‘Disabilitisation’ of medicine: The emergence of quality of life as a place to question the concept of the medical model

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Abstract

This article presents an archaeological inquiry into the early histories of Quality of Life (QoL) measures and takes this as an occasion to rethink the concept of ‘the medical model of disability’. Focusing on three instruments that set the ground for the emergence of QoL measures, namely, Karnofsky Performance Scale (1948), the classification of functional capacity as a diagnostic criterion for heart diseases (Bainton, 1928) and as a supplementary aid to therapeutic criteria in rheumatoid arthritis (Steinbrocker, Traeger and Batterman, 1949), I discuss how medicine, throughout the emergence of QoL, began to expand its gaze beyond the confines of the body to what that body does in daily life. Building upon Armstrong *et al.*’s notion of ‘distal symptoms’ (2007) and Wahlberg’s idea of ‘knowledge of living’ (2018), I propose the notion ‘disabilitisation’, by which I mean this very expansion in the field of clinical gaze, through which medicine has come to articulate diseases and their treatments in new ways, and in so doing, has inadvertently created disability as a new kind of knowledge category in itself – a category that is defined not through its reduction to mere pathology but through its dispersal into everyday life. I present the notion, not as a periodisation, but as a provocative discontinuity to the totalizing history assumed within the medical of disability, and in so doing, ask what, in fact, holds ‘the medical model’ together and whether there can be other ways of

understanding medicine's complex relationship to disability than what the concept of the medical model allows us to think.

Keywords

disabilitisation, disability, measuring health and disability, medical and social models of disability, quality of life

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This article takes the historical formation of Quality of Life (QoL) and its measurements as an occasion to question traditional criticisms of medicine developed in the humanities and social sciences. In an attempt at developing a 'critique of a critique', I begin with a summary of concepts that are inherently critical of medicine (such as the medical model), and move onto the history of making of QoL, which I term 'disabilitisation', as a way to take a distance from these criticisms, and open new avenues for understanding medicine's complex and evolving relationship to disease and disability.

Criticisms of medicine in the humanities and social sciences

The way Western medicine 'treats' disease and disability has long been studied in fields such as medical anthropology, medical sociology and disability studies, oftentimes from a critical perspective. For instance, following Arthur Kleinman's (1988) classic distinction between

'disease' and 'illness', a particular strand in medical anthropology has shown us how people experience illness and suffering in daily life as distinct from disease in the clinic. Medical sociology has introduced the notion of 'medicalization' (Zola, 1972) to think through how non-medical domains of life have been brought under the jurisdiction of medicine. The notion has paved the way for other concepts, such as 'biomedicalisation' (Clarke *et al.*, 2009), that have furthered our understandings of biomedical knowledge production. The strongest criticism of medicine has come, however, from within disability studies, as part of its 'demedicalization' of disability (Kasnitz and Shuttleworth, 2001). As disability scholar/activist Simi Linton writes, disability studies 'arose in part, as a counterpoint to the medicalized perspectives of disability emanating from the applied fields', such as health and occupational therapy, which resulted in what Linton calls 'Not Disability Studies' (1998: 132-3).

What are the epistemological differences between the ways medicine and disability studies[1] define disability? First, medicine locates disability within the individual body, its diseases, 'lacks' and 'abnormalities', that it then subjects to treatment. Disability studies and politics, in contrast, insist that disability is a *problem of society*: disability emerges from the discriminatory attitudes, oppression and barriers of a disabling society, not from the *impairments* of the body. Second, medicine uses statistical methods and standards that situate the healthy/abled/sane body as normal, against which those falling out of that arbitrary median range become 'pathological', 'deviant', 'aberrant', disabled. Disability studies, in contrast, theorises disability as human variation to be embraced, a resourcefulness to be learned from, and a socio-political identity to be celebrated. These differences constitute the binary framework of critical approaches to medicine in disability studies: the 'medical'[2] (or 'individual') and the 'social' models of disability (and, along with that, impairment versus disability). In this binary, medicine pathologises, and thus *individualises* disability while the social model turns to the social causation of disability.

While feminist (Crow, 1996) and phenomenological (Hughes and Paterson, 1997) critiques of the impairment/disability binary, and critiques of the social model (Shakespeare, and Watson 2002) have proliferated since the binary was formulated, understandings of the medical model remain rather ossified. More recently, scholars have begun to identify problematic consequences of the social/medical framework. Tom Shakespeare, for example, argues that the medical model has become 'a proxy for all that is wrong with traditional attitudes to disability', from medicalisation to professional authority to objectification, ableist ideas, and paternalistic research methods and practices (2006: 18). The result is that this 'powerful symbol' has become 'nothing but a straw person' (ibid.). In other words, the medical model risks reducing highly differentiated practices into a monolithic entity. The same is true for the ubiquitous use of related concepts, such as medicalisation and the biomedical model of disease, in social science critiques of medicine. These too can reify the conception of medicine. In this article, I seek to explore the dangers of this ossification as a barrier to effective criticism, through approaches to medicine developed in the field of science and technology studies (STS). In particular, this (sub)field has long argued that medicine is not a monolithic entity but comprises heterogeneous and often conflicting sets of practices that generate *multiple* objects, even though they are referred to medically as a *single* condition or disease (see Berg and Mol, 1998; Mol, 2002). This argument suggests that, as critics of medicine, we can become trapped in medicine's own epistemologies. For instance, Mol argues instead that we, following Foucault, look for 'noncritical strategies for escaping dominant ways of thinking', and suggests that 'a good way to escape from a medicine founded on pathology [might be] to wonder whether, in practice, medicine *is* indeed founded on pathology. This implies that instead of *criticizing* pathology's foundational role, we raise questions about it, we *doubt* it' (2002: 47). Taking Mol's suggestion as a point of departure, I ask: what if we do not *take the medical model for granted* but instead *doubt* it? Has medicine ever been a singular practice, with

definitive and frictionless objects of knowledge, as the medical model assumes it to be? Or is medicine composed of heterogeneous practices that create *multiple*, *unstable* and *evolving* objects even if they go by the same name (such as 'disability' or a specific 'disease')? Does medicine, in practice, actually apply the medical model? Or is the model an invention of social scientists as they sought to know how medicine knows its objects of knowledge?[3] What strategies can we develop to escape dominant ways of thinking, other than the criticism offered by the medical model, which has perhaps become too dominant a criticism and may prevent us from exploring medicine's evolving and multiple articulations of disease and disability?

There can be many ways to 'doubt' the medical model. In this article, I take as my entry point the emergence of QoL as a 'matter of concern' (Latour, 2004) in healthcare. QoL emerged within medicine and healthcare in the 1970s, and has since consolidated into a discourse in its own right. This history, I argue, gives us a more complex picture of medical knowledge than that offered by the model. First, however, I offer a brief account of where and how I encountered QoL, working at the intersection of disability studies, medical anthropology, social studies of medicine, and my own experience of chronic illness.

