



VIEWPOINT

The need for a dis-ease model for medicine: illness, sickness, disease, disorder and predicament

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Abstract

This paper presents an alternative to the standard medical model with its focus on disease. Medicine has moved to a high technology informed practice to the detriment of a more personalised and family anchored humane practice. This is a major complaint of patients and their carers. Through presenting a developmental perspective to the manner in which we learn to present and manage our discomforts, our primordial dis-ease takes centre-stage. This necessitates an understanding of the interrelationship of illness experience, sickness attributions, medical practice with the predicaments with which are challenged daily.

Keywords: Disease, Disorder, Diagnoses, Medical model, Illness, Sickness, Predicament.

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Citation: Wilkinson, S.R. The need for a dis-ease model for medicine: illness, sickness, disease, disorder and predicament. *International Journal of Clinical Neurosciences and Mental Health* 2017; 4:3

DOI: <https://doi.org/10.21035/ijcnmh.2017.4.3>

Received: 01 Jul 2017; Accepted: 10 Jul 2017; Published: 31 Aug 2017



Open Access Publication Available at <http://ijcnmh.arc-publishing.org>

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“Without proper names language cannot speak the truth.”
Confucius

When desperate because I can't tolerate a situation, all I want to do is scream—which is the only thing a baby can do to alert others to their acute need. Being able to convey my dis-ease in a more nuanced way would help all those trying to help me. How do I get those names, more or less accurately, for what is troubling me? How does my body adapt to my unrequited needs when the response is slow or inadequate? My hope is that through disentangling the developmental processes, which provide us with this language of distress, subsequently we can also better understand the physiological changes of living with unrequited needs—and communicate more helpfully with each other, and with our patients and their families. Clarity in concepts can facilitate communication and ultimately benefit health. Here I will present for discussion a paradigm for medical practice: take care of the patient's **illness**, the concerns of the caregivers as shown in their attribution of **sickness** to their family members, note the patient's and the caregivers' various **predicaments**—and limit communication amongst health professionals to the idiosyncratic (in terms of person-specific) labels of **diseases and disorders**.

I would like to suggest that many crises in modern medicine have arisen because we have developed our practice based on a medieval view of children as mini-adults, rather than adults as overgrown children. The early caregiving which the adults received, left them with an ingrained set of expectations about how their display of discomfort ought to be responded to, where the threshold for a serious complaint should be placed, and the language with which to present their more-or-less differentiated complaints. So, to turn the tables, let us view dis-ease from the child's perspective and see if it can help us get out of the medical muddle when disease is conflated with all illness, sickness and predicaments—the muddle whereby technology trumps compassion, and personalised medicine is equated with knowing the person's genetic make-up rather than the balance between their personality and how it affects their illness experiences. The child starts with an overwhelming need for comfort which is sought from their nearest VIP¹. The child's developmental pathway towards a more nuanced illness-language of adolescence starts with the VIP's responsiveness, the timing and sensitivity, and the language in which they envelop the child. Not least: does the response assuage the child? Do they call that stirring in the stomach hunger, a stomach bug, or the churning of the stomach with a serious worry? Do they differentiate emotional stirrings from physiological changes, from disease?

Translating this initial caring dance to dis-ease terms, we have the child's subjective discomfort for which we use “**illness**”, and the VIP's diagnostic expertise used to attribute a state of “**sickness**” to the child. Sociologists use

¹I am using VIP for Very Important Person, who can be of either sex, both mothers and fathers, and need not be biologically related.

“sickness” for the process of attribution when employees deemed themselves unfit for work, or fail to function in their social role. It is a lay process determined by evaluation of level of function in the eyes of a responsible person with whom the person is in a dialogue. It reflects disability attributed to “morbus” [1, p.117]. I am here refining the use of sickness as the attribution being made by the VIP to define the state of the child based on their conceptualisation of the child's dis-ease, of which disease may be one of several possibilities, and which relates to how they evaluate change in the form to their child's functioning in their relationship.

In **Figure 1**, I have adapted Bronfenbrenner's concepts from his Ecology of Human Development [2] to show the relationship between the child's position, at say 10 years of age (the relative size and positioning of the Venn diagram components changes with age), with his own illness experiences, and the family system, for which Bronfenbrenner uses the term microsystem [2, p.22], giving rise to sickness attributions. The child also meets the microsystem of health professionals who attribute a disease/disorder diagnosis (see below) based on their training and perceptual biases.

VIPs are best guessers—and sometimes get it wrong. They make use of previous experience to safeguard their children. It is always more important to pick up on the possible more serious danger, however slim the chance. Doctors do the same. The VIP's brain works this way [3], and, the more serious the perceived threat, it hops over the time needed to reflect on whether there really is a danger to the child's health.

My suggestion is that we start a consultation with awareness of these two elements: we build an alliance with patients, whatever their ages, through identifying their subjective dis-ease, their illness, we build our alliance with the VIPs through identifying the premises they have used for identifying sickness, their observations and rationale for believing their children sick. The latter may well require a three-generation perspective so that the early learning stored in the implicit memory systems of the VIPs can be illuminated—and we can meet the caregivers with compassion, even if they have misunderstood the signals from the child, and labelled them idiosyncratically.

