

Guiding principles on how to manage relevant psychological aspects within a CF team: Interdisciplinary approaches

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Abstract

Managing CF can be emotionally and physically challenging for patients and their relatives. The disease and its treatment influence the ability to tackle normal tasks of daily living and unexpected life events. The context within which psychologists work varies according to different cultural backgrounds and their professional and theoretical memberships. The benchmarks presented here focus on four crucial issues: (i) identifying a common base of tools and theoretical reflections through suggested readings, (ii) interdisciplinary work within a CF team and its importance for both persons with CF and other healthcare professionals, (iii) the benefits of an eclectic approach utilising cognitive-behavioural theories for specific psychological problems and, (iv) effective and evaluated transition programmes from paediatric to adult healthcare services.

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1. Premises and introduction

Cystic fibrosis (CF) care has advanced significantly during the last decade. Managing CF can be emotionally and physically challenging for patients and their relatives. The disease and its treatment influence the ability to tackle normal tasks of daily living and unexpected life events. There have been dramatic increases in median survival rates, with CF now

thought of as a life-limiting disease of adulthood. However, this has been achieved by a corresponding increase in the treatment regimen, which patients continue to find time-consuming and demanding. Over time, CF leads to respiratory failure which often results in long periods of ill-health and reduced quality of life before death.

This document comprises the work of the European Commission (EC)-funded Coordination Action EuroCareCF (WorkPackage 1 – Optimizing Patient Care and Team Work). EuroCareCF afforded a unique opportunity for the representative group of psychologists to focus on some of the needs of newly established European CF Centres. This document is intended to be a guide for psychologists and other psychosocial professionals and team members, particularly those who are new to interdisciplinary CF teamwork. Our aim is to share clinical experience accumulated over three decades with the

Abbreviations: CF, cystic fibrosis; EC, European Commission; ECFS, European Cystic Fibrosis Society; EuroCareCF, European Coordination Action for Research in Cystic Fibrosis.

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intention of achieving the EC challenge to CF teams, which establishes that European citizens with CF are entitled to have access to the same level of care and to be cared for with an interdisciplinary approach. The authors, all experienced practitioners in the field, hope that this contribution builds on the essential roles and responsibilities established in the ECFS Standards of Care Document [1] and stimulates debate on the production of further, topic-specific, psychological guidelines.

While the context within which psychologists work varies according to different cultural backgrounds and their professional and theoretical memberships, they always work with people who have CF and their families, who often face very difficult life-challenges, including death. Delivery of care systems are complex, with multi-layered and interconnected causes and effects. Circularity (A and B co-vary) instead of linearity (A impacts on B), is important to remember in teamwork and in interactions between team members and families. Feedback, user-involvement and evaluation are vital internal control mechanisms that help determine the usefulness of psychological interventions based on outcomes. “The deeper truth that we still think only in terms of relationships” [2] should not be neglected.

Psychologists must be prepared to work with a variety of psychological problems that interfere with management of CF. Moreover, working in medical settings, psychologists should establish a working platform in the CF team. Traditional medical teams are often not familiar with integrated access to psychology services and people with CF do not always understand that a CF psychologist aims to help improve their well-being and health outcomes just as any other CF team member, often because stereotypes. The benchmarks presented here focus on four crucial issues. The first identifies a common base of tools and theoretical reflections through suggested readings. The second focuses on interdisciplinary work within CF teams and its importance for both people with CF and other healthcare professionals using the Innsbruck Model as an example. While there is shared ability within the team to deal with psychosocial aspects of people with CF and their family’s lives, it is vital to integrate detailed psychological knowledge in the team and supervise psychological aspects of the work of others. The third highlights the benefits of adopting an eclectic approach while at the same time, utilising cognitive-behavioural techniques with proven efficacy for specific psychological problems in CF. There are also some important reflections and practical suggestions for the “day-to-day job”. The fourth and final focus is on effective and evaluated transition programmes from paediatric to adult healthcare services. This is also a message of hope for colleagues working in countries where the mean survival age for persons affected with CF is below 20 years [3].

