

# Holistic Health Care

## What is it, and how can we achieve it?

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### Summary

This paper develops a systematic and logically consistent model of holistic healthcare. Holism refers to an approach to health which acknowledges that health depends upon many inter-related components which interact in such a way that the overall effect constitutes health (or illness). The current understanding of illness is, in contrast, linear and reductionist. It assumes that all illness starts with a disorder **within** the body causing bodily symptoms that lead on to disability and restrictions on social life. This is the biomedical model. This paper demonstrates that this model is flawed in several ways: the underlying assumptions are false, it cannot explain functional (so-called non-organic) illnesses which are common, and it does not lead to well-managed healthcare systems. The biopsychosocial approach to illness is then explored, with a detailed description of one specific model based on the model underlying the World Health Organisation's International Classification of Functioning. The model is expanded to recognise four systems centred on the person – organs, the whole person, behaviour, and social role function – and four contextual factors that influence these systems – personal factors, physical environment, social environment, and time. The new model also draws attention to two important components of any holistic model of health, choice (free-will) and quality of life. Illness is then shown to be a socially determined state whereby the patient may initiate being ill but it requires others, usually healthcare professionals to validate illness before it is fully accepted. The paper then emphasises some lessons that follow from this model, illustrating its utility. Finally there is an analysis of healthcare which emphasises that healthcare is an active problem-solving process. The implications of the holistic model of health care both for clinical care and for the management of healthcare systems are then discussed, emphasising the complex nature of healthcare and the social aspects of illness. The important overall conclusion from this paper is that health and illness should be seen as socially construed states that involve a whole person in their own context, and that effective health care requires both a full analysis of a person's illness to identify all factors relevant to its genesis and a wide range of interventions across several domains. In people with complex or long-term conditions effective management will usually require many interventions delivered by different organisations, including those outside normal healthcare, over a long time. This requires a new approach to the management of healthcare systems. This new model is one of the first explicit descriptions of an approach to holistic healthcare; it can certainly be improved.

## Introduction

Holistic health care is perceived to be good, both morally and practically but it is difficult to find either any clear enunciation of what constitutes holistic healthcare, or any clear explanation of its practical utility. This paper aims to overcome these difficulties.

This paper first considers what holism is and then considers what a holistic approach to illness might be, and how this might improve healthcare. Although the paper is concerned with a philosophical analysis of the problems, it does also consider the evidence that supports the holistic model of health proposed. It also derives some practical conclusions in relation to both the clinical care of an individual and the delivery of services to large groups. The underlying theme is that illness is a socially determined state, not a biologically determined state and that healthcare is consequently a socially determined process.

Almost all healthcare practitioners would now claim to practice holistic healthcare. This applies not only to the United Kingdom's National Health Service (NHS) and traditional healthcare professions but to almost all practitioners of alternative health care. Indeed no-one would admit or agree that their personal, professional or organisational practice was not holistic.

At the same time, few if any of these professions, people or organisations make it clear what they mean by 'being holistic'. They do not provide any definition, or examples of how they manifest their holism. It is difficult to discover any criteria against which their success at being holistic could be measured. Indeed after searching using Google I could not find any sites that reported how holistic their practice was, let alone how the proponents measured it. I doubt that many of the people, professions or organisations actually have any clear

conceptual understanding of what they mean by 'being holistic'.

Politicians are equally prone to using the word. On March 11<sup>th</sup> 2004 the Right Honourable John Reid, then the UK Secretary of State for Health stated in a speech: "*The NHS must focus on good case management where patients with complex needs are identified and supported by skilled staff working in a holistic fashion in an integrated care system.*" But he failed to indicate either what he meant by this or how he intended to measure this. And this was at a time when the NHS was being given targets for everything, with precise measures!

Given this widespread use of the word, holistic, in relation to healthcare and given the assumption that holistic healthcare is morally and practically good, it is important to consider in some detail what the term might mean before progressing.

## Holism - origins, development, healthcare

The concept of holism may have a long history, but the word itself was coined by Jan Smuts in 1926 and was first published in his best-selling book, 'Holism and Evolution' [1]. The book is still in print, and a copy of the second edition (1927) is available for download on the Internet [2].

Jan Smuts (1870 – 1950) was a polymath. He started as a soldier fighting against the British in the Boer War but he later became a General and then a Field Marshall in the British Army. He also became a powerful politician and was twice the South African prime minister (1919-24; 1939-1948). He also had much wider interests and was a lawyer and a philosopher. It was as a philosopher that he wrote this book.

Jan Smuts defined **holism** thus: "*The tendency in nature to form wholes that are greater than the sum of the parts through creative evolution.*" I assume that he chose the word to

sound like 'whole' and that he deliberately left out the 'w' when writing the word.

The concept of holism was a part of a development in thinking in the twentieth century that led on to General Systems Theory [3] and later to theories of complexity and chaos. These theories are especially relevant in health care where the importance of complexity (as a mathematical phenomenon) increasingly recognised [4][5][6].

Complexity emphasises that in many systems relationships are not linear so that, for example, it cannot be assumed that there will be a simple relationship between cause and effect. Complexity should be distinguished from complicated, which may just mean difficult to understand or having many factors.

Holism has become increasingly popular within health care. There are now many associations and societies concerned specifically with holistic health care such as:

- British Holistic Medical Association [7]
- American Holistic Medical Association [8]
- American Holistic Health Association [9]
- American Holistic Nurses Association [10]

**Holistic medicine** was a phrase first used in 1960 by F H Hoffman [11] who wrote about "... concern with teaching about the whole man - 'holistic' or comprehensive medicine ..". This implies that holistic is synonymous with 'comprehensive' but he gave no further definition. A later article by R W Menninger was a little more explicit: "... holistic medicine that integrates knowledge of the body, the mind, and the environment ..." [12].

Another more recent definition - one of many similar statements found on the Internet - is that given by the American Holistic Medicine Association: "**Holistic medicine is the art and science of healing that addresses the whole person - body, mind, and**

**spirit.** The practice of holistic medicine integrates conventional and alternative therapies to prevent and treat disease, and most importantly, to promote optimal health. This condition of holistic health is defined as the unlimited and unimpeded free flow of life force energy through body, mind, and spirit." [8].

These definitions are imprecise and do not lead to any criteria for measuring how holistic an approach is. It is difficult to discover well justified and agreed definitions or explanations of holistic medicine, just as it is difficult to find any clear exposition of its alleged polar opposite, the "Medical model" of illness [13].

The term, holistic medicine now seems to encompass two separate concepts. The first concept is close to the original meaning, referring to a comprehensive analysis of illness, considering the whole system. It recognises that illness (being sick) is a human phenomenon, and that a full understanding and analysis of illness requires a broader perspective than simply focusing on disease.

The other more recent meaning attached to holism is that of using an 'alternative' approach - that is, **alternative** to the traditional biomedical approach to illness. There is usually also an implication that the approach being proposed is a morally better approach to illness, but rarely do the practitioners specify what they mean by holistic or how their practice manifests it.

**In summary**, holistic healthcare refers to an approach to analysing illness and providing healthcare that acknowledges and responds to all factors relevant to the health (or illness) of a person. The term itself does not signify what those factors are or how they are classified. The word holistic is also used to suggest a morally better and often an alternative non-allopathic treatment approach to illness. I will not consider this second meaning any further.

## Models of illness

A holistic approach to illness depends crucially upon using a model of illness that includes all the relevant components or factors.

A model is defined well by the Oxford English Dictionary (2006): “A *simplified or idealized description or conception of a particular system, situation, or process that is put forward as a basis for calculations, predictions, or further investigation.*” In other words it is an abstract method for describing and analysing the **relationships** between different factors which contribute to the outcome of interest. Its utility is in allowing prediction of the effects of changing a factor, for example treating a disease to cure illness.

In the context of health and illness a model will:

- Specify what factors are of importance in determining whether a person is ill (and conversely, by implication, what factors are not relevant)
- Specify the nature of the inter-relationships between these factors and being ill.

Further, a **holistic model of illness** will be one that:

- Identifies all the major factors relevant to the causation and understanding of illness
- Predicts or explains observed inter-relationships and other phenomena concerning illness
- Acknowledges explicitly the perceptions and experiences of the ill person (i.e. be person-centred).

An agreed holistic model of illness is needed so that anyone can judge whether a particular approach or organisation is giving holistic healthcare.

Measuring the degree of holism underlying a professional or organisational approach requires a comparison between the particu-

lar model or theoretical basis used by the profession or organisation and the standard holistic model of illness. This obviously depends upon the organisation explicitly formulating the theoretical basis of its practice.