My encounter with QoL measures in the clinic

In an ethnography of invisible disabilities that I undertook in 2009-2010, I worked with people living with disabilities related to rheumatoid arthritis (RA) – a disease that I also have – and filmed them performing daily household tasks. In the process, I witnessed that my participants came up with an incredibly creative set of survival techniques in their everyday routines. To think through these encounters, I engaged with James Gibson's theory of affordances (1979) in ecological psychology, which considers the action possibilities that emerge from the relation between an organism and its environment. In developing an entirely new theory of affordances, informed by a critical disability and performance lens, I proposed the concept, 'micro-activist

affordances'. This term refers to how the experience of disability can become a way of forging new organism-environment relations; of improvising creative affordances, which would not have been imaginable outside the experience of disability (Dokumaci, 2017).

My ethnographic research coincided with the time that I, as an RA 'patient', was asked to fill in various questionnaires at the clinic. These asked me to rate the severity of my difficulties: 'Over the last week, were you able to dress yourself, including tying shoelaces and doing buttons?' (HAQ); during the past four weeks 'Have you felt downhearted and blue?' (SF-36). The questionnaires were designed to measure the outcomes of a medical intervention according to patients' perceptions, including the ease with which they perform their Activities of Daily Living (ADLs); their social and emotional functioning; pain, fatigue, and mood; and their overall health, well-being and happiness. This contrasts with traditional ways of assessing health outcomes, which use clinical markers, laboratory and radiological results, mortality rates and survival times.

As I engaged with QoL measurements as a 'patient', I was struck by a paradox. My instinct, as a scholar working at the intersections of disability studies and medical anthropology, was to find these instruments reductionist, seeking to represent on a five-point scale the heterogeneity of micro-activist affordances that I had studied. Still, they did not fit with traditional models of assessment either. These instruments did not seem to reduce disability to a disease or a pathology, but looked at how diseases manifested themselves outside the skin. They marked *a rupture* from traditional biomedical indicators of health and the broader medical model of disability. It was precisely this *mismatch* that led me to ask: How has medicine ended up developing measures for entirely subjective perceptions about the entirely 'non-scientific' phenomenon of everyday living? What does the medical model have to say about the emergence of a discourse that make patients' everyday experiences of living with diseases and treatments into a matter of formalised medical concern, called Quality of

Life? What can the discursive formation of QoL tell us about the enunciative regularities and limits of concepts such as the 'medical model' that we are so familiar with? Can the emergence of QoL be a way to de-familiarise the familiar criticism?

QoL analysed from a social studies of medicine perspective

Even though QoL is a relatively new concept in medicine, various social studies of medicine scholars have taken it up (see Armstrong, 2009; Armstrong and Caldwell, 2004; Armstrong *et al.*, 2007; Dokumaci, 2014; Wahlberg, 2018; Wahlberg and Rose, 2015). In their genealogy of the concept of health-related quality of life (HRQoL), Armstrong and his colleagues argue that 'the conceptualisation and measurement of quality of life began to change the relationship between symptom and illness that had dominated the discourse of clinical practice since the 19th century' (Armstrong *et al.*, 2007: 581). After tracing processes – from interwar developments in questionnaire technology to the postwar proliferation of symptoms checklists, pain questionnaires and ADLs, and the eventual condensation of these domains into HRQoL – they write, 'symptoms increasingly detached themselves from their pathological anchor and began new attachments to aspects of the patient's psychosocial world' (ibid.: 581) – what the authors call 'distal symptoms' (ibid.: 575).

Similarly, anthropologist Ayo Wahlberg looks at a set of practices, including patient schools tailored to create 'expert patients', practical 'living with...' guides, and clinical trials measuring QoL, and how they formulate life 'not as an anatomical, cellular or molecular affair", but as "something that is lived [and] experienced' (2009: 166). He proposes the concept of 'knowledge of living', which comes from the study of 'how it is to live with disease' through the very methodologies used by medical anthropologists, as a methodologically distinct category from the biological 'knowledge of life', which involves the study of cells, molecules, organs and DNA structures (2018: 729-30).

Both ‘distal symptoms’ and ‘knowledge of living’ are useful in thinking through transformations in medical perception since the emergence of QoL. Using the insights provided by these two concepts to push towards a ‘critique of a critique’, I propose that the historical emergence of QoL can be considered a process of, what I term, the *disabilitisation*[4] of medicine. The ‘disability’ in disabilitisation is, to be sure, not the same ‘disability’ as in disability studies (which is itself multiple). But, nor is it the ‘disability’ of which the medical model is presumed to be a model. Indeed, this is exactly the point I seek to foreground with the concept of disabilitisation.

Disabilitisation, in the way I propose the notion, is a way of historicising QoL and thereby demonstrating that, as Mol and others have shown for other medical objects, QoL (and its conception of disability and disease) *is* or *can be* more heterogeneous than a single ‘model’ can address. Disabilitisation, in this sense, refers to the way the medical model becomes disrupted and *disarmed* when confronted with histories, such as the emergence of QoL, that do not neatly fit within its binaries. These disruptions provide a basis for understanding, outside of them, the model’s (somewhat) overworked critique. In brief, to consider the emergence of QoL as a process of disabilitisation is to consider medicine *not as one thing but many*; and how attending to that plurality may keep us from over-consolidating or empowering medicine in the first place. In other words, rather than reproducing the medical model as an object of criticism, the notion of *disabilitisation* is meant to create a space for ‘*doubt*’ in our use of critical concepts that have become (perhaps) too familiar.

Trajectory

Available histories suggest that early health status assessments paved the way for contemporary QoL measurements (see Bowling, 2001; McDowell, 2006; McHorney, 1997; Prutkin and Feinstein, 2002). These antecedents include symptoms checklists, pain questionnaires, ADLs

and visual analogue scales (see Armstrong *et al.*, 2007). There are also various assessments of function that laid the groundwork for QoL (see Prutkin and Feinstein, 2002). These include: a four-grade categorisation of disability to assess the medical needs of old age assistance recipients in New York City (1934); the PULHEMS system of functional classification developed by the Canadian Army during the Second World War to crossmatch available manpower with the range of military tasks necessary to achieve a 'manpower economy' (1943); a five-grade functional classification developed at the Home for Aged and Infirm Hebrews (New York City) to 'give a complete picture of the condition' of its residents (Zeman, 1947: 723); a four-grade classification of functional capacity to diagnose heart disease (Bainton, 1928); a four-grade functional classification for RA (Steinbrocker, Traeger and Batterman, 1949); and a performance scale developed during a chemotherapy trial with nitrogen mustard in the aftermath of the Second World War (Karnofsky *et al.*, 1948). It would be possible to consider these instruments in terms of the objects they generated as precursors to QoL. I have chosen to focus on the last three because they were developed strictly under medical auspices and were among the first precursors to QoL.[5] Whereas the first three assessments of function (emerging from welfare administration, military practices, and institutional geriatric care respectively) can more readily relate to everyday living, the last three emerged from clinical research and practice. If one were to follow the axioms of the medical model, these would be the most likely to equate disease with mere pathology, lacking any consideration of patients' everyday living with disease (hence making disability a sole problem of pathology). And yet even in this point of origin, we can find a disruption to a straightforward application of the medical model – a disruption that I seek to make evident.