To set the context, *three essential aspects to the psychologists role are set out in Boxes 1–3.*

2. Suggested reading and support material

It has been argued that psychosocial skills and the delivery of psychosocial care are not exclusive to specifically trained

Box 1

Pre-requisites for a psychologist to work in a CF team include: registration with national governing body, thorough understanding of individual psychological development of family relationships and developmental stages of CF to work more efficiently within the team. S/he should also have thorough understanding of the interdisciplinary approach to care delivered by an integrated team and in such a framework provide support to other CF team members.

Box 2

The essential responsibilities of a psychologist working in a CF team are:

- (i) evaluating the psychological effects of living with CF within the team,
- (ii) undertaking comprehensive assessment and intervention when emotional, behavioural and psychological difficulties arise,
- (iii) integrated post-diagnosis and annual reviews (comprising of assessment, screening and support), either face-to-face (which is preferable), and/or utilising psychometrically sound measures,
- (iv) assessing the patient’s and family’s psychological resources,
- (v) providing support and where necessary, appropriate psychological intervention before, and after, lung transplantation, and
- (vi) actively participating in transition programmes (to high school and adult services) if these programmes exist or try to establish them if they do not.

Box 3

It is desirable that a psychologist working in a CF team, in conjunction with other professionals and where appropriate, takes the lead role in applying evidence-based approaches to managing procedural distress, feeding behaviour problems, and adherence challenges as well as in addressing psychological factors associated with chronic pain and the effects of segregation and poor adherence.

staff [4]. Therefore, the following suggestions refer to reading that is particularly suited to improving the psychosocial competence of medical staff and to enhancing the patient-centeredness of care. Such reading is referred to below as “generic issues”, whereas reading listed under “special issues” applies more specifically to psychosocial experts/allied health professionals.

2.1. Generic issues

2.1.1. Breaking bad news

Buckman [5]: This is the basic book on breaking bad news, comprising lots of practical advice and very good examples on how the wording of your messages makes a difference. At

the heart of this book is the so called “six step protocol” to provide difficult conversation with a solid structure.

Bush [6]: This chapter of the psychosocial aspects of cystic fibrosis textbook edited by Bluebond-Langner, Lask and Angst [7] is the most comprehensive one specifically dedicated to CF, and unlike Buckman [5], it explicitly makes clear that breaking bad news in CF usually means talking to parents.

Clayton et al. [8]: The clinical practice guidelines by an Australian and New Zealand expert panel refer to communicating prognosis and end-of-life issues with terminally ill adults. This paper contains very clear examples on how to convey difficult messages. The authors also provide a useful acronym (“PREPARED”), as a reminder of the agenda of your discussion. Unlike the book of Buckman [5] this paper also includes an evidence based medicine perspective.

Russell and Russell [9]: This paper, referring to end-stage chronic obstructive pulmonary disease (COPD) patients, perfectly complements the above-mentioned approach and discusses problems of end-of-life care (including the concept of “social death”) in COPD patients. This paper is relevant for the care of CF patients.

2.1.2. Health education and counselling (including decision-making)

Rollnick et al. [10]: This book expands the approach of motivational interviewing (MI), originating from treatment of drug addicts, to the medical setting and to the challenge of life-style changes in particular. It is complete with practical advice and clear examples about how to word messages, as well as how to structure difficult encounters.

Lask [11]: This paper is particularly helpful in de-escalating conflicts in the patient–provider encounter. It enhances a non-judgemental, cooperative approach to the patient.

2.1.3. Family centred care

Patterson et al. [12]: This is a longitudinal study, describing the health impact of family dynamics on CF patients. It deserves more attention and may serve as a good reference to consolidate a family-centred approach.

McDaniel et al. [13]: This book does not specifically address CF issues, but it contains a very clear frame of reference about how to support families with a chronically ill child. It is particularly helpful with respect to concentrating on the family’s resources, and it describes an approach that is appropriate for families whose issues are primarily non-psychiatric. [14].

2.2. Specific issues

Suggested readings on the following issues are particularly useful if psychosocial health professionals are part of or contribute to the CF team. The most important suggested reading is the Textbook edited by Bluebond-Langner, Lask and Angst [7]. It is the first of its kind and covers an extensive range of important topics, including those of significance

to the delivery of care (see chapters on adherence, the CF team, lung transplantation, psychotherapeutic interventions, and problems of nutrition and growth).