In fact very few organisations or professions or individuals do specify the theoretical basis for their practice. A search of the UK Department of Health website does not reveal any discussion of the model of illness that underpins their decisions. Indeed I have not found any explicit statements by organisations commissioning (purchasing) healthcare or by organisations supplying healthcare, setting out how illness is analysed or conceived by the organisation.

This failure by such powerful organisations to specify the theoretical basis underlying their decisions is in stark contrast to the research community where the importance of specifying the theoretical underpinning of complex interventions (such as healthcare provision) has been stressed [14].

It is important because there are in fact very many models of illness. Some have been articulated and written down, but most are implicit and not formally described. Some are rather more logical and comprehensive than others.

In the absence of any acknowledged basis for the important political and practical decisions made by large healthcare management organisations, one must assume that the people responsible for decisions simply use the current, culturally dominant model.

## Current model of illness

Therefore we now need to review the assumptions made by most people concerning illness, so that we can deduce the model underlying most healthcare decisions both at the level of organisations and at the level of individual clinical decisions.

The first and perhaps most fundamental assumption made by most people is that all illness in an individual can be traced back to some specific, usually single disorder of a **part** of the body of the patient. This is termed the *disease*; it refers to some distinct abnormality in structure and/or function of a single organ or organ-system. It is also known as the *pathology*. The disorder is assumed to be **within** the body.

Thus, for example, observed weakness of arm movement could be attributed to a stroke (an area of cerebral infraction in the brain itself caused by a bleed from an artery). The patient would be described as having "had a stroke". Another term applied is the *diagnosis* – the patient has a diagnosis of stroke. This is a confusing word because the term *diagnosis* also applies to the process of discerning (diagnosing) the underlying disease.

A second assumption, almost as strong, is that all symptoms are due to disease, to a disorder **within** the body. This is particularly so because the very term *symptom* implies that the experience is symptomatic of something. If one believes that all illness is due to disease then it is natural to attribute symptoms to disease and if all disease is attributed to dysfunction of **part** of the body, then symptoms will be attributed to dysfunction of part of the body.

Thus, for example, if someone suddenly has difficulty in moving an arm, and notices that their speech is slurred and that their hand feels odd when touched, these would be referred to as the *symptoms* of stroke (or whatever the underlying pathology is).

A third, less strong assumption is that all disease causes symptoms. It is generally accepted that symptoms can sometimes arise late in the course of disease. Indeed this underlies the practice of screening for diseases such as diabetes, hypertension and carcinoma of the breast.

A further less well articulated assumption is that people have two parts to their existence – the 'physical' and the 'mental' – and that these aspects of a person are separate and unrelated [12]. This is a common belief [15], most obviously demonstrated in the almost universal separation between 'mental' health services and 'physical' health services.

This assumed separation is a form of Cartesian Dualism where a person's body and consciousness are considered as two separate entities; the problems that follow from this assumption practically [16] and philosophically [17] are covered elsewhere. More importantly, although it is less openly acknowledged, most people and many organisations are generally more sympathetic towards people with so-called 'physical' (or organic) disease than they are towards people with 'mental' or 'psychological' illness. This can cause problems.

There are some other more general, social assumptions about illness that were first articulated by Parsons in 1951 [18]. The first of these is that disease within the body is caused externally; the person who is ill is assumed to be the passive victim of the disorder and not responsible for his or her illness.

This leads on by implication to a second set of commonly held assumptions, namely that treatments are an external intervention that will (hopefully) cure the disease, and that the patient is a passive recipient of treatment with only a minor role to play if any.

Parsons also pointed out that being sick (i.e. being in the sick role) relieved the patient of many social responsibilities such as work, childcare etc until the person recovered.

At the same time he also emphasised that the patient had two concomitant responsibilities (which are now often overlooked). The first was to seek expert help for the ill-

ness from appropriate professionals, and to take any treatments or follow any advice suggested. The second was to strive to return to full social functioning as quickly as possible.

### The biomedical model of illness (figure 1)

These assumptions form the basis of the current dominant model of illness. This is best termed the biomedical model [19], sometimes referred to disparagingly as "*the medical model*".

It is in fact difficult to find an agreed definition or description of the biomedical model this model [13]. It arises from the scientific method of investigation which simplifies and reduces complexity, looking for direct cause and effect relationships. The biomedical model assumes linear uni-directional relationships and does not directly acknowledge complexity (non-linear or bi-directional relationships).

The biomedical model of illness fails to predict or explain some important observations. Some examples will be given, but there are many others.

It is now recognised that at least 20% or more of all people attending any hospital clinic do not have a specific disease that can account for their symptoms [20][21][22]. Furthermore 5%-10% of inpatient beds may be occupied by such patients [23].

There is no fully agreed word or label for this type of illness. The term used in this paper will be **functional illness** (or functional problems) but other current terms include medically unexplained symptoms, somatisation and non-organic disorders. This group of disorders includes such 'diagnoses' as fibromyalgia, chronic regional pain syndrome, chronic low back pain, migraine and headache, irritable bowel syndrome, ME syndrome and chronic fatigue syndrome. The biomedical model of illness cannot explain these illnesses at all.

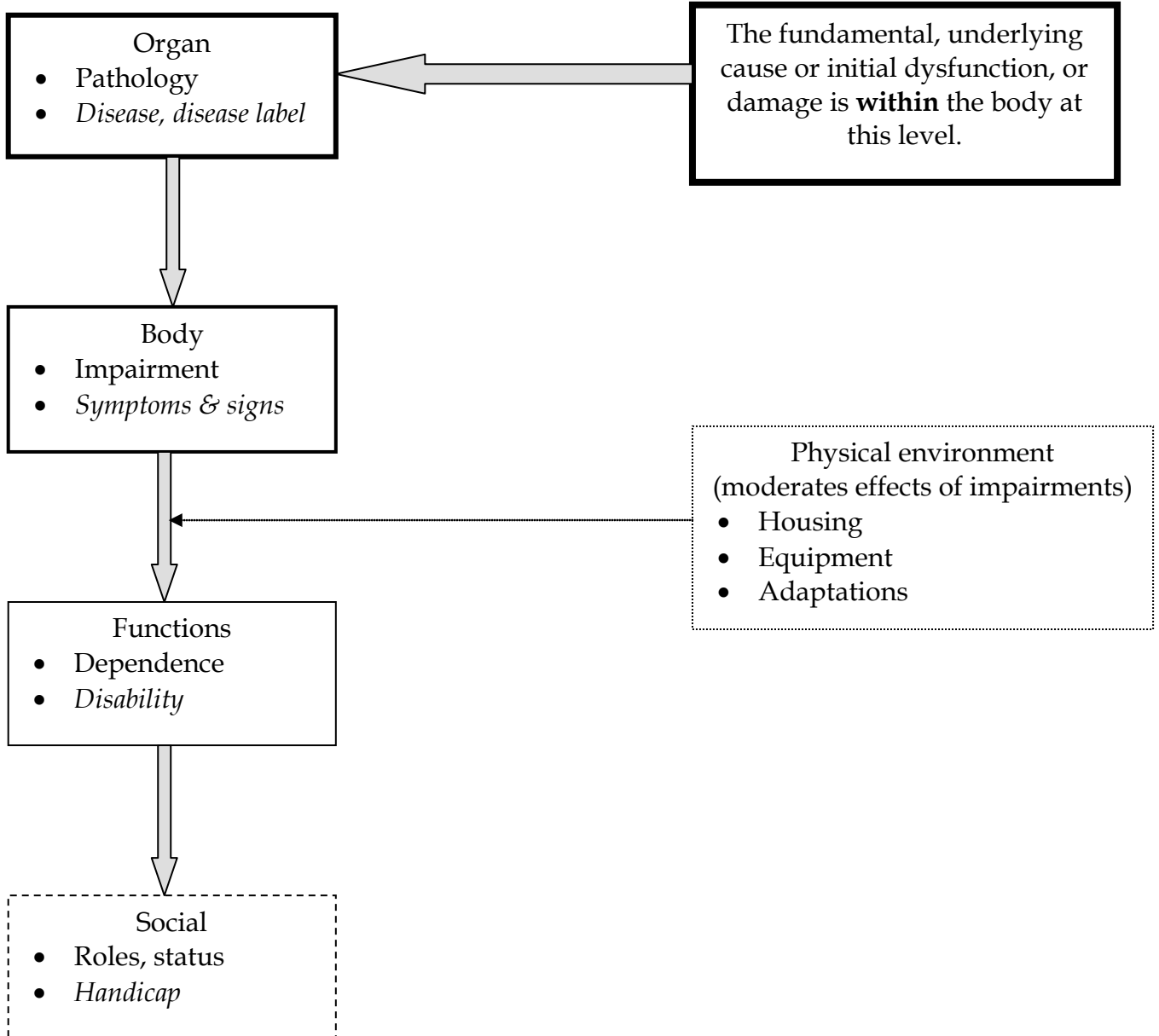
It is well established that non-medical factors determine retirement on grounds of ill health, despite the fact that it is a medically validated process. A doctor certifies that the claimant has a specific illness and that the illness precludes paid employment. For example in four of five UK organisations surveyed, the modal time of retirement on health grounds coincided with the time when an enhanced disability pension became available [24]. In a Finnish study, the rate of retirement on health grounds doubled in organisations which experienced major downsizing [25]. These unsurprising observations are not consistent with the simple biomedical model of illness.