The article comprises four sections. First, I present a Foucauldian analysis of the three selected cases. I then trace the history in which QoL was made into a 'matter of concern' (Latour, 2004) both in public life and in healthcare. Third, I introduce the concept of

'disabilitisation' to describe the emergence of QoL as a new way of articulating disease and disability in medicine. Finally, I discuss how disabilitisation can provide a space for thinking beyond the medical model.

Case #1: Classification of patients' functional capacity in heart diseases, 1928

In 1928, the Heart Committee of the New York Tuberculosis and Heart Association, Inc. published *Criteria for the Classification & Diagnosis of Heart Disease*, which expanded the nomenclature for cardiac disease published in 1923. The foreword identifies 'the establishment of definite criteria for diagnosis' (Bainton, 1928: vi) as a next step in the development of the field, and highlights 'the fundamental difficulty…found in the definition of the diagnosis [of heart disease] itself' since the same diagnostic term may mean different things to different physicians at different times and places (ibid.: ix). To navigate this ambiguity, the Committee presents four types of criteria, each explained in a separate chapter. The chapters enumerate 'etiological criteria', which range from hypothyroidism to neoplasm; 'anatomical criteria', which include diseases of the aorta and pulmonary arteries, of the myocardium, of the endocardium and valves, of the pericardium, and their corresponding signs and symptoms; and 'physiological criteria', the main categories of cardiac physiology. After 73 pages of heavily medical terms, the book goes onto to introduce its final criterion, 'functional capacity':

> At the present time, there is no clinical test which will accurately measure the functional capacity of the heart. This section of the diagnosis refers, then, to the functional capacity of the cardiac patient, as modified by his cardiac disease. Only an approximate estimate of this functional capacity is possible, and the most useful guide is found in *the patient's ability to perform physical activity.* (Bainton, 1928: 87, emphasis added)

In the absence of a clinico-pathological marker to assess the heart's functional capacity, a *surrogate* is invented: 'the patient's ability to carry on ordinary physical activity in so far as this is modified by the functional capacity of the heart'. The phrase 'ordinary physical activity' refers to 'all of the activities which would be expected of the patient had he a normal heart' (ibid.: 88).

While this ability to perform daily activities is a new criterion in the diagnosis of disease, it must be estimated using traditional clinical methods: through taking 'a careful history of the patient's symptoms on effort', created by asking how 'walking on the level or up a grade' or ascending stairs or running affects the patient, and where needed, by directly observing the patient perform the exercise (Bainton, 1928: 88-9). When it comes to rendering this knowledge enunciable, analysable, and measurable, however, something new is introduced into the diagnostic process: the use of a four-grade classification[6] to rate the patient's capacity to *perform daily activities*. Just as earlier chapters map out anatomical criteria and ways of knowing their signs (such as tapping or listening), functional classification appears as *the* diagnostic means of making functional capacity analysable and measurable. Through the production of a classification table, *the patient's ability to perform daily activities* becomes as significant as clinical signs in the diagnosis of a disease.

In their concept of 'distal symptoms', Armstrong and his colleagues discuss how 'the clinical gaze (Foucault, 1973), which for over a century had been firmly fixed on the pathological lesion, began to form new structures of perception, of organising and thinking about the nature of illness' through the emergence of new tools for health assessment (Armstrong *et al*. 2007: 574). In 'pathological medicine' pain in RA, for instance, would be a clinical symptom, a proximal indicator of an underlying pathology (ibid.: 575). But with the emergence of ADL scales, the 'inability to climb stairs' or perform other daily activities

became symptoms in and of themselves – symptoms as 'more downstream effect[s] of the disease' rather than 'immediate manifestations of pathology' like pain (ibid.). Armstrong *et al.* locate the emergence of distal symptoms in the postwar period (particularly the 1970s onwards) when QoL was consolidated into a formal concept. I argue that this consolidation can be traced to a much earlier period, in the classification of functional capacity that I have just described. (Even though it used clinical methods to assess functional capacity rather than the patients' own formalised estimates as identified in Armstrong *et al.*). It is precisely in the definition of this new diagnostic criterion, and its operationalisation by way of a table, that we can identify 'distal symptoms'. Functional capacity of the heart is not rendered enunciable through the workings of 'the clinical gaze', which looks at the 'tangible space of the body' to find hidden 'secrets, invisible lesions, and the very mystery of origins' (Foucault, 2003[1973]: 150). Instead, this capacity becomes knowable through *its effects on the patient's everyday life*.

Naming the patient's ability to perform activities of daily living as a diagnostic criterion in itself, and in instituting a classification system that renders this criterion enunciable, the *Criteria* extends symptoms beyond the envelope of the skin to everyday life. When a functional criterion is added to etiological, anatomical, and physiological ones, the clinical gaze extends beyond the inner workings of the body to see what this body *can do in life*. Moreover, functional capacity is not merely an add-on to 'objective' criteria (i.e. etiological, anatomical or physiological) – it is its own set of criteria that renders its own particular diagnostic information. As the Heart Committee wrote, functional classification 'should not be influenced by the anatomical diagnosis or by the prognosis', and 'should depend solely on the functional capacity of the patient at the time of the examination' (Bainton, 1928: 87).[7] And once functional capacity offered a new way of *looking at* diseases, and a diagnostic system had been put in place, it would be taken up by others (see Zeman, 1947: 721-2).

Case #2: Classification of functional impairment in Rheumatoid Arthritis, 1949

The *Criteria* discussed above delineates patients' ability to perform daily activities both as diagnostic and therapeutic criteria. This report does the opposite. In its recommendations for uniform therapeutic criteria for RA, the *Classification* considers 'subjective symptoms…unreliable' (Steinbrocker, Traeger and Batterman, 1949: 662) and notes that while functional capacity often correlates with disease activity, it 'may vary considerably in spite of an unaltered rheumatoid process, or as a result of such different procedures as orthopedic measures, physical therapy, psychotherapy, and many others which improve function without altering the activity of the disease' (ibid.: 660). The report emphasises the importance of 'distinguish[ing] between those therapeutic agents which show measurable objective effects and those which only influence subjective and/or functional features of the disease'. It concludes that '[f]or that reason especially, the criteria must be based entirely on objective evidence' (ibid.).

TABLE 2.—*Classification of Functional Capacity*

Class	
I	Complete Ability to carry on all usual duties without handicaps
II	Adequate for normal activities Despite handicap of discomfort or limited motion at one or more joints
III	Limited Only to little or none of duties of usual occupation or self care
IV	Incapacitated, largely or wholly Bedridden or confined to wheelchair; little or no self care

Table 1. Classification of Functional Capacity (Steinbrocker, Traeger and Batterman, 1949: 660). Reproduced with permission from *Journal of the American Medical Association*. Copyright©(1949) American Medical Association. All rights reserved.