2.2.1. Adherence

Meichenbaum and Turk [15]: This book is a milestone comprising highly important thoughts and concepts regarding the comprehension of problems with adherence/compliance as well as practical suggestions on how to manage treatment recommendations more effectively.

Pendleton and David [16]: This paper refers to the contemporary concept of shared decision-making and concordance [17], but specifically addresses the case of CF. In conjunction with the paper of Lask [11], it is a useful frame of reference to design patient education from a contemporary point of view. Important additional references are two recent studies both on barriers to adherence, one focussing on children and families [18] and the other on adolescents and adults [19]. Both are helpful in avoiding a misleading patient-focussed perception of adherence-related problems, the importance of which is stressed in a remarkable WHO report on adherence to long-term therapies [20].

2.2.2. Lung transplantation

Parsons et al. [21]: This paper is one of the most important practical contributions to the literature on (paediatric) lung transplantation. It describes a family-centred, directive approach that is characterised by discussing with a family the possibility of a child’s early death. Some readers will not fully agree with this approach, but the paper is valuable as it highlights the many pitfalls and problems encountered in the delivery of care to families in desperate situations.

2.2.3. Team functioning

Bush [22]: This paper is one of very few contributions to problems of multiprofessional, comprehensive care. It is the rare example of a paper written from the physician’s perspective. By contrast, most of the literature on collaborative work/“consultation-liaison psychiatry” originates from the psychologists’ or psychiatrists’ point of view.

3. Interdisciplinary team approaches

“Teams work better when they work together [23]”

Multidisciplinary work involves each discipline contributing independently to patient care, with team members working in parallel. In an *interdisciplinary* team, members work together closely and communicate frequently to optimize care for the patient, sharing a common philosophy. Each member of the team contributes his/her knowledge and skills to augment and support the contributions of the others, with each individual assessment taking the others’ contributions into account (holistic care).

3.1. The Innsbruck model

In its original form, the Team consisted of the professions representing the pillars of CF care: doctors, physiotherapists specialized in chest physiotherapy and dieticians. From the beginning the psychologist/psychotherapist was integrated in the team as a full member, attending all team meetings. Social workers and nurses were associated, but not regular members. Significant improvements in care and life expectancy altered the Team's philosophy to helping patients become more proactive in their treatment. The Team has become responsible for education, evaluation and prevention of clinical deterioration.

Today, the various professionals in the Team remain the same, but have increased in number. There are currently: three doctors (the centre director, one consultant and one resident), four physiotherapists, two dieticians and one psychologist, supported by interns. Nurses who have specialised in CF care, receive continuous education in this field, but so far, are not fully integrated to the core team (the same for social workers). Staff have remained constant over the years, with little turn-over. Patient-numbers have increased with around 145 patients (children and adults) cared for by the CF Centre. The Team is organised as a multidisciplinary care group, with:

- Daily pre-clinical meetings for discussion of in-patient therapies
- Weekly interdisciplinary meetings and in-patient ward meetings (attended by all staff who are involved in patient care); written records are mandatory
- Quarterly in-house education and research meetings
- Annual therapy planning sessions.

3.2. Underlying team philosophy

Comprehensive, holistic care should address five core aspects: (i) patient-centred (i.e. patient and relatives integrated in the care are encouraged to speak about their expectations, feelings and fears), (ii) family-oriented, (iii) information-giving and educational about the disease, (iv) utilising mutual support, and patient and carer organisations and, (v) organised to achieve the sustainable development of treatment.

CF patients and their parents cannot be viewed as a "psychiatric population" and do not view themselves as such either. Consequently, psychological interventions may be resisted because patients commonly put much effort into trying to live life as normally as possible, which is a major coping effort to neutralize illness-related threat. Therefore, independent of a patient's wish for direct psychological support, it is important to have the psychologist as a regular team member. S/he can offer easy access to psychological knowledge and skills for other team members. As such, the psychologist plays a vital role in the treatment process and its development. Psychological knowledge has already been integrated into patient segregation, infection control policies in inpatient and outpatient care and the setting up of treatment procedures including newborn screening, diagnosis, educating patients to become independent and self-

responsible, management before and after lung transplantation and palliative care.