Thirdly it cannot explain why the rate of invalidity (as indicated by **medically confirmed** sickness benefit claims) is increasing while at the same time the success of medical diagnosis and treatment is improving.

Last the biomedical model fails in terms of commissioning (purchasing) because in most systems the payment relates to the given diagnosis. This does not take into account such matters as the process of making a diagnosis, the effects of associated or unrelated diseases, the effects of 'social' factors and the effects of disease severity.

For example someone who has had a stroke might have a small lacunar cerebral infarct and recover more-or-less full independence within a few days with minimal need for any intervention. In contrast a person with an equally small volume of cerebral damage leaving them in the 'locked-in' state requiring major support and rehabilitation and huge changes in housing etc will require many months of rehabilitation in hospital. Attempts have been made to adjust the current payment systems, but none have been very successful.

**Figure one**  
The biomedical  
model of illness



The assumptions underlying the biomedical model of illness are also invalid.

First, 'symptoms' are extremely common. Studies have shown that most people have experiences that could be termed symptoms on a daily basis [26][27], and indeed may have about two 'life-threatening' symptoms in a six-week period without actually ever being sick or attending a doctor [28].

Thus, far from being rare events indicative of an underlying disorder **within the body**, symptoms are something that we all experience on a daily basis; most of the time we recognise that they are in fact within normal experience.

Second, much pathology (disease) is asymptomatic. For example about 10% of people aged 65 years or more have areas of cerebral infarction (stroke) on scanning, yet have never had any symptoms from it [29]. Screening programmes detect so-called abnormalities that are not only asymptomatic but probably would never be symptomatic. For example there is considerable debate around the cancers detected in breast [30] and prostate [31] screening programmes.

Next it is demonstrably untrue that patients are always 'passive victims' because so much disease is related closely to patient behaviour. For example, smoking causes many diseases; alcohol causes many diseases; obesity causes many diseases; practising unsafe sex may lead to HIV infection. These examples alone show that a proportion of diseases are caused, ultimately, by the patient him- or herself.

Further, even with surgery and drug treatments the patient has to be an active partner for treatment to succeed. At its most basic, if you do not take your tablets, you cannot benefit from them. More importantly, if a patient does not alter his or her lifestyle by exercising more, participating in rehabilitation, losing weight etc then the outcome will

usually be worse even to the extent of recurrence or maintenance of the disease.

Fifth, it is common experience that mood affects performance. Indeed whole management lectures and courses are based on the premise that altering motivation and engagement improves performance.

Last, and perhaps most importantly, the biomedical model of illness perpetuates a faulty logic in analysing and understanding illness. Specifically the assumption that all illness can be attributed to disease **which affects only a part of the whole body** prevents any exploration of an alternative explanation, namely that illness arises from a **problem at the level of the whole person** within their situation.

This logical failure is sometimes known as mereological fallacy, and a similar logical failure has been explored in relation to consciousness [17]. Mereology is concerned with studying and analysing the relationships between the parts of a system and the whole system, and whether a **phenomenon belongs to a part of the system or to the whole system**.

In relation to illness, the biomedical model assumes that there must always be a disorder of a **part** of the whole. It does not consider that the **whole person** may be ill without any specific part of the person being abnormal.

This logical fallacy has serious consequences in relation to functional illness (i.e. the 20% of people who have problems without underlying disease). Clinically it impels doctors to continue investigation for a disorder **within** the body. This may cause significant harm: all investigations carry risk, and the process may prolong and reinforce the illness behaviour.

In research it leads to a fruitless hunt for specific causes such as toxins and viruses; it

is likely that any abnormalities identified will be secondary phenomena anyway.

And in healthcare management terms, there is no diagnostic or payment code for functional illness. Consequently the existence of functional illness is not recognised by commissioning organisations who nonetheless pay large sums for these patients.

**In summary**, I have suggested that most modern healthcare is based on a biomedical model of illness. The biomedical model has been a spectacularly successful model for about 150 years, so much so that it is not overtly described at all. It has allowed the identification, classification and rational treatment of a huge number of diseases – the International Classification of Disease issue 10 (ICD-10) is the culmination of the process [32].

Nonetheless there are many ways in which it is no longer an adequate model of illness; it is reductionist and fails to recognise the multi-factorial and mathematically complex nature of most illness. A better model of illness is now needed.

### **Biopsychosocial models of illness.**

The need for a better model of illness was recognised at least 30 years ago when George Engel challenged healthcare practitioners about their use of the biomedical model. He suggested moving towards the biopsychosocial approach, so named because it recognised the importance of biological factors, psychological factors and social factors [33]. He also introduced the idea that General Systems Theory should be applied to illness.

Other authors have also emphasised the complex nature of illness, the utility of a biopsychosocial approach and the use of systems theory [34][35]. However, other than emphasising the need to consider biological, psychological and social factors, these authors have not developed a specific model.

At about the same time, in 1980, the World Health Organisation (WHO) published its first classification of the **consequences of disease** [36]. This did use the biopsychosocial approach to illness and theories of sociologists such as Nagi [37] to develop the classification which used three different levels or domains to encompass all the consequences of disease:

- **Impairments** – alteration in physiological functions of or within the body
- **Disabilities** – alteration in bodily functions
- **Handicaps** – alteration in social functioning

One specific feature of this first WHO classification should be noted: it completely ignored the importance of context and the environment.

The terms disability and handicap were considered stigmatising by some people, not unreasonably. Between 1980 and 2001 the WHO expanded and improved its classification, aided greatly by people with disabilities, and it finally published the International Classification of Functioning (WHO ICF) in 2001 [38].

This revision included significant advances both in terminology and in the underlying concepts. The word disability was replaced by (limitation in) activities; this was not only less stigmatising but also emphasised that the core concept was of change in goal-directed behaviours. The word handicap was replaced by (change in) participation in social life; this was also less stigmatising and importantly emphasised that the core concept was of a change in social position.

More importantly the WHO ICF (2001) acknowledged that contextual factors might moderate the effects of disease, and suggested two domains (physical and social).

However it must be noted that the WHO ICF remains a **classification** of the **conse-**

**quences** of disease. This implies a continued dependence upon the biomedical model of illness. The classification itself is probably unworkable in practice – despite enthusiastic advocates [39][40].

There is one particular failure in its classification; it does not include any consideration of quality of life or well-being. This failure is understandable because the concept of quality of life is difficult to define, and impossible to categorise or measure accurately. Nonetheless well-being is a vital domain of each person's life that should be included in any holistic model of illness.

**In summary** the biopsychosocial model of illness seems to be a significant advance upon the biomedical model of illness. It has been used as the basis of a system for classification of various aspects of illness, and the implied model of illness underlying the classification has been used as a basis for research and policy for many years and has been useful, for example in national guidelines on acquired brain injury [41], multiple sclerosis [42] and stroke [43]. It could be a good basis for a holistic model.

### Brief overview so far

So far we have established that:

- Models of illness are used to analyse how illness arises and to predict what treatment might be effective; most models are implicit and not formally described.
- The biomedical model, which primarily assumes that all illness arises from **within** the body and is caused by an initial dysfunction of a **part** of the body, is the current dominant model of illness.
- The biomedical model of illness has several weaknesses:
  - The underlying assumptions are all invalid.
  - It is not successful at explaining some illnesses, especially the group of 'functional illnesses'.
  - It is not successful when designing health care systems.
- The biopsychosocial model of illness is an alternative model that:
  - Acknowledges the importance of factors other than disease.
  - Suggests a systems approach to illness.
  - Has been used as the basis for an international classification system.
- A holistic model should:
  - encompass **all** factors that relate to illness in some way.
  - explain or predict all illnesses, especially functional illness.
  - improve the organisation and commissioning of healthcare.
  - improve clinical management of individual patients through allowing a better analysis and understanding of the whole situation.