If functional capacity and subjective experiences are deliberately excluded from treatment evaluation, why is the *Classification* of interest? The answer lies within the broader 'system of classification and evaluation' (Steinbrocker, Traeger and Batterman, 1949: 662), in which this therapeutic criterion is to be incorporated. Like the committee on cardiac diseases, the committee on RA begins by noting 'the manifest difficulty inherent in therapeutic evaluation in any disease of unknown causation with no specific treatment' (ibid.: 659), among other confounding factors that impede the evaluation of results, notably subjective factors, especially pain, psychogenic and psychological influences, and *patients' level of functioning*. To provide a standardised process of treatment evaluation, the report proposes a four-grade system of therapeutic classification *based on objective information only*, namely clinical, laboratory and roentgenic evidence. But then, it adds:

> In the course of the Committee's efforts to arrive at practical therapeutic

> criteria, it became increasingly clear that the effective use of such standards requires agreement on other preliminary considerations. These have been designated as supplementary aids to the therapeutic criteria. They consist of a definition of rheumatoid arthritis, a classification of the stages of rheumatoid arthritis, and a classification of functional impairment. (ibid.: 660)

Clearly, therapeutic criteria based on objective evidence cannot stand alone. They require a *functional* supplement (table 1) with which *daily living with* disease becomes indispensable to medical diagnosis. With this functional supplement created, the ease with which patients live with their diseases in the everyday becomes a set of statements and an essential form of knowledge, even though it is apparently sidelined as merely a supplemental aid. The key role attributed to functional classification can be observed in the Committee's statement: 'The first consideration in undertaking the treatment of a patient with rheumatoid arthritis is to determine: (1) the stage of the disease, (2) the presence of rheumatoid activity, (3) the degree (class) of functional impairment' (Steinbrocker, Traeger and Batterman, 1949: 662).

Case #3: Karnofsky Performance Scale, 1948

The final case study belongs to an experimental chemotherapy trial undertaken at the Sloan-Kettering Institute for Cancer Research (SKI) in New York.[8] Historians of medicine note that until the beginning of the Second World War, chemotherapy was considered less scientific than surgery and radiation, and often likened to quackery (see Bud, 1978: 440; Gaudillière, 2009: 498). In the wake of the war this situation began to change, particularly in the United States. Chemotherapy afforded ways to connect experimental investigations with clinical applications – a strategy well suited to the postwar enthusiasm for 'organized science' (Bud, 1978: 429-35).

The National Cancer Institute was established in 1937 and a rise in research funding for chemotherapy followed. Another impetus for the rise of chemotherapy was the translation of wartime research on poisonous gases and nutrition into a 'model [for] civilian clinical research' (Gaudillière, 2009: 498). This research model would provide "a firm basis for the development" of early chemotherapy screening programmes (Zubrod *et al.*, 1966: 350).

The Karnofsky Performance Scale (KPI) emerged from a screening programme initiated at the SKI. Its author, David Karnofsky, had studied the biological effects of mustard gases on goats under the Chemical Warfare Services (Burchenal, 1970: 549). Upon his discharge, he worked at the SKI, joining its director, Cornelius Packard Rhoads.[9]

Table 2. Performance Scale (Karnofsky *et al.*, 1948: 635). Reproduced with permission from John Wiley and Sons. Karnofsky, D. A., Abelman, W. H., Craver, L. F. and Burchenal, J. H. (1948) 'The Use of Nitrogen Mustards in the Palliative Treatment of Carcinoma', *Cancer* 1(4): 634-56. Copyright © 1948 American Cancer Society.

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

At SKI, Karnofsky continued his investigations on HN-2, nitrogen mustard, on humans, and in a 1946–1948 study he and his colleagues tested its potential as an anti-cancer drug on

35 patients with inoperable carcinoma of the lung (and, for comparison, 18 other patients with inoperable neoplasms). Recruited patients had not responded to or were considered unsuitable for roentgen-ray therapy, or were relapsing after a temporary response (Karnofsky *et al.*, 1948: 634). In other words, this 'highly experimental treatment' was for palliative purposes, 'a last attempt to intervene rather than let the disease take its course' (Timmermann, 2012: 4).

To evaluate the effectiveness of this aggressive treatment as a potential antitumor agent, the researchers took four criteria into consideration. The first criterion, 'Subjective Improvement' (SI), was evaluated in terms of how the patient felt; whether appetite and strength was increased and whether he was relieved of symptoms (Karnofsky *et al.*, 1948: 634). Instead of being measured objectively, these factors were assessed in general terms, indicated as G (good), F (fair) or 0 (none) (194). The second criterion, 'Objective Improvement' (OI) involved 'quantitatively measureable' fields such as decrease in the size of lesions, and nodes, and gain in weight (Karnofsky and Burchenal, 1949: 194-5), indicated as 0, 1+, and 2+. The third criterion, 'duration of improvement' was measured in weeks beginning from the administration of the agent to conclusive signs of relapse.

While subjective symptoms were formalised as therapeutic criteria in themselves, the authors, like the committee on RA, considered these criteria to be 'a notoriously poor method', and prioritised objective measurement over subjective ones as 'the most substantial method of demonstrating activity' (Karnofsky and Burchenal, 1949: 194). Thus, while SI and OI could occur simultaneously, OI alone was the yardstick to demonstrate treatment effectiveness. Of crucial importance, however, was a third possible scenario in the researchers' study design, namely when the patient improved both in subjective and objective terms, while *the way he lived with the disease* did not:

> The fact that subjective and objective evidence of improvement can occur in a

> patient, while the patient remains bedridden, has suggested to us the need for another criterion of effect. This has been called the performance status, or PS. It is a numerical figure, in terms of percentage, describing the patient's ability to carry on his normal activity and work, or his need for a certain amount of custodial care, or his dependence on constant medical care order to continue alive. These simple criteria serve a useful purpose, in our experience, in that they measure *the usefulness* of the patient or *the burden* that he represents to his family or society. (ibid.: 195-7, emphasis added)

The fact that people do not get cured, but live with chronic diseases for the rest of their lives, necessitates and even legitimises the consideration of 'living with' (Wahlberg, 2018) a disease as a medical outcome. In this particular study, however, it is not only the question of chronicity, but also *the specificity of the treatment*[10] that makes daily living with disease a matter of concern to medicine. Not only does nitrogen mustard fail to cure the disease, if it were to prolong life, it would only do so at a potential 'expense' to patients, their families, and society. In other words, when testing a drug that can at best be expected to prolong lives, and where those prolonged lives would not always prove 'useful' (in the wording of the researchers) to the individual, his family or society, looking only at what is going on inside the body proves too limited a way of assessing therapeutic effectiveness. The particularities of the disease and its treatment require that disease be viewed not solely as a pathological phenomenon (inside the confines of the body) or as a series of symptoms, but as *a phenomenon lived in the everyday*. That is, in terms of *what patients can and cannot do in daily life*, and *what others have to do on their behalf*.

