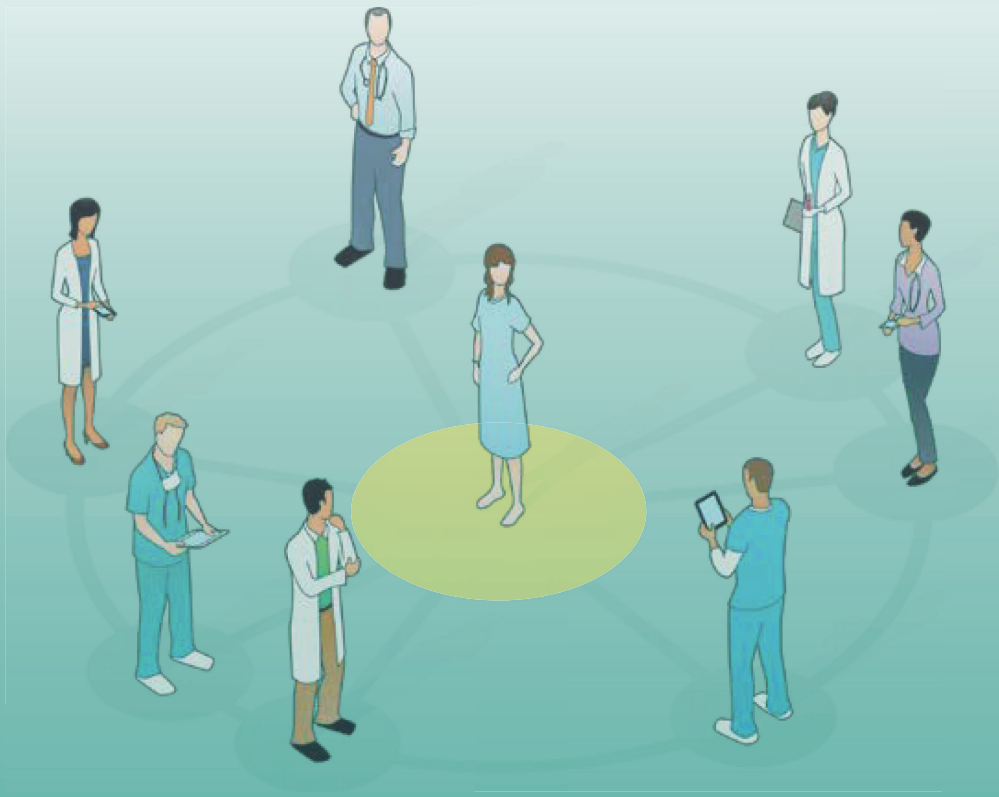
CONTENT

1 INTRODUCTION



1.1 WHY DID WE WRITE THIS BOOK?

The field of oncology and lymphology is constantly expanding in knowledge. Accordingly, evidence on the physiotherapeutic modalities used is evolving as well:

- during or after the treatment of cancer;
- in oncological rehabilitation;
- in the treatment of chronic edema and breast edema;
- in the management of surgical scars.

However, there is a gap between the evidence from scientific studies and the implementation of these new insights and evidence in clinical practice, often because of a reluctance to let go of old beliefs. Therefore, this book was written to inform the reader of the current evidence from a physiotherapeutic point of view and to provide insight into how to integrate current evidence into daily clinical practice.

1.2 WHAT WILL THIS BOOK BE ABOUT?

This textbook combines scientific evidence and clinical knowledge concerning physical therapies during or after oncological treatments, edema therapy and the therapies used to treat surgical scars. There is a clear relationship between different parts of this textbook. Many oncological treatments rely on surgery, which leaves surgical scars. Many patients suffer from fatigue, increased or decreased weight, loss of muscle mass and muscle strength and decreased physical endurance or lymphedema after the treatment of cancer. Needless to say, these complications hamper Activity of Daily Living (ADL) activities and affect a patient's quality of life.

The aim of this textbook is to provide basic knowledge concerning oncological rehabilitation, the treatment of scars and burns and the treatment of chronic edema on behalf of improving patient-centred care.

1.3 FOR WHOM DID WE WRITE THIS BOOK?

Although this textbook is written by a team of authors with a strong connection to physiotherapy from both a scientific and clinical perspective, other health-care professionals will find the information in this textbook useful. Physicians will gain more insight into the conservative approaches to treating the side effects of oncological treatment, the treatment of chronic edema including breast edema and the management of surgical scars before redoing surgery to treat a scar. The textbook will also familiarize physicians with the different treatment modalities, as well as the evidence motivating the use of these modalities. As a result, physicians will be able to refer patients and prescribe physiotherapy more accurately. The information contained in this book will be of help to patient-centred care in general.