### A holistic model of illness

I am now going to present a holistic model of illness that is based on and derived from the WHO ICF classification of the consequences of disease. I will refer to this as an **expanded WHO ICF model of illness**. Throughout the description I will simply refer to the person, because the model should encompass and be applicable to all people, whether or not they are ill at the time. The model is illustrated in **figure two**.

#### *Four person-centred systems*

The model first suggests that there are four levels or systems centred on the person that are relevant to illness. It should be noted that each level can, in principle at least, be subdivided into two perspectives: that of the person and that of external observers. More importantly it must be emphasised that it is not necessary for there to be any abnormality at any particular level when someone is ill. Specifically disease is not the cause of all illness.

The first system to be considered is that of an **organ** or organ system **within** the body of a person. Alterations in the structure or functioning of an organ (as a subsystem of the body) are referred to as **pathology**, with *disease* being the common synonym. The personal aspect of this is the disease **label** applied to or used by the person concerned.

This system is itself further divided into systems such as cells, genes, and chemical pathways, and these systems are currently the main focus of most biomedical attention, both clinically and in terms of research. However when considering the phenomenon of illness as a whole, it is not necessary to be concerned with these lower levels.

The next system is that of the **whole person** (to include both bodily and mental domains); it is the overall functioning of all the different organs and organ systems present within a body.

Alterations in the structure or function of the person as a whole are referred to as **impairments**, and the common synonym is *symptoms* (and, medically at least, *signs*).

Several important aspects of impairment must be emphasised. Many impairments such as pain, altered sensation and double vision are personally experienced and they can only be known about because the person tells someone. These impairments cannot be externally verified.

Second, many impairments described as *signs* are no more than externally derived constructs; in other words they are a method of summarising a series of observations into a single word. For example a neurologist will analyse a person's speech and state that they have *aphasia*, an impairment of the use of language, but this is not otherwise verifiable. The presence of aphasia is simply a deduction based first on observing communication and second on using a model of how speech and communication occurs in order to determine the abnormality.

The power of constructs is that they are generally very useful; the danger is that they may be considered as 'objective' or concrete phenomena that can only have one explanation. We have demonstrated that 'upper motor neuron weakness and spasticity' can arise without any disruption of the nervous system [44].

Third, the common synonym for impairment, symptom, itself implies that there is always an underlying cause, specifically an underlying disease, but this is not necessarily true.

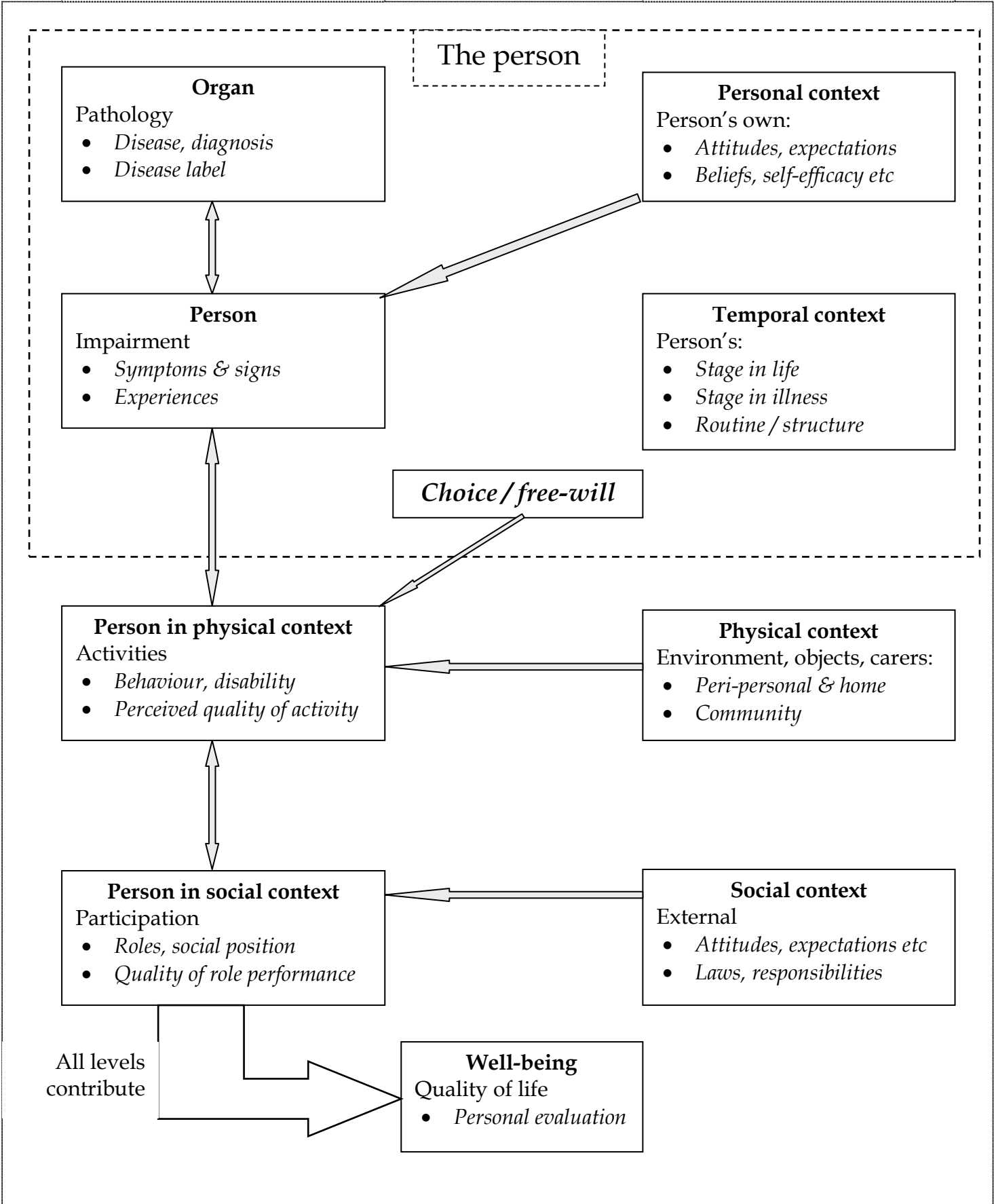
**Figure two**  
The holistic model of illness

**Level / system**  
Name in model

- External synonyms
- Person's perspective

**Context**  
Location

- Components



Thus another way to consider this level is to refer to the **experiences** that the **person** has (such as pain, or altered sensation, or fatigue, or difficulty in moving a limb and so on) and/or to describe both the observations made **and** the deduction made. There is otherwise a real risk that the impairments will be 'objectified', being made concrete by being named when in fact they are no more than reported personal experiences or implications derived externally on the basis of observed behaviour.

These first two systems - the individual organs within the body and the whole person - refer to the person alone. The next system to consider is the person's interaction with the physical (observable) environment. This consists of the person's **activities**, the behaviours that they undertake usually to achieve various goals. The goals may vary from the immediate (satisfying thirst) to the long-term and abstract (becoming a grandfather, or head of a department). Alterations at this level are still usually referred to as **disabilities**, although the WHO ICF refers to them as *limitations on activities*.

Three important points must be made about this level. First, it encompasses externally observable actions; a person's interaction with the environment is open for all to observe, and can be recorded (for example) on video.

Secondly, there is also a personal perspective on the performance of activities. Although observers can both measure and describe the activity, only the person can rate their own perception of their performance of the activity. For example a therapist might describe gait as being '*slightly slow with a minor limp*' but to the person concerned the visible limp might be of major importance, for example because it shows to others that the person has a problem they do not want to disclose. Alternatively they may be unconcerned about a limp or even appreciate it as it discloses that they have a problem;

many patients with cognitive losses after head injury are very upset because their "hidden disability" is not recognised or acknowledged.

Last, this system is the one that depends almost entirely upon a person's goals. Behaviour is goal directed, and *disability* can only be understood with reference to a person's goals.

The fourth and final level is the most abstract, and is best considered as the person's interaction with the **social** environment. It refers to the roles that they play.

A role is determined not only by the person (as actor) but also by others (as audience). Roles, and social position depend in part upon a person's ability to undertake certain activities but they are also determined by many other factors. Roles are extremely difficult to observe 'objectively' because they depend entirely upon the perceptions of those involved, both the person and others. Most roles need to be agreed mutually.