To measure performance status (PS) the authors introduced a scale (table 3)[11] that expressed living with a disease and its treatment as varying degrees of ability to perform

'normal' daily activity, ranging from as independently, effortlessly and symptom-free as possible, at one extreme, to no longer alive on the other. These four criteria (including the PS) yielded the following results:[12] four patients showed some improvement in PS but no OI, and their SI was unchanged; six patients showed no improvement in PS but some improvement in either or both the two other fields; three showed some improvement in PS and in either OI or SI; 10 patients showed no improvement at all; and fourteen patients improved in all three categories. Based on these outcomes, the authors conclude that HN-2 had 'immediate palliative effect of varying degree in 74 per cent' of the cases; but this response was temporary, and there was no evidence that the medication had a significant impact on the course of the disease (Karnofsky *et al.*, 1948: 653). In fact, given the lack of significant therapeutic effectiveness and the risks and side-effects involved, the authors recommend, 'HN-2 must not be used indiscriminately. Its use in a given case may be justified if there is some prospect that it might relieve discomfort or distressing symptoms or prolong useful life' (ibid.: 655).

Here again, the nature of the disease, much like that of RA, has clearly complicated the process by which the treatment was going to be assessed for its outcomes, mainly because it lacked a once-and-for-all cure. But unlike the therapeutic criteria for RA, which was a generic framework for all treatment regimens, the PS was developed to measure the effectiveness of *a specific agent* – one that was, in fact, toxic enough to owe its emergence to chemical warfare. This very toxicity further complicated the process. The difficulties involved in assessing its medical outcomes becomes clear in the authors' observations below:

> If a drug is of curative value there should be relatively little difficulty in ascertaining this fact. Unfortunately, such drugs are not known, and most agents proposed for the treatment of cancer can only be expected to modify the course of the disease, or alleviate some of the symptoms. In evaluating drugs

> in this range of effectiveness, particularly in a disease as complex and variable as cancer, one is faced with a formidable task. It almost appears that *the ease in determining the activity of a drug will vary directly with its true effectiveness.* (Karnofsky and Burchenal, 1949: 191, emphasis added)

It is within these constraints that the researchers came to invent a scale that would allow them to assess not (just) how much the tumour shrank or how long it took before a relapse, but (also) what the patient was *able or unable* to do during (potential) shrinkage and remission. What came to be known as the Karnofsky Performance Scale enabled the measurement of this emergent object of medical concern. One might say that the instrument not only *did not* reduce disease to mere pathological markers, but owed its very emergence to the inadequacies of doing so, given the particularities of the type of disease and the highly experimental treatment.

Furthermore, the scale was not designed to measure a 'distal symptom' if this symptom is understood to be a linear consequence of an underlying disease progression or remission. What was to be made enunciable through the use of the scale did not have to be a direct correlation of (potential) tumour shrinkage or relapse. The authors emphasise that: 'While it is important to know that subjective and objective improvement have been produced, the picture is filled out if we also know whether the patient remained flat on his back or was able to return to work' (1949: 197). KPS was *not* developed merely to support what objective and subjective measures had already proven, but because it might contradict subjective and objective improvement. Just as functional classification of cardiac patients was designed to serve as a diagnostic criterion in itself (not an appendix to objective criteria), KPS was designed to serve as an outcome measure that allowed the researchers to 'fill out the picture' and assess outcomes in new ways.

Returning to the medical model: The question of 'function'

To discuss assessments of function as part of an attempt to question the medical model may appear counterintuitive or paradoxical. Disability scholarship has long taken issue with the way disability is traditionally defined by 'functional limitation' in practices ranging from rehabilitation programmes to official statistics and welfare services. As many have noted, this has to do with the history of defining disability[13] in relation to working capacity, which in turn has to do with the emergence of nation-states. One of the main claims of early British disability studies is that the transformation to an industrialised capitalist mode of production resulted in 'the creation of the disabled individual'; as, in the process, 'what was essentially a labour market issue [was turned] into an individualized medical problem' (Oliver and Barnes, 2012: 16). As Deborah Stone also shows, disability emerged as an administrative category in welfare states as a way to control labour supplies (1984: 26). Two distributive systems, work-based and need-based, Stone argues, defined how wealth and services should be distributed in capitalist societies. But the question of how to determine who 'truly' belonged to which system disrupted their distributive logic. Disability was made into a bureaucratic category to solve this irresolvable dilemma. 'Validated' by the clinical gaze, Stone claims, the category of disability would legitimise exemption from paid work and the 'true' need for social aid. Assessments of function designed to crossmatch an impairment with the requirements of work or everyday living, have since been extensively used by welfare bureaucracies, government programmes and insurers to determine whether and how much a person is worthy of public assistance.

Given this history, functional criteria hardly seem worthy disruptors of the 'medical model'. In fact, disability scholarship has long called to task such reductionist assessments of function and their incorporation into 'fit for work' evaluations, and the calculation of social security benefits, compensation, pensions and disability living allowances. Identifying the 'individual model' of function as problematic, Mike Oliver, for instance, writes that it 'focuses

on the functional limitations of individuals in attempting to use their own environment'. In contrast, the social model 'sees disability as being created by the way housing is unsuited to the needs of particular individuals' (1983: 25). In this perspective, the instruments discussed above do not appear to disrupt the medical model. Disablement as a social and political process is certainly not their concern. Further, these instruments preserve the pathology-disease-disability causal link, and do not implicate inaccessible environments and discriminating attitudes, thereby reducing disability to impairment, to a 'problem' of the individual body (as has long been argued with the concept of the medical model).

But what if the disease to which disability is reduced is *not about biology, anatomy,* or *pathology* either? This is the question I want to raise with the notion of disabilitisation. In the classification of functional capacity in cardiac diseases, we are not dealing with heart rates. In the functional classification of impairment in RA, we are not talking about sedimentation numbers. In the KPS, we are not looking at tumour sizes. In short, we are not dealing with disease characteristically defined in the medical model as strictly a 'problem' of the body, its pathologies and abnormalities. I call attention to the three instruments precisely for this reason. No matter how narrow their scope, these tables and scales expand the clinical gaze beyond the body to *the everyday activities of that body*. In so doing, they bring about a new way of looking at disease itself. This new way of *seeing* and *knowing* disease (alongside other historical contingencies I will address later) would, over time, extend beyond *how a body functions* to how 'well' it lives in a social world throughout the making of QoL that I call disabilitisation. My argument is that it is precisely disabilitisation, and the shift in medical perception that emerges from it – the shift from the inner depths of the biological body to patient's everyday lives – that challenges the medical model.[14] Thus, I discuss the three instruments not because of what they do in themselves (i.e. classify function) but because of the history they belong to – the formation of QoL – and what that history of disabilitisation does *to* the concept of the

medical model.

Now I shift to this history and trace how QoL has emerged as a 'matter of concern' both in public life and in medicine. My argument is that the history of QoL can either situate its emergence outside the medical model (in a way that challenges its validity) or if it were to be incorporated into the model, the critiques embedded in it would become so dilated that it would not hold together with any coherence.