3.3. Standards in psychological intervention

Disclosure of diagnosis: This critical talk is the basis for establishing a long-term therapeutic relationship. We have developed a special protocol based on literature [5] for conducting such an interview with special emphasis on CF care focussing on the philosophy of prevention and coping.

A second talk takes place two months later, with other talks offered at monthly visits. An extensive discussion with the parents is conducted one year after diagnosis to maintain contact, reflect on their attitude towards and experience of CF and to check how they cope and determine whether support is needed.

An extensive discussion with the doctor and the psychologist is offered to adult CF patients to discuss illness perception (fears or denial), questions dealing with future planning, sexual encounters, contraception and fertility issues, relationships etc. The patient is invited to bring their partner for an extensive talk with the doctor and the psychologist. In our experience, this is a welcome opportunity for the couple to openly discuss questions related to the illness in a confidential setting.

In 2000 we decided to establish a yearly routine assessment according to a standardized time schedule including;

- Disease Specific Quality of Life Questionnaire (CFQ-R) [24]
- CF Problem Check list (CFPC) [25]
- Life Event Scale from Karolinska Quality of Life Questionnaire (LES) [26] (since February 2008 by touch screen)

Since 2006, patients complete a patient satisfaction questionnaire according to ISO 9001:2008 as part of routine outpatient visits. Psychometric results are reviewed by the psychologist and included in subsequent doctor-patient consultations [27].

Parents and patients can also address the psychologist personally to gain quick and easy access to any psychological or psychiatric support:

- Individual talks as well as family talks with a CF-doctor dealing with disease-specific questions and occurrences,
- Crisis intervention and supportive talks to cope with illness progression or frightening occurrences (e.g. hemoptysis),
- Diagnosis and consultation with illness-unrelated psychological problems. For long-term treatment patients and parents are referred to private practice or professional counsellors.

3.4. Key components of a well-functioning team

Initially, the interdisciplinary team approach was used to acknowledge the psychosocial dimensions of patient care and team interaction using a holistic care approach. Apart from the wish to offer the best care for patients, the respectful cooperation of team members must be guaranteed.

A good team must meet the patient's needs with a high degree of respect. The illness itself, delivery of care and

quality of life must be a focus – the patient satisfaction questionnaire represents one core process in our quality management process. Once a year the whole team reviews the medical therapy plan and sets goals based on essential parameters of the individual patient considering (i) adherence, (ii) psychosocial situation and (iii) patient reported outcome data. These suggestions are communicated to patients and adapted to their needs and preferences to establish a common goal. The agreements upon the goal and the plan are then entered in the CF database.

All team members are familiar with the professional capabilities of other team members and should be willing to acknowledge greater expertise and, in some instances, defer to other team members.

Confidence, esteem and trust in other team members are highly essential to avoid duplication. Successful teams are aware of the expectations of the team itself and have a “culture of rites”; commitment, punctuality and politeness. Mutual congress attendance increases team knowledge and fosters team cohesion and the same is true for celebrating personal events. Every team will experience instances of conflict, where psychological intervention or team counselling can be of great benefit.

A shared database offers confidential access to all team members to update them on current patient status and provide an overview of patient’s actual point of view.

The team approach must be dynamic and open for evaluation and revision continuously. Digitized databases offer the possibility of immediate reaction in case of deterioration of an individual patient. On the basis of long-term medical data every patient is reviewed and treatment is adapted accordingly.

3.5. Conclusion

Patients seek continuity and coordination of care and it is only via a well-coordinated CF team that these needs will be met. Each new team member must be co-operative and willing to adhere to the Team norms and culture, otherwise the advantages of interdisciplinary cooperation may be lost.

4. Psychological models in day-to-day practice

Psychological models can be applied by a psychologist working in a CF centre. The most well known theoretical models are the health belief model, health locus of control model, self-efficacy model, coping model or the stages of change model (including motivational interviewing). Behavioural or cognitive interventions can be established in line with these theoretical models. In clinical practice, an eclectic approach is often developed, adjusted to the problem or question at hand.