These four levels are concerned primarily with the person. It is worth restating that only activities are externally observable. Impairments are deduced from observations of behaviour and/or report from the person. Disease is initially diagnosed on the basis of a characteristic pattern of abnormalities sometimes confirmed by direct observation of the organ (e.g. by biopsy). Social participation and roles are also indirectly inferred from observed behaviour.

#### ***Four contextual factors***

The model then recognises four factors that may moderate the interactions between the four systems; these contextual factors may themselves also cause alterations directly in any of the four person-centred systems.

The contexts are:

- **Physical**; the observable environment
- **Social**; the local cultural environment
- **Personal**; the sum of a person's experiences and personality
- **Temporal**; both the stage a person is within the illness and the stage the person is at within their life.

The physical context is the most obvious, and the easiest to understand. It refers to **all** objects and structures that a person may use or be affected by. Obviously it includes the structure of the house and built environment but it may also include adaptations made to the environment such as adapted cutlery, clothing adaptations, rails etc. Further it will include any specific equipment provided such as walking aids, prostheses, and orthoses.

Less obviously it is important also to include other people as providers of hands-on ("physical") care as part of the physical context. This does not mean that one can ignore the separate but vital role of other people as social contacts. However it is clearly important in a practical sense to consider how hands-on help with dressing, feeding or cooking will be delivered, and in some circumstances it could be from someone living in the accommodation with no family or other emotional relationship at all with the ill person (e.g. a lodger might prepare and leave a breakfast before going to work.).

This understanding that carers will usually provide both 'physical' and 'social' input may alert one to a common practical problem. Many younger people who are dependent upon carers on account of a head injury, or multiple sclerosis or cerebral palsy may also consider these carers as friends. This is unsurprising because often the carers are the major or only social contact a severely disabled person has. Unless there is formal recognition of the distinction between the role of carers in providing necessary 'physical' help and the incidental but

inevitable social interaction and relationships that develop, practical problems can arise in the delivery of care.

The social context needs careful consideration. It primarily refers to the particular people in contact with or of importance to the person, and it concerns the attitudes and expectations of those people. However it also includes the broader aspects of culture as evidenced by people met incidentally in the community, officials and bureaucracy, and applicable laws and other rights and responsibilities proscribed in some way.

The importance of social context in determining illness has been demonstrated in at least one study [45][46]. The social context may also explain the observations made concerning disability pensions [24][25].

The personal context is less obvious but possibly the most important. It encompasses the person's 'personality' and general coping skills (themselves derived from both genetic factors and past experiences), the person's own expectations, attitudes and goals, and also the person's specific experiences of the illness that they have and of other illnesses and events. For example a history of reported childhood abuse is associated with functional illness [47].

It could be argued that the personal context is part of the 'body system' or 'impairment' level, but the difference is that impairments refer to experiences and changes whereas the personal context refers to a response set, the factors that influence **how** a person responds and adapts to a particular circumstance and **what goals they have**.

The last contextual factor is time, and there are three aspects to the temporal context.

The first is the person's stage of life. This primarily concerns their age and the expectations associated with that age. It also affects both the resources available to them at

their stage of life, and the responsibilities that they have (e.g. caring for children).

The second is the person's stage of their illness. A person's concerns when they have only just become ill will be different from their concerns four years after disease onset. And people acquiring their illness at birth or in early childhood will have yet different concerns and expectations.

The last, important aspect of the temporal context is specifically important in rehabilitation, and it concerns the structuring of time. Throughout life most people have a routine which is largely imposed externally. This routine affects the day, the week, the year and longer periods. Although there is obviously variation and choice, nonetheless most people have a highly structured life pattern.

In contrast many people with illness, especially long-term illness lose all routine. They may go to sleep at any time, get up at any time, and have very little to do in the day. The effects of a lack of temporal structure have not been well researched but may explain the increased rate of illness and mortality seen shortly after retirement from work and the low mood and low level of well-being of many people with long-term illness.

### *Two other factors: choice and well-being*

There are two other major factors that need to be included in any comprehensive model of illness: the person's free-will, their ability to make choices; and the person's judgement on their own level of well being or quality of life.

Choice is important. It is generally agreed that all people can make choices and are responsible for their behaviour; this is the basis of the criminal justice system. Yet much healthcare seems to forget that people attending healthcare will make choices.

Choice is particularly important in long-term illness because healthcare professionals are rarely able to give any firm evidence-based advice or treatment knowing the long-term consequences. Patient involvement in all choices about treatments should be the normal expectation. Furthermore even if the choice is not to follow the "best advice" given, the choice should be respected not least because we can rarely actually know whether our advice was necessarily correct or best!

At the same time we should also recognise that explicitly acting to alter a person's choice is quite legitimate, provided it is done openly and without deceit or by immoral means. For example if someone with a head injury is screaming to gain attention, we may choose to ignore it but to respond when he is quiet, so that he chooses not to scream. More generally people are now receiving direct incentives to improve their health in some situations [48].

It is also quite legitimate to face the person with the consequences of their choice. For example if someone with poor balance chooses not to use a rollator when walking, they should be informed of the risks and of any actions that could reduce that risk.

Quality of life is another concept that is important, but difficult to define or measure. It is ultimately a judgement made by the person about their situation. It is probably influenced by many factors, including personal preferences. It is also likely that quality of life often renormalizes over time in chronic illness.

### **What is illness?**

The next step is to discuss the nature and aetiology of illness using this model. The main contention is that illness is a social state usually initiated by the person and confirmed by others.

The central characteristic of illness is that **the person will consider themselves 'sick'** (i.e. ill); they will also generally enter "the sick role", generating behaviours indicative of this such as attending doctors or other healthcare professionals (including, now, alternative healthcare practitioners). The person will also often absolve themselves of some responsibilities by limiting other behaviours. It should be noted that entering the sick role fully requires at least one other person to accept that the person is ill.

The presence of disease does not inevitably cause someone to be ill. One may have a 'silent' pathology (e.g. an ovarian tumour with no symptoms), or one may have experiences such as odd episodes of tingling that are attributed (by the person and/or others) to normality while in fact they may be related to early multiple sclerosis.

It is also possible for a person to be considered ill by others but not to consider himself ill. The most obvious example is a person with delusional mental illness, or psychosis where the behaviour is dangerous to the person or others but the person has no insight into the unusual nature of their experience and behaviour and does not agree that they are ill. Less commonly, people who simply behave in socially unusual ways, for example choosing to live in squalor rather than tidying their house are considered ill by others and referred to healthcare for diagnosis and treatment.

More importantly, this analysis suggests that it is quite possible to be ill without disease. The central feature of illness is that the person acts in a way that indicates a belief that he or she may be ill. Leaving aside deliberate pretence (e.g. malingering), this simply requires that the ill person thinks that they have or may have something wrong with their health. In the current culture, this translates into a belief that they have a disease or disorder within the body.

In the current culture, most other people will take a similar view if presented with the same experiences. Thus if a person presents themselves as ill, and this presentation is accepted by others, especially but not necessarily by healthcare professionals, then they indeed will have an illness.

Therefore illness is best described as a range of behaviours that are understood by others to indicate that the person considers him- or herself to be ill. Occasionally, but not always correctly, a person's behaviours may be considered by others to indicate that the person is ill despite not seeking help.

In other words **illness is a socially constructed state** within the system, being based upon the behaviour of the person.

### *Becoming ill*

If this definition is accepted, then the next question is how or why does someone consider herself ill and behave in that way; just as interesting is why others, especially healthcare professionals consider that person to be ill and thus validate the illness.

There are four steps to achieving illness.

The first step is that someone notices a change in himself. The alteration may be the occurrence of new 'symptoms' or it may be a change in existing 'symptoms', or it may be a change in the ability to perform activities or fulfil roles. It is a change in experience.

For example a person may experience pain in the knee without necessarily any alteration in walking or a person may experience a change in walking, such as a limp without any symptoms. In practice either could arise from the same underlying pathology, osteoarthritis of the knee.

The next step is for the affected person to consider that this change is not simply expected (in the situation), but represents the

effect of some other underlying disorder. The nature of this disorder will be determined by the model of illness used by the person. Given that most people use a bio-medical model, most people attribute change to a disorder **within** the body (a disease).

For example the person with a limp would not be concerned if he had sat on a hard seat and developed a 'dead leg' (due to pressure on the sciatic nerve). However, if the person could not think of an alternative benign explanation, he might consider the limp to be caused by some underlying disorder. The specific attribution (of causation) is clearly subject to many influences such as expectation in relation to a specific change. For example, some people worry that any limp might represent motor neuron disease, perhaps because a relative presented with that disease in that way.