The making of Quality of Life into a 'matter of concern'

Even though I discuss QoL in relation to medicine, the notion emerged, not from medicine, but from what came to be known as 'social indicators movement', or rather, in the affluence 'crises' that have beset advanced industrialised societies since the 1960s (Armstrong and Caldwell, 2004; Noll, 2004; Rapley, 2003) as 'developed' nations began to face the societal and environmental costs of 'progress', 'great society' and economic growth with rising crime, overpopulation, pollution and housing problems. Amidst growing concerns over looming crises, social scientists began to develop surveys, statistics and indicators to measure subjective variables such as happiness, well-being and life satisfaction. The idea of 'quality of life' became the springboard for these instruments, which were intended to monitor social progress, evaluate welfare, and more broadly, create 'an information base which supports the policy making process' and the setting of priorities (Noll, 2004: 154). As doubts increased as to 'whether "more" should continue to equal "better"', the notion of quality of life came in 'as an alternative to the more and more questionable concept of material prosperity in the affluent society' (ibid.: 3). Regardless of whether people thought societies were headed towards progress or decline, 'all agreed that quality of life was the goal and potential arbiter of the debate' (Armstrong and Caldwell, 2004: 368). The concept was vague enough that differing viewpoints could find common ground and set 'a common goal often across very different

political programs' (ibid.: 363). Through its ambiguity, quality of life trickled across modern societal domains, from advertising to public policy. This did not happen independently of other contemporaneous developments, however. With the rise of corporatism and consumer movements in the 20th century, concepts such as 'service quality assessments', 'consumers', 'choice', 'value for money' and 'satisfaction' entered into the rhetoric of governments, public policy and service sectors, such that 'the idea of quality of life has come to be intimately bound up with the broader discourses of managerialism and corporatism in contemporary Western societies' (Rapley, 2003: 124-5).

Medicine was no exception to broader developments. The postwar period saw an unprecedented rise in drug discoveries and medico-technological inventions but not all of these advances delivered their purported benefits, or when they did so, their biological benefits were not always accompanied by subjective improvements. In fact, saving or prolonging life (from otherwise fatal diseases) could come at a high 'human cost' to patients (Armstrong and Caldwell, 2004: 364), as with aggressive chemotherapy treatments like the agent used in Karnofsky *et al.*'s study. At the same time, successful medical interventions and rising living standards contributed to the growth of ageing and chronically ill populations, including 'people living with and beyond cancer' (MacMillan Cancer Support, 2017), whose care needed not just a focus on survival, but on '*living well*' (Petchey, 2016).

Meanwhile, in 1948 the World Health Organization's constitution famously defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. Studies in social medicine and epidemiology from the 1970s began to call critical attention to medical outcomes and the lack of correlation between the amount/type of care provided and the level of improved health (see Bury, 1994; Timmermans and Berg, 2003: 15). These studies, Bury notes, coincided with a 'restructuring of welfare' and cost-containment efforts in late modern societies, particularly as healthcare became more and more

'extensive and expensive' (1994: 123). The very idea that the outcomes of treatments can be assessed systematically, he adds, quickly became linked to 'the issue of value for money' (ibid.). As discourses of managerialism and corporatism begin to enter into the governance of healthcare, the new 'managers' and 'purchasers' of services have sought *information* and *evidence* on which to base decisions on resource allocation in overstrained health systems. With the infiltration of consumer culture, the category of patients as recipients of care has morphed into that of active 'consumers', who can make informed 'choices' among treatment products (see Rapley, 2003). These consumers can hold healthcare providers and controllers accountable for their services and *the outcomes* they produce (Ware, 1984: 2316). With this 'outcomes movement' came the idea that changes in health resulting directly from antecedent medical care could be assessed so as to document the effectiveness of healthcare services, monitor quality of care, plan optimal resource use and set future health policies.

It was within such 'various fields of constitution and validity' (Foucault, 2010[1972]: 4) and contingent histories ranging from economic concerns to policymaking and epidemiological changes, that QoL emerged as a new object of knowledge and a 'matter of concern' in medicine. QoL became a versatile tool to address a whole new set of tensions and questions, through which medical knowledge and healthcare were beginning to be articulated (see also Armstrong and Caldwell, 2004: 368). Where there was little or no chance of a cure, QoL provided medicine with new goals. When lifesaving and prolonging treatments began to take their toll (with adverse effects like toxicity and nausea), QoL offered a new criterion for both drug development and approval, and for clinical decision-making. When alternative treatments had equivalent biological outcomes, QoL provided a new means of comparison for policymakers to find the "best buys", or for the pharmaceutical industry to gain competitive advantage. Where medicine's professional authority was being called into question through the rise of an evidence-based paradigm and outcomes movement, QoL measures offered a means

to oversee performance and assess quality of care. In an era of ageing and chronically ill populations, generic QoL measures enabled research in health services to make comparisons across different disease populations in terms of the 'burden' they posed. Preference-based QoL metrics like Quality-Adjusted Life Years (QALYs) allowed policymakers and economists to compare treatments targeting different diseases and their health 'gains'. In sum, from newly-emerging consumer-patients who should be able to make 'informed' choices between alternative treatments, to healthcare planners seeking 'evidence' for 'best buys'; from regulatory authorities that encourage the use of QoL endpoints in clinical trials, to the pharmaceutical industry who incorporate QoL data into product labelling, QoL turned out to be a resourceful and adaptable tool addressing the vested interests and concerns of various healthcare actors.

The consolidation of QoL in medicine did not happen overnight. As Armstrong's genealogy (2009: 114) suggests, it has taken decades of 'stabilising' efforts to make QoL into a 'hard' scientific fact, a measurable clinical endpoint, and the 'thing' that we all now have. First was the 'advocacy phase', when QoL appeared mostly in discursive and educational publications that worked hard to 'sell' this rather vague notion to a doubtful medical profession as a 'new goal for medicine' (ibid.: 105). Once this new rhetoric begun to gain currency, attention was turned to making this nebulous concept a measurable entity, and an applicable clinical endpoint. From the 1980s, publications surged in which new QoL instruments were designed and tested, the methodologies of instrument development were addressed, and more and more diseases and conditions were considered in terms of their effects on QoL. By the 1990s, QoL publications came to be dominated by the area in which QoL is today mostly deployed: *outcomes research* (ibid.: 107-8). In this phase, now-formalised QoL instruments were used to evaluate the outcomes of medical interventions, most notably to compare treatment effectiveness in randomised clinical trials (ibid.: 109).