Today's care for patients, especially for patients suffering from a chronic condition, needs to start from a patient-centred view. Therefore, the information in this textbook is highly relevant to those health-care professionals (e.g., nurses, dietician, psychologists, medical suppliers) who are involved in the care of oncological patients, patients with chronic edema and patients with surgical scars. It provides them with information about the physiotherapeutic modalities and can discuss more accurately how and when other types of interventions should be implemented in the plan of care for certain patients. Our overall aim is to improve care for these types of patients.

1.4 THE EVIDENCE-BASED APPROACH

The information in this book was written based on carefully composed clinical questions using the PICOST methodology.[1] These clinical questions were answered in line with the scientific and clinical knowledge available at the moment of the writing of this textbook. After obtaining this information, the evidence was translated into the clinical reality of daily practice.

To obtain the evidence, several systematic reviews were performed. Additional information concerning the systematic reviews can be found in the online platform Sofia. Apart from the systematic reviews that were executed by the teams of the different authors, information/evidence was appraised from other guidelines, systematic reviews and meta-analysis as well as original research; all based on the 6S approach as depicted in figure 1.1.

You can find links to the International Lymphoedema Framework and the Journals at the University of Arizona on the online learning platform Sofia.

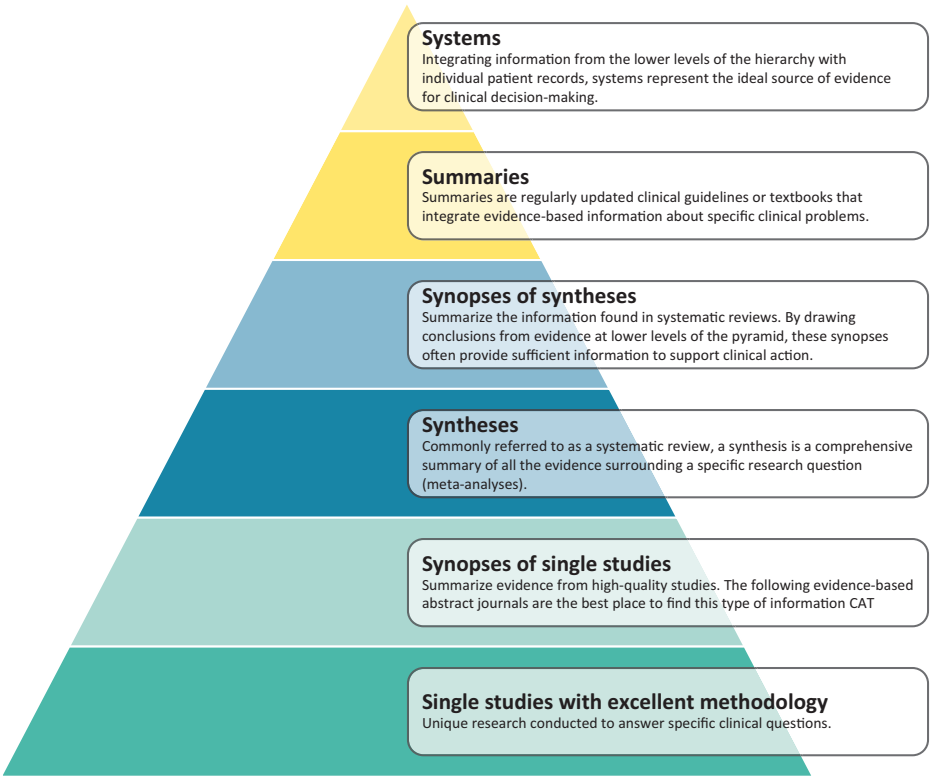


Figure 1.1 The 6S pyramid for pre-appraised evidence.[2]

The clinical questions that formed the basis for retrieving the evidence used for this textbook were:

- What are the side effects (both short-term and long-term) of an oncological treatment and how can a physical treatment provide relief for these side effects?
- What are the common aspects of an oncological rehabilitation?
- Do we need to take metabolism into account when setting up an oncological rehabilitation programme?
- What are common arm and shoulder complaints that warrant a physical treatment during or after the oncological treatment of breast cancer patients in particular?
- Can preventative action be taken to avoid chronic edema formation after oncological treatments?
- What is the physical treatment of a chronic edema from a primary and secondary aetiology?
- What is the treatment of choice for treating a chronic edema in the intensive phase and maintenance phase?
- What is the current physiotherapeutic management of breast edema?
- What is the current physiotherapeutic management of surgical scars?