The third step is for the person to consider that the possible cause is within the remit of the healthcare system. This is also a cultural phenomenon and depends upon the dominant model of illness within the society.

The last step is for at least one other person to agree that the person has a change that is or may be due to an underlying condition that is accepted as causing someone to be ill (rather than 'bad', or unlucky or simply not ill). Full validation usually depends upon a person within the healthcare system, not necessarily a doctor. Indeed many people now have illnesses 'diagnosed' by a variety of practitioners where the diagnosis is not accepted by many doctors (e.g. chiropractic diagnoses).

### *Functional illness*

This analysis offers an explanation of functional illness. In brief the hypothesis suggests that illness arises as part of a person's adaptation to changes within the whole system. Many illnesses arise when an organ is diseased; as the disorder progresses there

comes a point when the body cannot adapt, and symptoms arise. This is the traditional understanding of illness.

However it is also plausible that increasing demands upon a person from other factors may equally lead to symptoms. Indeed few people will cope with excessive demands without developing symptoms. If the demands are obvious (to others) and evidently (to others) excessive, then most people will both admit to the symptoms and will acknowledge the cause.

However it is also plausible and in fact inevitable that some people are less able than others to adapt to demands that lie within the normal range. Moreover some demands are self-imposed. Under these circumstances the person is just as likely to experience symptoms but is much less likely to attribute them to external or self-imposed demands. Instead the symptoms or other problems will be attributed to internal disease.

This attributional bias towards 'organic', internal disease rather than acknowledging the relevance of other factors arises for cultural reasons. Culturally it is not acceptable to admit that one cannot cope with a situation unless the situation is exceptional. Culturally it is usual to attribute symptoms to disease. Furthermore the prevailing culture in healthcare (exacerbated by a legal framework) means that specialist hospital doctors are unrealistically afraid of failing to diagnose disease even when it is obvious that the person must have a functional disorder.

Consequently neither the person who feels unwell, nor his friends and family, nor his medical advisors will consider the role of contextual factors, at least in the early phases of illness. By the time that it is obvious that there is no underlying disease it may be too late to alter and reverse the beliefs of the person who is ill.

### Summary of holistic model

In summary the expanded WHO ICF model of illness:

- Recognises four major systems concerning the **person**
  - The organs **within** the body
  - The body **as a whole**, generating experiences and skills
  - The body's (person's) **interaction** with the physical environment, generating goal-directed activities
  - The person's **interaction** with the social environment, generating social roles and social participation
- Suggests that four major contextual factors can affect the person's interactions and experiences:
  - The physical context
  - The social context
  - The personal context
  - The temporal context
- Identifies two major factors difficult to locate elsewhere:
  - Choice or free-will
  - Well-being, or quality of life
- Suggests that illness is a socially determined state requiring four steps:
  - An experience that is outside normal
  - Without any obvious (external) cause
  - Attributed to an internal cause within the remit of healthcare
  - Accepted by others as being the situation
- Predicts that illness will arise when
  - The external or internal demands upon or changes within a person
  - Exceed the capacity of that person to respond or adapt to the changes or demands
  - Leading to symptoms/experiences that are attributed to disease

**Is the holistic model valid?**

The last section of this paper developed a holistic model of illness largely without reference to evidence. It is now time to consider the evidence behind this model.

Ultimately theoretical models cannot be proved. They can only be disproved. Evidence showing that the simple biomedical model of illness is invalid has already been given. Thus a new model is certainly needed, and this is one. Models can however be validated or strengthened in several ways such as being consistent with and able to explain existing observations.

This model can easily explain observations such as the influence of social context upon rates of disability pensions [24][25]. Furthermore there is experimental evidence that altering social (cultural) context can alter rates of invalidity [46]. This model is consistent with and able to accommodate current observations.

The biopsychosocial model is considerably strengthened by its success in predicting experimental findings. A biopsychosocial model was used explicitly in the development of a measure of clinical case complexity for use in healthcare. This measure was the INTERMED [49][50][51] and a series of studies have confirmed experimental findings that would be predicted by the holistic model.

For example the measure can identify people with back pain who are unlikely to return to work [52], and people on renal dialysis with a lower quality of life [53], and people with lung disease who use more healthcare resources [54], and people with multiple sclerosis who needed more complex healthcare input [55]. The INTERMED seems to encompass a single construct of biopsychosocial complexity [56]. And using this measure also may help identify people who benefit from additional multidisciplinary care [57][58].

A related, powerful piece of supporting evidence is that this model would predict the occurrence of functional illness. Although the model cannot predict the expected frequency of functional disorders, a systems approach to illness would predict that a person might become ill without having any specific underlying disorder. This occurs.

The model's analysis of functional illness is supported by several pieces of evidence. Interventions to alter cognitions and behaviours (cognitive behavioural therapy) improve functional illness [59][60]. Functional illness can be diagnosed by analysing the actual language used by people with a functional disorder [61][62]. And the variable nature of symptoms [63] is only consistent with a multi-factorial aetiology.

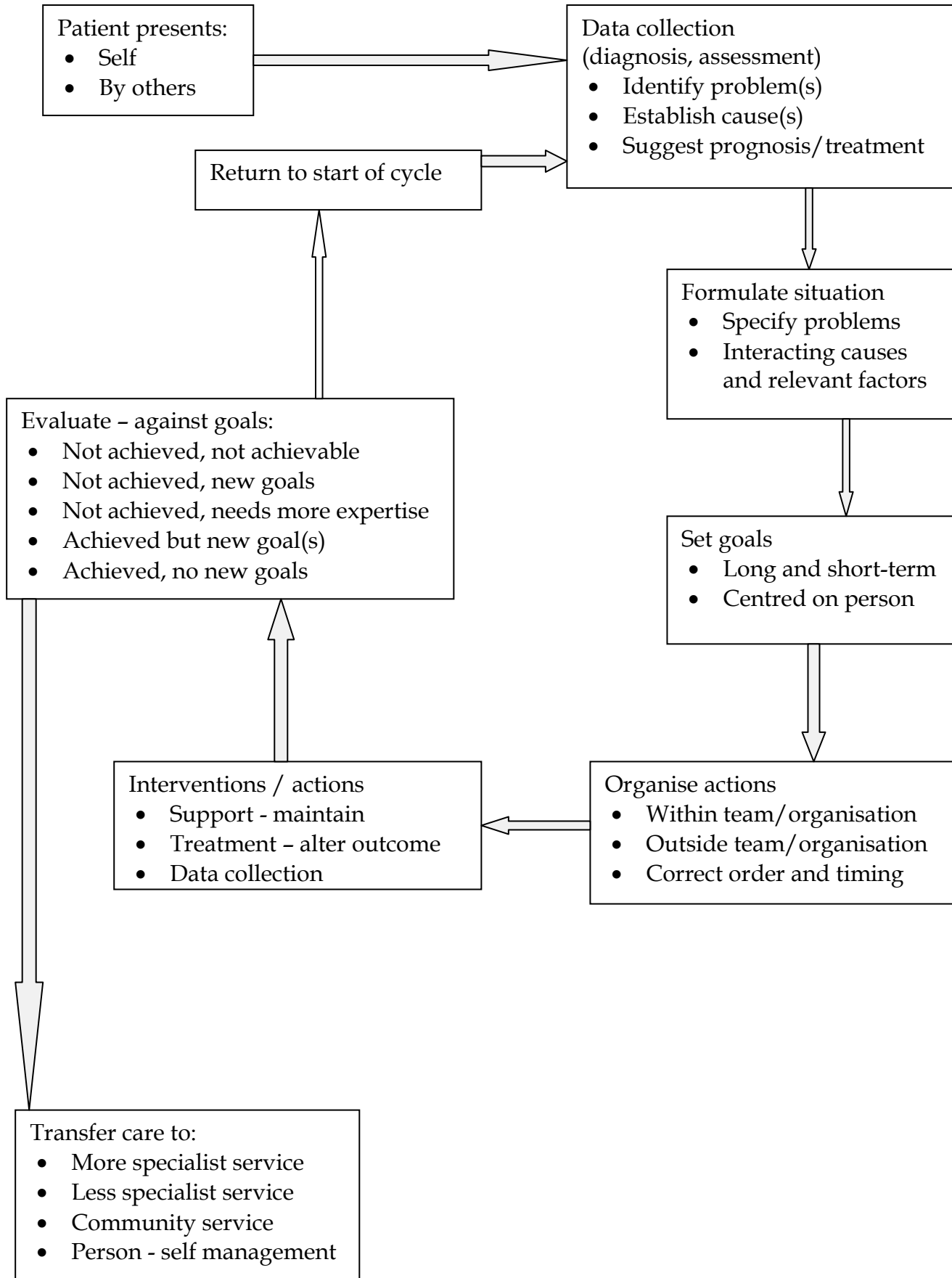
The model put forward here is also supported because it has been found practically useful. The original WHO ICF classification model is now widely used in rehabilitation (not the classification itself, but the ideas of impairment, activities, participation and context). The expanded model has been used successfully to structure large complex guidelines such as the NICE National guideline on multiple sclerosis [42] and the National Clinical guideline for stroke [43].