Most CF centres will care for patients of different ages (children, adolescents and adult patients (and their families) and stages of illness. Therefore the above models should be used within the context of the patients’ condition:

1. *patients’ developmental stage*: baby, toddler, pre-school child, school child, adolescent, young adult, adult

2. *the illness stage*: diagnostic stage, mild–medium or severe illness stage, transplant stage
3. *cognitive abilities and understanding/concept of illness*.

For example, the process parents go through in coping with their baby being diagnosed with CF shows stages of *grief* for the lost their healthy child, *learning* about the illness and treatment, *individual coping*, social interaction between spouses, siblings and the extended family etc. The theory of *health locus of control* may be applied here because parents can learn how to gradually regain control over the care of their baby, even though they may initially feel overwhelmed in their loss of control as doctors and nurses take over. The cognitive abilities of the parents and their understanding of the illness and treatment should be taken into account in guiding parents through the process of regaining control. Most importantly, parents (and siblings), need time to adjust and cope with their new situation.

Another example is the stage of adolescence. Teenagers identify with their peers and often want to be like their peers. However, CF and the intensive treatment required often prevent a teenager from doing so and it is not uncommon for a teenager to decide to give up on treatment (i.e. “s/he does not want to be different”). Here, the health belief model can be used to explore the underlying beliefs (beliefs and barriers) for non-adherent behaviour.

At the other end of the spectrum, namely pre-transplantation, the focus of counselling may be on goal seeking and finding ways to cope in an often seemingly hopeless situation. Most pre-transplant patients completely lose control over their lives because of pain, fatigue, shortness of breath, helplessness, physical inability to care for themselves, anxiety, fear of death, etc. They can do their treatments, but often only with extreme difficulty. They have to cocoon (protect), withdraw and isolate themselves, because their future perspective is uncertain and grim.

Counselling pre-transplantation patients is complex and requires flexibility and insight into the developmental, emotional and cognitive processes patients may experience. Adolescent patients go through the transplantation experience very differently from adults. For example, an adolescent will go through a life phase of identity seeking and some degree of rebellion towards parents or authorities. An adult will most probably have settled into a daily routine, often has finished education, sometimes is in a professional job with a partner and/or children, etc. The theoretical construct of self-efficacy may be used in counselling pre-transplant patients. Patients will understand that “believing they can do it” is important to continuing and most will describe that they will “pretend to believe they can do it”. Denial and humour at this stage are vital, as patients often feel they have to “pretend” their situation is not as bad as it is in order to cope and survive. Counselling will focus on helping a patient realize what is happening, but also provides tools to get through the day “pretending” it is not too bad. Empowering, psycho-education, seeking ways of maintaining some control is all part of the counselling process. In addition, defining goals for the future is imperative: “why is the patient going through the waiting period, the operation,

the recovery stage etc?'. Defining goals for use during future counselling sessions is helpful for both the patient and the counsellor. On the other hand, the counsellor will also need to create openings for a patient to talk about fears and anxieties, the pressure patients experience from family, their wishes and worries about what will happen when they die etc. Some patients will not want to talk about this with their family, but have a great need to talk about this with a counsellor. At times, it seems that patients can best cope when there is an opportunity to talk about fears, hopes, motivations, goals, wishes as well as pretending it is not all that bad.

Whatever the question or problem at hand, the counsellor needs to be flexible and attentive for patients' (and families) needs and abilities. S/he may use theoretical models, but should make sure that the theory is adapted to clinical practice without being rigid.

5. A strategy for transition

Transition from paediatric to adult healthcare services for people with CF is a process of events rather than a one-off event. The paediatric team will have spent many years in a relationship with the child with CF and their family, observing development and life stages from birth to young adulthood. The long-term multidisciplinary relationships formed in paediatric services mean that a precedent is set for the type of care expected in adult services and planning for this handover of care requires preparation and adaptation from all involved. It is acknowledged that certain countries lack the necessary resources to practice a planned transition policy; perhaps there are no adult services available or the paediatric centre cannot give time to patients deemed to be of adult age. However, there are examples of good practice which may be helpful to services wishing to improve current practice. The following is a description of the strategies and practise implemented in a Transition Programme at a paediatric CF centre.

