

## Book review

### Psychosocial aspects of cystic fibrosis

Myra Bluebond-Langner, Bryan Lask and Denise B. Angst (Eds.), *Psychosocial Aspects of Cystic Fibrosis*. London: Arnold, 2001. 482 pp. L 75.00 (HB). ISBN 0 340 75891 0.

This book provides a comprehensive up-to-date summary of the psychosocial impact of cystic fibrosis (CF) on persons with CF, their families and caregivers. In the light of their social context and their specific health care systems 47 authors from North America, Europe and Israel introduce clinicians to the challenges of a life with CF. The authors represent all major health professions involved in the CF management, hence the variety of views and approaches with respect to the complexities of burden and care is manifold.

Following an introduction on cause, course and treatment of CF, which usefully creates the contexts for the following chapters, the book is organised into five parts (30 individual chapters) covering eye witness accounts, growth and developmental issues, the wider network, therapeutic approaches, and contemporary issues in research and treatment.

In the first part it is the patients themselves, a mother, a father, a partner, and a sibling who are given space to speak 'in their own voice'. The readers may share with the persons most affected a wide spectrum of personal experiences, hopes and fears. Obviously, anecdotal reports reflect only one man's opinion, but many of the statements may prove true across people and countries. The reports cover a time span of 30 years and therefore, reflect changes and developments to which a contribution by the professional caregivers adds perfectly. A short retrospective reminds of the early years as a time of despair, followed by many advances that led to increasing hope which turned into cautious optimism over the last 15 years. Although beginners in the field of CF will benefit most from these chapters, they also have much to offer to caregivers who are not part of a multidisciplinary team or whose professional work is restricted to only a segment of CF care.

The following part begins with the initial communication of the diagnosis of CF. The author not only describes what happens psychologically but also gives practical advice about how to break bad news. The fol-

lowing contributions deal with growth issues across the major developmental stages. The challenges and task of each stage along with suggestions for interventions are presented. These include the quality of infant–adults relationships in infancy, the impact of dependency caused by CF on the process of separation and individuation in pre-school children, the experience of difference and the development of social competence in school-age children, and the impact of physical and emotional changes during adolescence on coping and adherence. The last chapters deal with transition to adult care and specific adult issues such as partnership and reproduction.

Part 3 looks at the wider network, in particular at siblings, family relationships, and the CF team. One contribution moves specifically into the area of the well siblings describing their changing perception of CF as the disease progresses and the characteristics of their relationships with the parents and the ill siblings. Another contribution tries to overcome the so far often atheoretical research on family functioning, by explaining various models that offer new insights into the complexity of family relationships in CF. Like families, CF teams vary in their structure and resources, they represent unique entities and their members have to learn to define their roles and functions. In addition, team-specific tasks and challenges such as patient–clinician boundaries and burnout are being addressed in this chapter, together with many suggestions for enhancing competent collaboration and optimal team functioning.

Part 4 illustrates therapeutic work in more detail and describes several different approaches such as family therapy, group work, psychodynamic psychotherapy and behaviour therapy, the latter also with application to feeding and eating problems. In contrast to such approaches that are based on mutual agreement and voluntary uptake two chapters focus on concepts that are applicable to most patients and may be woven into the treatment, namely self-care and health education. Another chapter deals with adherence with an emphasis on the need to view treatment-related behaviour from the perspectives of the patients and their families and on the creation of a therapeutic alliance. Working with individuals with CF inevitably includes death and dying and

issues around the terminal phase such as hope and choices are being addressed in the last chapter of part 4.

The final part presents major contemporary issues. With regard to genetic testing and counselling, the authors tackle the challenges caused by population screening and carrier testing including the concerns that the knowledge about specific mutations in terms of predictability of the course of the disorder may bring with it. An overview of new therapies looks at the growing spectrum of choices and discusses the pitfalls and promises of gene therapy. Transplantation, one of the new therapies for end-stage lung disease, is described in a separate chapter. The authors explore the phases from assessment to follow-up care, and clearly differentiate between issues specific to adults and to children. The concluding chapter considers ethical issues covering a wide range of complex items. The authors' comment that in case of conflict or unresolvable disagreements 'there is no widely acceptable single method of moral decision-

making' may well relieve health professionals who fight the daily battle of following guidelines and individualising treatment.

In summary, this is a book containing much wisdom and experience and undoubtedly deserves to become a well-loved standard. Each chapter is up-to-date, information-packed and easy to digest. Two aspects of this book deserve particular mention. Firstly, most chapters not only describe the impact of CF, but also many forms of interventions to be used preventively or therapeutically and secondly, many case reports are given. The book is easy to read and rich in ideas; as such it is recommended to all health professionals who dedicate part of their lives to a better understanding and treatment of individuals with CF or other chronic diseases.

I. Götz

*University Children's Hospital,  
Währinger Gürtel 18-20, A-1090 Vienna, Austria*

Psychosocial stress and coping in families with cystic fibrosis (CF) are described. The illness does not lead to specific psychopathological disturbances, but with additional intra- or extra-familial stress, patients and family members are more vulnerable to psychoreactive disorders. Interdisciplinary and family oriented bio-psycho-social care is required. The role of the child psychiatrist is discussed. Download full-text PDF. Source. Cystic Fibrosis (CF) – As CF is a non-curable disease, it leads to so many psychosocial problems on patients and their families – These children are at greater risk of having significant emotional or behavioural problems. Life expectancy in CF – The life expectancy of children born with CF has been steadily increasing over the past two decades as a result of major advances in diagnosis and treatment – The median life expectancy is now 33,4 years – Within this context, quality of life is increasingly recognised as an important therapeutic consideration and variable to measure.