As psychometric and other empirical methods are invented; as more 'precise' techniques of measuring subjective states are introduced; as the field of quantifiable and classifiable domains is expanded (e.g. pain, fatigue, moods, feelings, social interactions, well-being); as new diseases and conditions are rendered relevant in terms of their effects on daily living; and as more and more specialties (e.g. gerontology, psychiatry) and actors (clinical trial units, policymakers, regulators, healthcare funders, governments) take interest in these instruments, QoL has become a discourse in its own right, and 'an industry in itself' (Bowling, 2001: 10). But, as Foucault reminds us, the autonomy of a discourse does 'not give it the status of pure ideality and total historical independence' (1972: 164). Indeed, as I summarized above, the production of QoL cannot be understood in isolation from other contingent events, processes and practices. Some of these were 'not themselves of a discursive order' (ibid.: 164), such as public concerns about a looming social crisis, curbs on public expenditures and the restructuring of welfare systems. Others were of a discursive order but not necessarily of medical origin, such as the functional assessment developed for recruits in wartime and measures of well-being and happiness introduced by the social indicators movement. Some others came directly from medical discourse but predate the introduction of QoL, such as the three assessments of function analysed in this paper.

From a contemporary perspective in which QoL is established as a discourse (and an industry) in its own right, the instruments analysed in this paper hardly qualify as QoL instruments since the discourse distances itself from crude assessments of physical function. Instead it frames itself as a broad construct that also includes emotional, social and cognitive functions as well as domains such as well-being, life satisfaction and happiness. But, genealogically speaking, one can argue that it was because these crude instruments (alongside the aforementioned discursive and non-discursive developments) put in place certain possibilities and opened up new ways of mapping objects of knowledge, that the discourse of

QoL could have emerged. These assessments, no matter how narrow their scope, made it possible to take a clinical perception beyond the body and situate it in patients' everyday lives in formalised ways. Once this formalisation had occurred it could be rectified and remade within newly-developed instruments, with which medical perception would now look not at only *how a body functions;* but also how 'well', 'happy', 'satisfied' the *patient* feels, how 'good' her life is, and how much 'quality' it has. Surely, the daily living measured and the disability made enunciable in the KPS is not the same as that rendered knowable through the use of, say, the EORTC QLQ-C30.[15] Nor is the formulation of the ability to perform everyday life as a therapeutic criterion in RA (1949) the same as the ability formalised within contemporary measures of QoL in RA. We are not, to quote Foucault, 'dealing in each case with the same discursive event' (1972: 143). But from a genealogical lens, it was because these rudimentary instruments turned the body that performs functional tasks in daily life into a classifiable, knowable and measurable category that this category could be remade into a body that has emotions and moods, gets tired, feels pain and symptoms, and is gradually transformed into 'an individual' that socialises, and has a good, happy, quality life.

In sum, it was, on the one hand, new ways of mapping diseases that were opened up by these crude classifications of function (as well as by social indicators movements, developments in psychiatric methods and questionnaire techniques); and it was, on the other, new matters of concern to medicine that were brought up by non-medical processes (i.e. economic, epidemiological, political and social) that have made QoL into *a new way of knowing and thinking* in medicine. I argue that it is precisely this history of disabilitisation, its conditions of possibility, and the shift that it incurs within medical objects of knowledge – from pathologies and lesions[16] to physical, social, emotional function, activities of daily living, happiness, well-being and life satisfaction – that opens up a space to question the medical model and its basic tenets. Because the questions are:

- How can we explain the emergence of a construct characterised by a history of 'distancing' medical perception from intra-corporeal lesions to patient's everyday social worlds (Armstrong *et al.*, 2007: 581) with the concept of a medical model that assumes medicine to reduce disability to disease, and disease to pathology? The making of QoL could in fact be read as a continuous manifestation of the medical model's limitations rather than of its successful applications.
- How can a construct which, despite the decades of 'stabilizing' work to make it a scientific fact, is still full of frictions and offers no consensus on with regard to *what* it is and how it should be measured, be held together by the idea of a medical model that rests only upon only fixities when it comes to articulating medicine's objects of knowledge? (Within the history of QoL measures, it becomes clear that not only are constructs, methods and techniques *not static* – unlike the static object of disability supposedly constructed within the medical model – but also transformation, mutability and multiplicity are inherent to them.)
- How can a discourse with such dispersed conditions of emergence be understood through the lens of the medical model – a concept that ensures its coherence only by attributing totality to a discourse?

These questions suggest that the concept of the medical model *is but one* way of understanding medicine's complex relationship to disease and disability, and perhaps quite a limiting one. As I have tried to show, there are other histories to which the medical model cannot be as readily applied. It is to foreground this friction, and to tease out what it could offer to our current understanding of medicine within disability studies and related fields, that I consider the emergence of QoL as a process of *disabilitisation* of medicine.

'Disabilitisation' of medicine

As stated earlier, the 'disability' in disabilitisation is not the same 'disability' that has been reclaimed and theorised within disability studies (namely, disability as an identity, a social justice issue, a cultural category, and a form of aesthetic and everyday creation). To claim that medicine has expanded its gaze towards patients' ability to perform the everyday does not mean that it has finally turned to social aspects of disablement, and de-individualised disability in the meantime. But, as noted earlier, the 'disability' in disabilitisation is also not the same 'disability' considered the subject of medicine by the medical model of disability. As the discourse of QoL has made it possible to take medical perception from the inner depths of the body, and locate it within patients' everyday worlds through standardised measurements, diseases would be configured, not as pathological lesions and anatomical abnormalities, but as 'living with' (Wahlberg, 2018) those states. As a corollary, disability would be articulated not through its reduction to an idea of disease in the inner depths of the body, but through its expansion to an idea of disease that is *experienced, embodied, and lived with in the everyday* – an expansion that I call as 'disabilitisation'. By the provocative notion of disabilitisation, I mean how QoL emerged as a matter of concern in medicine and healthcare, and how this historical process has brought about new articulations of disease and disability that the medical model remains too limited a tool to explain. As medicine gets to be disability-sized throughout the making of QoL, diseases and disabilities would be sought, not within the biological body – as is presumed to be characteristic of medicine in ideas of the medical model or the clinical gaze – but within *the everyday* where that body performs activities, feels emotions, engages with others and lives a life for better or worse. I propose the notion of disabilisation as a way to capture precisely these new configurations of disease and disability that weaken the traditional conceptualisation of medical perception within the medical model of disability.

Disabilisation, in the way I conceptualise it, also refers to the relations between the discourse of QoL and the non-discursive events included in its conditions of possibility, and

how those relations may challenge the medical model in other ways. For example, according to the medical model, disability is a 'deviance', an out-of-the-ordinary body that sparks the curiosity of the medical gaze, which seeks to treat and correct this 'aberration'. Disability becomes a 'tragedy', a 'loss' that needs to be avoided at all costs. While this argument can easily be applied to certain histories, it is harder to hold onto it within a chronically ill and ageing population, in which QoL has emerged as a major concern for medicine. In this epidemiological landscape, being chronically ill or disabled does not figure as 'extraordinary' but as highly ordinary – states any of us could reach if we live long enough. Accordingly, the goals of medicine are directed not just at eradicating diseases or halting their progression, but also at providing patients with 'a life that is as comfortable, functional and satisfying as possible' (Sullivan, 1992, in Bowling, 2001: 11). The National Cancer Strategy of Ireland (2017–26) is a case in point: 'Since many forms of cancer are chronic yet highly survivable, the definition of successful treatment can be seen to have shifted toward maximising the quality of life of individuals diagnosed with cancer for as long as they live. In short, it is not a question of "just surviving" the aim is to maximise quality of life' (Department of Health, 2017: 109).