1.5 THE ICF MODEL AND PATIENT-CENTRED CARE

This textbook is written from a perspective that incorporates the International Classification of Functioning, Disability and Health (ICF)[3] and patient-centred care.[4]

Fortunately, for most people, functioning in daily life is something they take for granted. They can – within limits – do what they want. Yet in our care settings or in patient populations, there are people with physical and psychological problems that are so severe that they affect daily life or even make it impossible. Pain, associated with oncologic (or other) conditions, can cause sufferers to reduce their activity level significantly. Restrictions in mobility sometimes lead to not participating in sporting activities. Environmental factors, such as poor family support, colleagues who smoke or an unsuitable workplace, can adversely affect the work situation.

The ICF model (figure 1.2) was created by the World Health Organization in May 2001 to create a common language for Functioning, Disability and Health.[3]

You can find a link to the International Classification of Functioning, Disability and Health on the online learning platform Sofia.

The advantage of the ICF model is that it looks at health as a continuum and it applies to everyone. The ICF as a biopsychosocial model addresses factors at both the individual and the social level. Additionally, the ICF model focuses on both positive and negative aspects of health.[3]

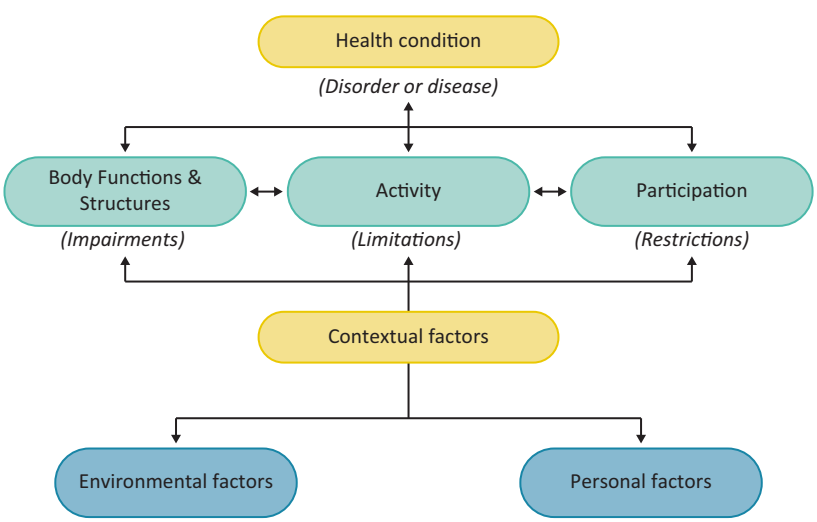


Figure 1.2 The ICF framework as described by the WHO.[3]

The ICF is a framework used around the world to describe a health condition of a patient in a broad biopsychosocial context. It applies to everyone, not just to people with functional problems. Everyone's functional health condition can be described using the ICF. It is now widely used, for instance to measure health status at the population level, in clinical and epidemiological settings to classify functional status assessment at the individual level, and to identify goal settings, treatment planning and monitoring as well as outcome measurement. The ICF describes different domains of functioning from a body, individual and societal perspective. Its core structure consists of two parts:

- functioning and disability;
- contextual factors.

1.5.1 Functioning and disability

Within functioning and disability two subcategories are recognized:

- body functions and body structures;
- activities and participation.

The **body perspective** is further divided into two components:

- The first is **body functions** and lists all physiological functions of body systems.
- The second, **body structures**, lists all anatomical parts of the body.

The individual and societal perspectives are elaborated in the component **activities** and **participation**.

1.5.2 Contextual factors

Both **environmental** and **personal factors** comprise the **contextual factors category**.

The **contextual factors** (environmental or personal factors) may affect (facilitate or inhibit) all components of functioning and disability. Environmental factors include the physical, social and attitudinal environment (e.g., profession, living environment, social support) and personal factors refer to one's attributes (e.g., age, gender, coping strategies) or internal influences on functioning.[5]

- Definition of body functions: physiological and mental (psychological) properties/functions of the human organism/body systems.
- Definition of body structures: anatomical parts of the body such as organs, limbs and their components or position, presence, shape and continuity of parts of the human body.