Crocodile tears may be distinguished from the real thing (as if there was a clear overlap, rather than a dimension of distress where the child can be seen as having ‘gone over the top’). VIPs identify eventual deceit, or, more helpfully, acknowledge the balance between the child's display of discomfort with the believed underlying experience. And doctors are no exception. How do we do it? What developmental processes bias our perception to leave us erring on the one or other side when perception is thought to be about 90% memory [4]? How important is it to fine tune our discriminatory skills when behind the crocodile tears there is a degree of distress? Trivers [5] suggests that the average person deceives himself about 200 times daily without this hindering good enough communication. In case you doubt

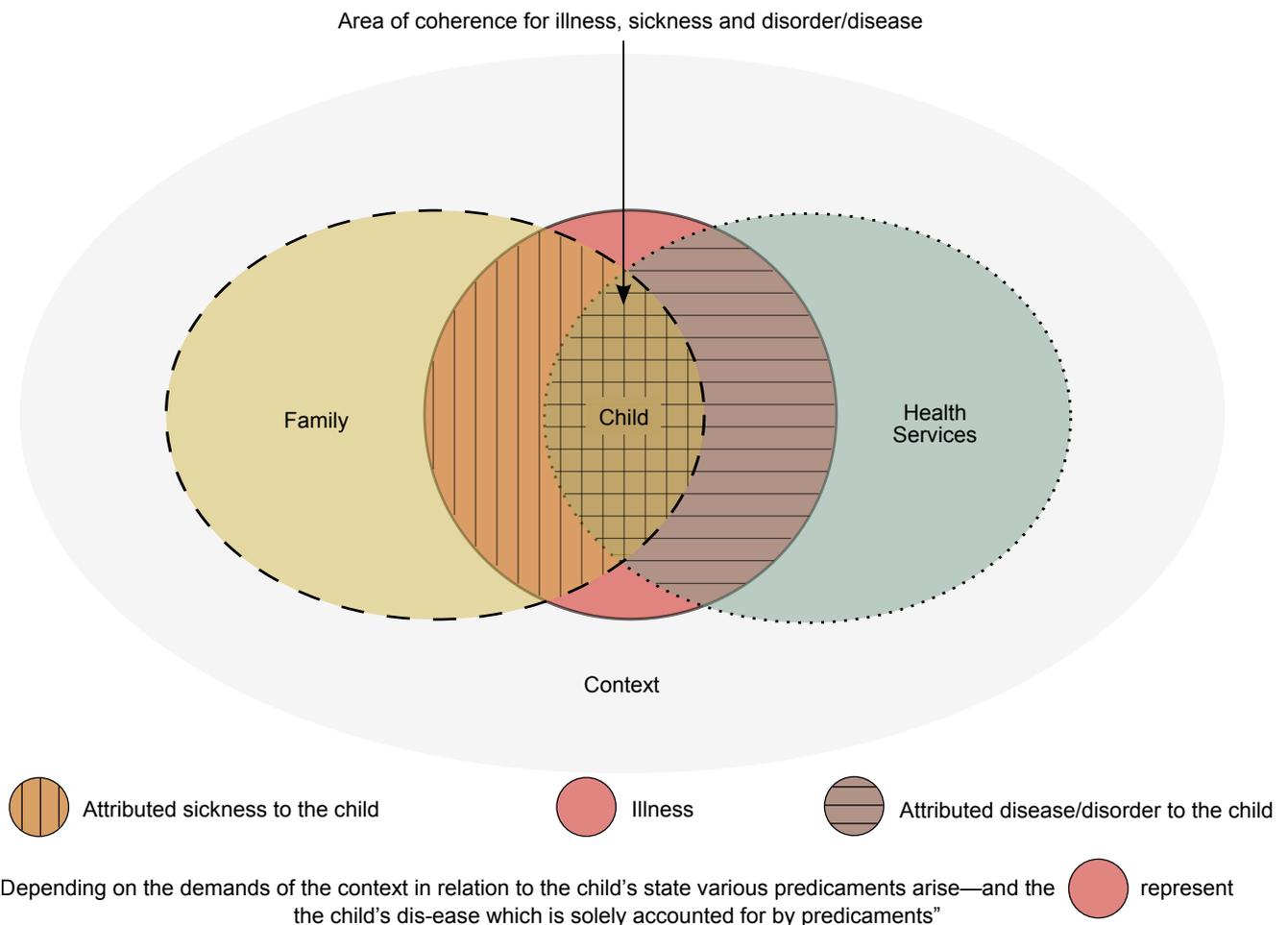


Figure 1. The ecology of dis-ease.

this frequency, remember that Wittgenstein pointed out that there is nothing as simple as deceiving oneself. Disentangling each other's various deceptions lead us up the paths illuminated by Laing's Knots [6]. There are the variants where we have learnt to maximise our self-containment and self-soothing, and hidden or disguised our dis-ease, as exemplified in Type A attachment strategies; and there are the variants where dis-ease is distorted and flagged to maximise its effectiveness in eliciting a VIP response, as in Type C attachment strategies [7, p. 118-211].