Finally the model is very useful in understanding many other phenomena and in suggesting some solutions. The table at the end shows some general lessons that can be derived from using the model. There is a considerable body of evidence that supports the validity and the utility of this model. I am unaware of any evidence that proves this model to be flawed.

**The healthcare system (figure three)**

Finally, before discussing how holistic healthcare can be carried out and how it might benefit patients and healthcare systems, it is important to analyse the healthcare system itself, briefly.

**Figure three**  
The health care process



Healthcare is best considered as a problem-solving process, with different parts of the healthcare system focusing on different aspects of illness and sometimes, possibly, having different goals. However all healthcare processes will have the following general structure. The amount of effort devoted to each stage will vary according to the situation and setting.

The first step is for the patient to present to the healthcare system. Usually this will be initiated by the person. In two circumstances this is not the case. If the person falls ill suddenly and loses the power or ability to seek help, others may need to do initiate healthcare involvement.

Second, if the person's illness is such that they are unaware of their abnormal state, for emotional, cognitive or delusional reasons then someone else may initiate contact. It must also be recognised that others may sometimes refer a person who has no illness to the healthcare system simply because they do not like or understand their behaviour or choices.

The second step is for the healthcare system to collect information to establish:

- That there is indeed any problem present that is appropriate to healthcare
- What other health problems exist
- Information needed to identify the cause(s) of the situation
- Information needed to identify the best treatment(s)

In medical settings this process is known as making the diagnosis; in rehabilitation settings it is often referred to as the assessment process. In either case the goal is to understand what is wrong, why the problem has arisen, and what can be done to alleviate the situation.

The next, third step is to use the data collected formulate the case, specifying the nature and extent of the problem(s) and the

causes and factors relevant to management and resolution of the problem. In practice these two steps (data collection, and formulation of the situation) occur in tandem, and experienced professionals collect data to confirm or refute initial hypotheses.

The fourth step is to use the information to set management goals. The potential goals fall into one or more of the following three categories:

- *Providing support.*  
**Support is defined** as interventions needed to maintain life, safety and well-being. In some situations support may be long-term (e.g. someone who needs long-term ventilation or someone who needs long-term nursing care). In principle support does not lead to sustained change; as soon as it is withdrawn the situation deteriorates.
- *Undertaking treatments.*  
**Treatments are defined** as interventions that are intended to alter the natural history of a condition. In principle treatments are limited in time and one expects the achieved change to be maintained upon withdrawal of the intervention.
- *Collecting more data.*  
This may be needed to improve the analysis and understanding of the situation.

Goal setting is rarely done explicitly in acute settings, but it is certainly implied. However it is vital in rehabilitation where it is usual to set long-, medium, and short-term goals both to help motivate and engage the patient and to help structure and organise the many actions needed.

Thus, in complex cases at least, an important component of the fourth step is to organise the many actions needed. This may require collaboration between many different people, professions and organisations.

The next step is for the planned actions to occur. These actions, especially treatments are often considered the main part of the health care process. Indeed in 'item of service' payment systems, the payment is generated by the specific treatment even if there are many preceding actions, concurrent actions and subsequent actions. This is fair only in the rare situations where variation around the pathway leading up to and following on after the treatment event (usually an operation) is small.

In the sixth step the situation is re-evaluated to determine whether:

- treatment goals have been met
- further problems needing more action have been identified
- any problems remain needing treatment
- longer term support needs, if any, have been identified and plans made to meet these needs

If unresolved problems remain, the cycle reiterates.

The seventh and final step, if no further problems remain to be resolved by the particular part of the healthcare system, is for the patient's care to be transferred away from that system.

The options are to transfer care to:

- a more specialised service, if problems remain which could be resolved given more specialised input
- a less specialised secondary care system
- primary care (community care)
- the patient and family (self-management)

The final disposition should be to self-care. Some people may have no further health-care problems, but most people with long-term problems will need instruction on how best to manage their condition, and on when and how to make contact with specialist services, and they will usually need advice on life style.

### Improving patient care

It is now possible to consider how the holistic model of illness might improve patient care both directly, and through improving the healthcare system.

Patients who have a single disease that can be treated will generally be well-served by a healthcare system based on a biomedical model of illness.

However many people now have complex health problems:

- they have multiple pathologies, often in different systems
- the diseases are often not cured, and may need long-term specific management
- the patient has multiple impairments that interact with each other
- many patients have significant limitations in many activities such that they need support on a daily basis
- many patients have very limited social roles, and 'being a patient' may constitute an important role
- the patient's beliefs and expectations may be quite different from those of the healthcare team
- the social and physical context is often unsuited to people with a long-term and disabling condition

This complexity has several consequences. It is difficult for a service focused on a single disease to recognise and analyse the situation fully. The management of the situation often involves a multitude of different professions working in different organisations. Many different treatments are needed. And the evidence-base is very limited, so that there is always considerable uncertainty about prognosis and the most efficient management plan.

Nonetheless if **all clinical staff** and **all specialist services** used a holistic model of illness when undertaking their **initial formu-**

**lition**, it is likely that clinical decisions would:

- be more appropriate, taking into account all relevant factors
- be more patient-centred, taking into account the person's own views
- include an early referral onto an appropriate rehabilitation service (e.g. geratology)

At present this proposal is simply my opinion, but it is a testable hypothesis. The question is "*Does ensuring that the initial clinical encounter with a specialist hospital service includes collection and consideration of information across all domains of the holistic model of illness lead to a better patient outcome including overall well-being six months later?*" In support of this hypothesis, several recent NICE guidelines have set out general principles that seem to endorse a patient-centred and holistic approach [64][65][66].

One particular group of patients have a complex illness, namely those with one of the 'functional illnesses'. Within this group one might also include the large number of people currently labelled as having 'common mental disorders' such as depression and anxiety [67].

Functional illness is in many ways "*the elephant in the room*" or the '*hidden iceberg*' in the health service: there are many people whose have functional illness; there is no systematic way of recording this in health-care systems; there are no specialist services; and there is little research into treatment. Consequently few people with functional illness get a satisfactory service.

Using a holistic model of illness might help this large group of patients. If there were a general recognition and acceptance among clinical staff that not all illness is due to underlying disease, then it is possible that the true nature of the illness would be recognised much sooner. In fact early recognition of the illness is not difficult [47], and at the

very least would avoid the person being exposed to unnecessary and potentially harmful investigations and treatments.

More importantly, the available evidence suggests that a comprehensive approach using several different interventions would help most people:

- Acceptance by the person that there is no hidden disease within their body
- Reduction of any exacerbating factors identified that can be ameliorated
- Cognitive behavioural therapy,
- Anti-depressant drugs,
- Increasing exercise,
- Good sleep hygiene

Thirdly, the healthcare system should start educating the public into a new way of considering illness. The effectiveness of a public education approach to altering the accepted model of a particular illness has been shown for low back pain (a functional disorder) [46]; interestingly the public education also changed the behaviour of clinical staff. Changing clinical culture should improve individual patient care.

Next it must be recognised that health care is a process, not a single action. Few patients will follow a predictable pathway centred on one specific action. This is especially true for patients who have complex problems:

- any patient who has a long-term condition that fluctuates over time
- any patient with a condition with several diseases
- any patient who requires a series of specific treatments to achieve a good outcome.

These patients now use the majority of healthcare resources.

Thus in practice the healthcare system resource is rarely centred on a single constrained episode or organisation. Consequently commissioning and payment sys-

tems that focus on specific actions within the process will rarely be an appropriate way to manage the process, and they will often lead to less efficient and/or less effective patient care as clinical behaviour adapts to the payment system.

Financing and management systems need to recognise that most people, especially those with long-term and disabling conditions will need multiple inputs from many organisations over a prolonged time. They need to facilitate collaboration and cooperation across all boundaries, both within healthcare and between healthcare and other statutory and non-statutory organisations.

