Social science
assessment methods were used, with one
of the first being the Medical Compliance
Incomplete Stories Test (Koocher, 1982;
Czajkowski and Koocher, 1987). Objective
measures such as arterial blood gases and
pulmonary function tests were used to
determine the relationship between
objective measurements and adherence.
Interviewing and social surveys were the
favoured tools of social scientists.

By the 1990s a wider perspective was
taken with emphasis not just on social and
psychological dysfunction but on the
‘quality’ of added years. This resulted in
considerable interest in quality of life
studies (Congleton et al, 1996; Abbott et
al, 1997; Stabb et al, 1998; Quittner et al,
2000).

Previously quality of life studies
had used chronic respiratory disease
questionnaires such as the St George’s
Respiratory Questionnaire (Jones et al,
1992) but they were neither sensitive
enough nor specific to the multi-
dimensional aspects of cystic fibrosis. This
was highlighted by Abbott et al (1997)
who sought to define quality of life in
people with cystic fibrosis and attempted
to measure it. She stated that: ‘The aim of
the quality of life measurement in cystic
fibrosis should be to quantify and evaluate
the impact of both the disease and its
treatment on the wider aspects of the
patient’s life.’

There has been a developing interest in
the added ‘quality years’ to the lives of
cystic fibrosis patients. The measuring
of quality of life (Abbott et al, 1997) needs
to result in an outcome that is meaningful
to health professionals and to patients and
their families, complements existing
clinical measures, and is an effective way
of determining the impact of treatments
on how patients feel and function. It can
also provide information for policy
makers who are interested in the impact
of expensive treatments.

None of the varied approaches to
measuring health related quality of life,
until very recently, has been specifically
valid for use in the United Kingdom for
people with cystic fibrosis. There are
three approaches to measuring health-
related quality of life: generic, utility and
disease specific.

**Generic Measures**

Generic measures are wide-ranging and
aim to define the health of populations
from the patients’ perspective in
numerical terms, covering a wide range of
clinical groups which can then be
compared to healthy groups. Typical
examples are the Sickness Impact Profile
(Bergner et al, 1981), the Nottingham
Health Profile (Hunt and McKenna, 1991;
Wane and Sherbourne, 1992) and the
Short-Form 36-item (SF-36) questionnaire
(Brazier et al, 1992). These questionnaires
have established validity and reliability
and are used to obtain factual informa-
tion on a wide variety of diseases, yet can
be insensitive to the changes resulting
from an alteration in the disease state,
making interpretation difficult.

**Utility Measures**

The European Quality of Life Instrument
(Euro QoL Group, 1990) and the Quality
of Well-Being Scale (Kaplan and
Anderson, 1987) are utility measures
which are a useful device for purchasers
of healthcare as they can provide a cost
comparison of the same intervention with
different diseases. Most recently Waiters
(2001) used the EQ5D version of the
EuroQoL instrument in her millennium
survey. However, utility measures are
limited in their range of sensitivity and
inadequate for providing suitable
measures to reflect disease progression.

**Disease Specific Measures**

Disease specific measures lend them-
selves more readily to longitudinal studies,
which can reflect the changing pattern of
the disease and evaluation of treatment.
The Chronic Respiratory Questionnaire
(Guyatt et al, 1987), the St George’s
Respiratory Questionnaire (Jones et al,
1992) and the Asthma Quality of Life
Questionnaire (Juniper et al, 1992) have
been validated in other respiratory disease
groups but they have not been validated
for use in cystic fibrosis. However
Quittner et al (2000) have produced a
validated questionnaire specific to cystic
fibrosis for use in the United States of
America based on the work of Henry et al

The first disease specific tool designated
for people with cystic fibrosis and
validated for use in the United Kingdom
was published by Gee et al (2000) who
produced a cystic fibrosis health related
quality of life questionnaire. Its development was patient led; perceived areas of concern to adults and adolescents with cystic fibrosis were identified by the patients themselves, and contributed to the development of this questionnaire as an effective measurement tool.

By combining both the natural and social sciences a more detailed understanding of the objective disease process and the implications it has on the 'reality' of the disease will enable a more structured approach to cystic fibrosis to be developed and consequently point the way to a better future. Knowing why people do not adhere to treatment may lead to greater accuracy in predicting which patients are likely to waver. This will enable an education programme to be individually tailored to improve adherence to physiotherapy and promote a better quality of life.

**Patient Education**

The ideal for health education involves two-way communication and it is crucial for physiotherapists to be aware of and understand patients' health beliefs, their locus of control, and their perception of cystic fibrosis. Only then can programmes be made appropriate and relevant to the patients' perceived needs.

Moreau (2002) highlighted the importance of a patient's health beliefs when he stated that they 'determine his response to illness or the threat of illness. His health beliefs tend to enhance his willingness to learn.'

Moreau (2002) also defined the patient's locus of control as 'a patient's perception of his ability to bring about change'.

The *Core Standards of Physiotherapy Practice* (CSP, 2000) look for a greater perception by physiotherapists of patients' needs, by acknowledging factors such as culture, lifestyle and preferences, when defining the most appropriate plan of care (Mead, 2000). To this end, physiotherapists and patients need to collaborate in planning a treatment programme (Carr *et al.*, 1996).

Education is an increasingly significant feature in the treatment and management of long-term diseases. Deccléache (1995) stated that: 'For many years, patient education has been limited to considering only compliance and coping factors related to the patient him or herself, and features of the disease and treatment. Knowledge of disease or treatment, ability to cope, self-efficacy, health locus of control, and degree of acceptance of illness, are some of the many factors that have been taken into account in designing and carrying out patient education work.'