The VIP's attribution of sickness depends on there being a change in the quality of the way the child relates. What has made that difference? On this paradigm a child born with thalidomide deformities is neither ill nor sick—but the child does have a disability, a predicament, which taxes their VIP and poses challenges for usual development. There may be the additional predicament of stigma in the eyes of the neighbours. It is the same with any vulnerabilities present from birth, something of which the neurodiversity movement is trying to make people aware [8]. When we get into a predicament we attempt to find a way out whilst we keep face [9, p.5-46]. Predicaments need to be up there with illness and sickness as defining labels for dis-ease [10]. They need to be acknowledged—not diagnosed! But remember these are all different logical types

[11, p.127-141], governed respectively by foci on function, subjective distress and the concern of others. In the figure the dynamics of the microsystems correspond to the characteristics of each logical type. The context determines the form of the predicament posed for the child—and the predicaments of the health service and families in caring for the child (in Bronfenbrenner's terminology it corresponds to the macrosystem [2, p.26]).

And yet we haven't got to the central plank of medical practice, the focus on disease and disorder of the health service microsystem (Fig. 1). The labels we use can obfuscate through adapting outdated languages—take rhinitis, or confuse through the ever-changing limits set for a dimensional condition where the cut off point for high blood pressure or depression varies (see Coghill and Sonuga-Barke [12] for a clarification concerning the differentiation between categories and dimensions amongst the psychiatric disorders of childhood). Disorders give us the greatest headaches. As Kendell and Jablensky [13] pointed out diagnoses in psychiatry have no validity, but they have an essential utility. They are aids to communication amongst the initiated. Helpfully, we are reminded every so often, when the defining characteristics are redefined (for example DSM-IV goes to DSM5), that there is a continuing need to keep abreast of changing fads. In the meantime

bureaucrats continue with their reification of outdated labels for economic and other ends, just as parents excuse their skills by claiming their child has ADHD with an implied ‘the fault is all in you, not us’. Disorders and diseases are of different logical types, and the application of a disorder label, as if it reflected a reified entity, is yet another variety of logical confusion. When we address the area represented in the figure by cross-hatching there is no difficulty in agreeing—illness, sickness and disease/disorder cohere. It is here that communication between the family, the child and the health service representative is particularly potent in facilitating the development of an effective language of dis-ease. But it will be clear from the figure that there will be many scenarios where sickness can be seen to occur without illness being felt or disease/disorder diagnosed, illness without sickness or disease/disorder and disease/disorder without illness or sickness. Hopefully this understanding through a dis-ease model can help us avoid the traps posed through a lack of differentiation in the language we use if all is subsumed under ‘disease’. For example, with designing screening procedures the focus cannot be on illness or sickness. Predicaments are person specific and require adapted coping strategies, rather than treatment for the associated dis-ease, even though the person may believe himself ill. Health education in schools should be addressing how we cope with predicaments—and I personally believe that, before leaving primary school, all children should have learnt the skill of self-hypnosis.

So, my message is “keep it simple” through avoiding confusing these different logical types. They have too easily been equated to the detriment of our patients, their carers and those working for a fair distribution of resources to hard-pressed health services. Remember that all big fry were once small fry, who tried to survive in the adults’ jungle of missed opportunities. Disentangle this web so that:

- We meet our patients with a focus on their **illness** experiences,
- Meet their caregivers (VIPs) with an awareness of the source of their concerns, the basis for their attribution of **sickness**,
- Note the **predicaments** of both our patients and their VIPs – and acknowledge our own as workers within a health service,
- When putting all together, land on the best-fitting diagnosis of a **disorder** or a **disease** for communicating with professional colleagues
 - and ensure that diagnostic labels are not bandied about for purposes for which they are ill equipped, when offered to those who do not understand their vagaries.

Through distinguishing the different areas of expertise which coalesce in a consultation in this way I would hope people could optimise the working relationships that need to be established for successful health care and treatment. The particular conditions that I would expect to benefit

most, are those often regarded as nebulous by the health professionals, but particularly bothersome for patients and their VIPs—the somatoform disorders, which cost UK society more than the combined costs of both cancers and heart disease. I would hope the dis-ease differentiation could lead to attitude changes bearing more respect and compassion, and reducing conflict in consultations. Let’s take the currently most conflicted diagnosis—CFS/ME. The diagnostic label reflects a battle in which all parts are losing respect. The Chronic fatigue syndrome name emphasises patient illness experience, and is a typical example of a label for a disorder. Myalgic encephalitis/encephalopathy is optimal for those aiming for an alliance based on prioritising a disease model. I hope we can imagine that progress might be made if we included the sickness defining and maintaining processes, the diagnostic defining and maintaining processes, and the predicaments affecting the patient, the VIPs and health professionals involved. The consultation becomes muddled when there is a moral high ground amongst some parts of the medical profession for disease models—and the other actors become overwhelmed with face-saving manoeuvres, or are banished because of the lack of them. Disease, disorder, sickness and illness, within the context of life’s predicaments, need to be made explicit and given equal respect.

Competing interests

The author declares no conflict of interest.

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