Fifth, this analysis shows that it is not possible to use specific criteria when considering whether a patient should or should not be seen by a neurological rehabilitation service.

The primary reason is that there may be many factors from many different domains that are influencing a person with a long-term condition but in any specific individual only some of these will be amenable to action. However across the population of people who will benefit from rehabilitation there will be individuals with almost any characteristic.

Thus if specific inclusion and/or exclusion criteria are used then inevitably some people who would benefit from specialist healthcare will be excluded.

There are many other reasons that have already been published [68], including a lack of evidence and a high probability that even for a specific intervention the criteria will not have appropriate sensitivity and specificity.

Finally the holistic model of illness emphasises that being ill is a social phenomenon, and emphasises that it is a person's social

context and personal context that probably have the greatest influence upon behaviour.

Therefore healthcare should always aim to return a person to their own context as soon as possible, and health services should always be fully aware of the person's context. For example specialist services should develop out-reach and supportive services so that more healthcare can be delivered to more patients more locally [69][70]. Secondary care services should collect data about a person's home and social circumstances at the earliest opportunity.

Moreover, one must recognise that leaving the sick role and stopping 'being ill' is a positive process and not simply inevitable. Healthcare systems should be very concerned with ending illness not simply through curing disease, but through ensuring that there are suitable resources in the community to allow an ill person to develop new roles in place of the sick role [71].

This means ensuring a range of suitable accommodation where someone can develop a new or adjusted set of social roles, and ensuring that the person can get to suitable venues to develop an active social life. Simply discharging someone home alone with all physical care needed is ultimately inhumane and will often lead to the person returning into healthcare as their only escape. Healthcare services need to work closely with organisations responsible for more general social policy. It is almost certainly in their interest to do so in terms of reducing healthcare costs.

## **Conclusion**

A systematic holistic approach to illness and healthcare can help in the understanding and management of the problems faced by individual patients. It emphasises that in most illnesses there are many factors that may contribute to the person's experience and that may be amenable to change when helping the ill person. It also predicts that in some people illness may arise without any disorder within the person; these are functional illnesses. It emphasises that most people with complex and/or long-term conditions will need multiple interventions from many professions working for different organisations delivered over long periods if we are to achieve the best outcomes.

This holistic model also suggests why and how the current problems in the healthcare system arise. It suggests that a competitive, market-driven system based on episodes of care and/or single specific actions is inevitably going to deliver worse health care; this prediction is amply demonstrated by the health care experiences in the United States.

The holistic healthcare model put forward here is, as far as I know, the first one to be defined and published. It undoubtedly can be improved. However progress and improvement will only occur through defining and publishing the theoretical models that underlie healthcare. This is a first step in a long journey.

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**Table**  
Lessons from WHO ICF model (based on ref 72)

Observation	Comment
<b>Time</b>	
The time frames are different at each level.	<p>Change and management at levels of pathology and impairment are generally quick (hours/ days), but change and management at levels of disability and handicap are generally slow (weeks/ months/ years).</p> <p>Therefore systems managing different levels should be separated; people with rehabilitation needs are inappropriately placed in an environment focused on disease management</p>
<b>Health services</b>	
Hospitals and health services focus on pathology.	<p>Hospitals are environmentally unsupportive of disability; hospital systems are procedurally set in short time frames (hours/ days); health service data is usually predicated on a definite diagnosis which is often not available, certainly at presentation.</p> <p>Therefore it may be necessary to have two systems, one for diagnosing and managing pathology and one for diagnosing and managing disability. Each would have different methods for commissioning, and would use different data to guide management of the system.</p>
Dependence at the level of disability determines main cost of long-term ill health.	<p>Supportive care provided is main resource used in health care, even in acute phase. The resources used are not related reliably to pathological diagnosis.</p> <p>Therefore payment for services should not be related to disease diagnosis; they should relate to dependence and to rehabilitation treatments needed.</p>
<b>Disability and context</b>	
Disability refers not only to 'quantity' (e.g. dependence or otherwise) but also to quality	<p>For some people it matters more how normally they act than whether they can undertake an activity; the social implications of altered behaviour may restrict that behaviour; measures rarely take account of the quality of task performance.</p> <p>Therefore outcome measures should consider the perspective of the person in addition to that of others.</p>
Disability is strongly influenced by the goals of the patient (the personal context)	<p>All behaviour is goal-directed, and so disability cannot be considered 'context free'; many factors including financial considerations may determine the activities undertaken by a patient.</p> <p>Therefore all treatment should be patient-centred, based on a good understanding of the patient's own specific goals, interests and concerns.</p>

Observation	Comment
<p>Observed disability also depends upon the physical and social context</p>	<p>How someone behaves is inevitably affected by environmental factors and may be significantly constrained by the environment. The 'environment' includes the capabilities, wishes and expectations of relevant others.</p> <p>Therefore all interpretation of outcome requires information about all aspects of context such as accommodation, time after onset, presence of family etc.</p>
<p><b>Relationship between levels</b></p>	
<p>The nature and extent of the relationships between levels are weak.</p>	<p>The <b>severity</b> of a person's illness (from their perspective) is rarely determined by the observed extent of disease. For example patients may have 'silent' pathology (i.e. disease without symptoms or signs).</p> <p>Therefore this gives scope for rehabilitation. It also implies that measures of the extent of pathology are poorly related to the extent of disability in many cases.</p>
<p>Causal relationships may extend in any direction, 'up' or 'down' the hierarchy.</p>	<p>The relationships are not all one way from pathology through to handicap. Changes in behaviour may 'cause' pathology. For example, electively not moving a shoulder may lead to the pathology of adhesive capsulitis (frozen shoulder).</p> <p>Therefore one must not always simply seek the cause of pathology in cellular or genetic domains; the cause may be in the context. The 'cause' of most lung cancer is the availability of cigarettes.</p>
<p>Not all illness need start from pathology</p>	<p>A systems analysis of the model would predict that illness may start at any level, and interact down the systems as well as up the systems. Abnormal beliefs (part of personal context) may cause as much disability as pathology (abnormal organ structure or function). Indeed it is noted that functional illness is common in neurological practice, and this model both predicts it and may help understand and manage it.</p> <p>Therefore management should focus on altering the perceptions, attitudes and behaviours of the ill person and those around the ill person.</p>
<p>Prognosis depends upon pathology (if present)</p>	<p>The prognostic field for an individual patient is usually determined by the specific disease, but the specific prognosis within that field for a particular patient is usually related to impairments and other factors.</p> <p>Therefore it is important that relevant expert doctors are integral to all rehabilitation (they are also needed to confirm the apparent, given main diagnosis and to diagnose any new clinical problems).</p>

Observation	Comment
<b>Measurement and normality</b>	
Measures should only encompass items from one level.	<p>It is invalid to add scores from items or measures covering domains from different levels.</p> <p>Therefore any existing measures or proposed new measures should be checked before use or development.</p>
'Normal' becomes much less easy to define, and becomes increasingly personal	<i>The metric against which structure, function, behaviour or performance is judged varies:</i>
<b>Pathology</b>	Structure or function measured against any human, with some allowance for age and gender.
<b>Impairment</b>	Structure or function measured against humans matched for age, gender, and other demographic characteristics.
<b>Activities</b>	<p>Behavioural performance and repertoire measured against:</p> <ul style="list-style-type: none"> <li>• Socially normative behaviour for some activities</li> <li>• Previous personal behaviour for some activities</li> <li>• Desired behaviour for some activities</li> <li>• Expected (e.g. by family) behaviour for some activities</li> </ul>
<b>Participation</b>	<p>Social role performance and social position measured against:</p> <ul style="list-style-type: none"> <li>• Socially valued and expected roles for whole society</li> <li>• Culturally valued and expected roles for local, personal society</li> <li>• Personally valued and expected roles</li> </ul>
<b>Miscellaneous</b>	
The terminology used all assumes abnormality	<p>There are currently no good words for the opposite of impairment, disability or handicap.</p> <p>The 'new' terminology of <b>limitations on</b> activities and participation overcomes some of this, though there is still no obvious opposite to impairment.</p>
Interventions may occur at many points	<p>While removal of the prime cause of an illness is the ideal, and this prime cause will often be at the level of pathology, interventions at other points are often also effective, especially when there is no pathology or when pathology cannot be altered.</p> <p>Therefore payment systems that only reward one specific intervention are an invalid way of funding the management of long-term conditions and will certainly distort good practice and make rehabilitation less efficient and effective.</p>