- Definition of activities: the execution of a task or action by an individual/components of an individual's actions.
- Definition of participation: a person's participation in society or involvement in a life situation.
- Definition of external factors: one's physical and social environment in which people live and conduct their life.
- Definition of personal factors: a person's individual background.

1.5.3 Human (dys)functioning

An individual's functioning consists of an interaction between the different components and ICF domains. There is a dynamic relationship between the ICF domains, and the interactions work in two directions, as illustrated in the figure. These components of human functioning and their problems can be represented in two ways. On the one hand, they can be used to indicate non-problematic aspects of human functioning, using the umbrella term human functioning. On the other hand, they can be used to describe disability and indicate problems, such as impairments in body function/structure, activity limitations and participation restrictions, using the umbrella term disability.

You can find a link to a practical manual on how to use the ICF on the online learning platform Sofia.

- Definition of impairments: abnormalities in or loss of functions or anatomical features.
- Definition of limitations: difficulty a person has in performing daily activities.
- Definition of participation restrictions: problems a person experiences with participating in social life.

Disability involves dysfunction at one or more of these levels: impairments in body function or structures, activity limitations and participation restrictions. Patients encountering devastating medical conditions may be confronted with long-term impairments in body structures (e.g., scars, edema) and body functioning (e.g., pain, limited mobility), activity limitations (e.g., inability to write) and participation restrictions (e.g., inability to go to school or work) during their rehabilitation. The interaction between all aspects of functioning has a dynamic character: interventions on one aspect or factor can bring about changes in other related aspects and factors. The interactions are specific and do not have a predictable one-to-one relationship. As stated earlier, the interaction

takes place in both directions; the presence of functioning problems can influence a disorder or disease. It is important in the care process to collect data on these constructs independently and then to investigate possible relationships and causal links. For a complete description of (dys)functioning, all components are important. External and personal factors also influence a person's state of health and level of functioning. They can each separately or together influence functioning problems at every level.

The positive aspects and strengths within functioning can also be highlighted. The biopsychosocial vision of the ICF may make the very complex consequences of oncologic pathologies more comprehensible. The overall goal for every health-care practitioner is to recover the patients to the pre-injury state and to strive for an optimal functioning and reintegration into society with unaltered potential.

1.6 PATIENT-CENTRED CARE

Patient or client-centred care (PCC) is defined by the Institute of Medicine as follows: "Providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions".

In their often-cited literature review, Mead and Bower describe PCC as encompassing five conceptual dimensions:[6]

- the biopsychosocial perspective, i.e. beyond the disease state and including the psychological and social domains;
- the 'patient-as-person';
- understanding an individual's particular illness experience within his or her unique life context;
- sharing power and responsibility (an equal caregiver-patient relationship);
- the therapeutic alliance (care-giver-patient), with empathy, congruence and unconditional positive regard.

If we implement patient-centred care within the caregiver process, the use of patient-reported outcome measures (PROMs) seems imperative. PROMs are the gold standard for patient-centred care to efficiently evaluate the patient's feelings, thoughts and complaints about a clinical intervention or disease. Clinicians use PROMs to guide and audit routine care and support PCC. Many questionnaires are already part of standard intake

procedures within oncologic rehabilitation. At the patient level, data can be used to monitor individual progress, investigate the effects of medical and surgical interventions and improve communication between patients and caregivers.[7] Functional outcome is often measured using PROMs. Expert consensus exists on using both generic and disease-specific Quality of Life (QoL) questionnaires to capture the full impact of a health condition.[8]

The concept of Health Related Quality of Life (HRQOL) overlaps with that of health and Quality of Life (QoL). Different definitions of these three concepts exist.[9] In this manuscript we make no explicit distinction between the different concepts and use the term QoL as an all-encompassing term to talk about HRQOL and QoL measures for the readers' convenience.

> According to the WHOQOL group (1995), QoL is defined as: "An individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment."[10]

We encourage all health-care workers to approach patients in a holistic biopsychosocial way and in a patient-centred way. These are not empty concepts but require commitment, interaction and effort from all parties involved. At regular intervals in the care process, the following questions seem important to us:

- What is my patient's wish?
- What is my patient's idea, opinion or feeling?
- How has his or her biopsychosocial functioning changed?
- How can I empower the patient as part of the (multidisciplinary) team?

Figure 1.3 Important aspects of patient-centred care.

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