5.1. Strategies for the introduction of transition

The expectation of eventual transition to an adult CF service should be raised at an early stage with parents and the child as they get older. Positive discussions about an active adult life with CF should be frequent including the acceptance of starting a new relationship with an adult healthcare team who will support management of CF in adulthood. These ideas can be formalised in terms of:

- Psycho-education programmes
- Transition alert letters – as prompts in the teenage years
- Support groups – parents of the teenage child with CF
- Video, leaflets, books
- Information about the adult healthcare system

5.2. Strategies for transition collaboration between paediatric and adult services

Paediatric and adult services should get to know each other, the format of service delivery, expectations of patients,

and multidisciplinary team membership so that accurate information can be given to patients and families in making decisions about when to transfer care. This can be done by:

- Introductory meetings at both paediatric and adult centres
- Establishment of joint transition clinics where potential patients can be seen
- Discussion between teams about patient needs
- Development of a transition checklist between centres to ensure consistency

5.3. Role of the paediatric team

- Not to show bias (e.g. lack of confidence in the medical skills of the adult physician; parental anxiety, over-protection and fear that their child will receive inadequate care; adolescents themselves' fear that adult services take them one step closer to death)
- Respect the right of the teenager to choose – when and where
- Provide family support
- Service must accommodate biological, social and psychological growth
- Information and education about the differences in adult and paediatric approaches

5.4. Emotional preparation

In order for a young person with CF to collaborate fully in the transition process, they have to assume a degree of responsibility for their health and treatment management. This requires preparation of the young people themselves and also support for the parents to transfer their skills and authority for treatment from parent to child.

- Adolescent/youth orientation and approach from the paediatric team
- Facilitation for patient to collaborate in treatment decisions
- Gradual separation from parental control
- Information and practice to negotiate an adult healthcare system

5.5. Age of transfer

This is a difficult question to answer because it involves many variables. Ages between 16 and 18 years are common, but this is something that should be decided on several emotional and social criteria:

- When patient is able to communicate effectively about their condition?
- When patient is able to look after own health?
- Health status criteria?
- When patient is able to advocate for him/herself?
- Best source of local financial and other resources?

5.6. Transition programme established at the Great Ormond Street Hospital for Sick Children in London

1. Preparation

- Preparation for patients to increase responsibility
- Shift decision-making from parent to young adult
- Facilitate skills to become an adult healthcare consumer
- Enable patients and parents to anticipate the adult service

2. Structure

- Information given about adult centres
- Transition clinics – jointly attended by paediatric and adult teams
- Informal visits to the adult centres
- Availability of adult CF team – for informal questions/queries by patient

3. Process

- The concept of transition is raised early
- A flexible approach to the age of transfer
- Contact names and numbers of the adult CF team are provided to family for personal contact and research

4. Initiation

Discussion and planning for transition with the patient and family:

- The patient/family choose the centre
- Time and date for transfer agreed
- A clinic appointment is made at the adult centre

5. Completion

- Liaison between the paediatric and adult centre teams
- A final paediatric centre appointment (to say goodbye)
- Staff liaison continues
- No further appointments or consultations with the paediatric team

5.7. Summary

Transition is a “right of passage”, which requires preparation and adjustment both before and after transfer. There should be frequent contact with adult team prior to transfer, with the paediatric team supporting the notion that the adult team are experts in adult issues associated with the effective management of CF.

6. Overall conclusions

Despite dramatic improvements in longevity, living with CF continues to be stressful, particularly when there is decreased lung function, chronic bacterial colonisation of the lungs and reduced quality of life. While there is much hope for the development of new medications and drug delivery devices, more treatments increase the challenge of managing the disease for patients and their families. As such, it remains essential that good psychological care, both preventative and reactive, is integrated into CF teams. There is now a

substantial body of literature that guides psychologists who are new to CF teams on what are considered the essential elements of the role and where time allows, those that are highly valued and useful. This document builds on the core psychosocial framework established in 2005 [1] and offers more detailed guidance on how key issues can be addressed and tackled.

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Conflict of interest

None declared.

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