However, for some patients the usual methods of patient education, ie books, videos or the internet, may be inadequate as denial is a significant feature of their coping strategies. To ignore the disease and recommended treatments enables them to get on with their lives until they can no longer do so. For these patients establishment of realistic health beliefs is essential if their adherence to treatment is to change.

Health education has been defined by Ewles and Simnett (1995) as planned opportunities for people to learn about health and to undertake voluntary changes in their behaviour, while health promotion has been defined by the World Health Organisation as 'the process of enabling people to increase control over, and to improve their health' (WHO, 1984). Physiotherapists require an understanding of adult learning theory in order to develop educational strategies to improve adherence.

**Adult Learning and Andragogy**

The concepts of adult education were initially recognised and developed by John Dewey. His work *Experience and Education* (1938) was a major exponent of progressive education. Dewey identified teachers' leadership responsibilities as being in a partnership with learners.

Since the 1970s adult education has been a source of increasing interest as educationists and psychologists have complemented each other's work. Educationists such as Malcolm Knowles, Robert Gagne, Paulo Freire and Jack Mezirow began to develop educational theories, while the humanistic psychologist Carl Rogers emphasised the self-actualisation of adult learners (Jarvis, 1995). Learning theorists had previously focused their research on childhood and adolescence. The development of adult education was influenced by humanistic perspectives. Malcolm Knowles (1989) was one of the earliest humanistic educationists to distinguish adult learners from child-centred educational perspectives. To
identify the concept he coined the term 'andragogy', a derivative of the Greek 'aner' meaning man, and it was first used in an education context in the mid-19th century in Europe. Although Knowles' theories have been under considerable discussion, credit has to be given for recognising the separate identity of adult learning and teaching. Knowles placed significant emphasis on the 'self' and further recognition has been given to this in healthcare in the 1990s by recognising the concept of patient 'empowerment' and having patient-directed health education programmes.

This humanistic approach to education recognises the empowerment of the adult as a feature of the learner. The learner-teacher is more of a partnership. This is a different approach from the pedagogical perspective, where health professionals take an authoritarian approach and the learners a correspondingly more passive role.

Jarvis (1995) described adult instructors as 'andragogical teachers' who had become the managers and designers of the learning process and the learning contract. Freire focused on the relationship between learners and teachers and drew attention to the role of teachers as facilitators who can stimulate the learning process, rather than imposing the correct 'knowledge' and values that have to be acquired. Placing value on the 'humanity' of the teacher/learner relationship reflects the emphasis given to the patient/professional relationship in the medical context (Mead, 2000).

This approach shows an increasing emphasis on individuals and how their experience of a process will influence their learning. It is from these perspectives that educational strategies for cystic fibrosis patients can be developed in order to improve adherence to physiotherapy with recognition given to the distressing nature of the disease and the impact it would have on a learning process.

Discussion

Adherence will be compromised if clinical improvement is not detectable by the patients or they are not convinced that deterioration is a result of neglecting treatment.

Treatment and management programmes have been dominated by professionals. If they are not established in partnership with patients, then adherence may well be compromised. If they are to adhere to treatment it is important to establish the patients' health beliefs in order to plan patient-centred treatment programmes. Additionally, provided patients are making informed decisions and not coping by means of a denial strategy, if they decline treatment their wishes must be respected. Patients need to take responsibility for their own healthcare.

Educational strategies must be designed to empower patients to take more control. Patient empowerment will help them to influence the course of their disease, their treatment programme and consequently the impact the disease has on their quality of life. Supported independence, encouraged through educational strategies based on the humanistic principles of the teacher/pupil being an equal partnership, needs to be developed.

Quality of life is a very complex parameter to measure objectively. It will vary over time. There may not be a direct link between adherence to physiotherapy and improved quality of life until therapeutic levels of treatment are established. The multi-factorial aspects of the disease, the large numbers of variables involved and the difficulty in designing measurement tools provide researchers with challenge.

Physiotherapists are actively involved in teaching patients, yet little attention has been paid in the profession to andragogy. A greater awareness of patient education needs to be encouraged as part of increasing professionalisation and to ensure high standards of clinical practice.

Conclusion

Cystic fibrosis is at a challenging stage in both treatment of the disease and the professional development of physiotherapists. In this complex multi-system disease considerable medical advances have resulted in an improved quality and length of life. The disease provides an excellent example of both natural and social sciences playing a significant part in treatment and management. With increasing longevity, greater acknowledgement is given to the 'humanity' of cystic fibrosis and the impact treatments have on the patients' quality of life. As
physiotherapists have a greater understanding of the health beliefs and 'social reality' of cystic fibrosis, a deeper insight from the patients' perspective can be gained. This information can be used in planning patient-centred treatment programmes where patients and professionals function in an equal partnership. As patients are empowered to take responsibility for their treatment the potential exists to improve adherence to treatment as a step towards mitigating the symptoms of cystic fibrosis and consequently improving their quality of life. The development of educational strategies may well contribute to and be adapted for other chronic respiratory diseases.

Physiotherapists need to undertake longitudinal studies on individually tailored evidence-based treatments, accommodating patients' health beliefs in order to improve adherence to physiotherapy and potentially their quality of life.

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Key Messages

- Developing professionalisation can be achieved by greater emphasis on patient centred values and less on professionally driven agenda.

- Physiotherapists need to establish evidence-based therapeutic levels of treatment which will bring about a discernible clinical improvement or prevent deterioration.

- Patients’ health beliefs need to be identified in order to improve adherence to physiotherapy.

- A greater awareness of andragogy needs to be encouraged in order to develop effective patient education programmes.

- Longitudinal studies need to be conducted using valid and reliable measurement tools, in order to identify the variable pattern of adherence to treatment and the impact this has on patients’ quality of life.