Second, the medical model is based on the presumption that medicine has a totalizing power and professional authority. The emergence of QoL makes this argument untenable, especially in view of the economic concerns, political events, and institutional practices that have partaken in it. In post-industrialised societies, the governance of healthcare is dispersed among various actors and practices. In these changing constellations of knowledge/power, we see the emergence of new categories such as *patient experts* whose 'knowledge and experience' is considered 'an untapped resource…that could greatly benefit the quality of patients' care and ultimately their quality of life' (British Department of Health, 2001: 5, cited in Rapley, 2003: 139). We also see categories such as *patients as survivors* who can be educated and guided towards self-managing their care and maximising their QoL (Department of Health,

2017: 9). New actors are emerging in the restructuring of healthcare practices: the 'consumers', 'buyers' and 'managers' of healthcare. It is to these actors that 'the use of performance and quality measures, including quality of life measures, appears to provide…an important "window" onto providers' activities, and acts as a check on professional autonomy' (Bury, 1994: 126). The formation of QoL that I call disabilitisation thus points not at the exercise of a resolute knowledge/power, but at its diffusion, and at undermining medicine's professional autonomy.

What if we integrate a critique of QoL into the medical model?

To argue that QoL does not represent the workings of the medical model does not mean that it cannot be critically questioned. First, QoL instruments articulate disability in relation to an external 'social' world rather than a 'biological' body. But, no matter how far this expansion goes, the link between disease and pathology is preserved, and 'the issue of causality' (Oliver, 1996: 31) – long criticised by disability scholars – is left intact. In other words, no matter how far QoL measures 'distance' their gaze from the body; the individual body remains their point of departure. This leads to the creation of a linear sequence: pathology –> disease –> disability.[17] Disability as well as disease remain *individualised* as the individual/medical model claims it to be.

Second, measuring living 'well' and a life with 'quality' involves measuring essentially unquantifiable phenomena (e.g. values, beliefs and experiences). Scholars of disability and medical anthropology (see Hahn, 2001; Warren and Manderson, 2013) have already highlighted the importance of qualitative enquiries into experiences of living with chronic illness and disabilities, parts of which might get lost when translated into quantities.

Third, as I have argued with the notion of micro-activist affordances, chronically ill and disabled people may invent new ways of being in the everyday, which might not be imagined

in the absence of pain, illness or disabling factors. Unlike the ADLs enlisted in QoL measurements, these improvised affordance-creations cannot be abstracted from the locality of their occurrences and subjected to mathematisation.

Fourth are the controversies surrounding QoL measures in policymaking and resource allocation decisions, particularly the use of metrics such as QALYs. These evaluations of 'value for money', and the utilitarianism undergirding them, have been debated (including in the field of QoL itself) especially for the bias they create against disabled, elderly and poor populations. Hays *et al.*, for instance, point out that disability communities 'fear that…the designation of quality of life (QOL) might be used as a threshold or triage principle in the allocation of resources' with potential detrimental consequences to their lives (Hays, Hahn and Marshall, 2002: S5). Disability rights activists Harlan Hahn (2002: 180) and David Pfeiffer (2000: 1082) denounce metrics like QALYs and Disability-adjusted Life Year (DALYs), for equating disability with a 'burden' to be gotten rid of, and for opening the door to eugenics.

There are many other angles from which QoL discourse can be criticised: how QoL rhetoric can function as a form of governmentality through which individuals self-rate, self-surveil, and become complicit in their own subjection;[18] its problematic vocabulary as evidenced by the use of words such as the 'burden' or 'usefulness' of patients; or the implicit assumption that a life with quality is one that is lived independently, productively and self-sufficiently, contradicting the interdependence, vulnerability and care ethics theorised within disability studies.

What do these criticisms of QoL mean for the medical model? First, to criticise QoL instruments for preserving the link between pathology and disability is not the same as criticising them for reducing disability to mere function or for turning subjective experiences into numbers. Second, a conceptual criticism of QoL instruments is not comparable with a criticism of their fields of application (such as economic evaluations and resource allocation

decisions). Each of these is a different criticism. Finally, the limits of QoL methodology, its vocabulary or its philosophical underpinnings, are all different domains, requiring differently formulated critiques. The point I want to make is: just because there is always a way to contest or critically question heterogeneous sets of practices and knowledge formations, does not imply that the medical model is necessarily present. The possibility to criticise QoL discourse from multiple aspects does not make it the instantiation of an *overarching* model, nor of a totalising history of *this* or *that* model of disease or disability. Room for criticism does not imply a space to be filled by the medical model. On the contrary: any critique of the disparate knowledge practices within QoL needs to be as specific, and singular, as the object of its critique, and take into account its particular conditions of possibility.

Disabilitisation: A proposal to move beyond the medical model

Considering that objects of medical knowledge are incomplete, elusive, and undergoing ongoing transformation, concepts that lock this incompleteness into fixity and subsume all the tensions and differences within medicine under a totalising rubric can hardly provide a productive framework. In this article, I have taken Mol's suggestion 'to doubt' as my departure point to examine the limits of the traditional criticism of medicine, particularly as it is voiced in the medical model of disease and disability. In discussing how QoL discourse brings up discontinuities to the tenets of the medical model, I have sought to find occasions for *not* taking the model for granted and to begin to 'doubt' it instead.

For sure, to 'doubt' the medical model in no way denies the appalling and atrocious treatments to which disabled people have historically been subject under the auspices of medicine, as in histories of institutionalisation and eugenics. Nor does it mean that disability and disease have not been reduced to pathologies in certain histories and medical practices, or that disability has not been medicalised in other discursive formations. The question is: Why

should it? Why should "doubting" the medical model end up equalling to those things? Is there no way of describing medicine's objects, concepts, and styles of enunciation without simultaneously adhering to the criticism enabled by the medical model of disability (or by 'medicalisation', 'normalisation', or 'disciplining' for that matter)? Or have certain concepts, while owing their origins to specific sets of practices, become institutionalised over time, and turned into discursive regulations in and of themselves, regulating the objects of which we (as disability studies or medical anthropology scholars) can speak, and allowing us certain subject positions (and not others)? With the notion of disabilitisation, I seek to offer one such space for doubting – a space that can allow us to think beyond the concepts that have (perhaps) become too familiar.

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Notes

1. Here, I mean disability studies as it came to be formed in English-speaking countries. In the case of the Netherlands, for instance, QoL and its diverse applications are considered an integral part of disability studies (see Schippers, 2010).

2. While it is clear that the dual concept comes from disability studies in the United Kingdom, it is less clear from where, and in reference to what context exactly its ubiquitously used meaning comes. Tom Shakespeare notes that earliest use of the medical/social model distinction appears in the writings of Peter Townsend (Townsend, 1981: 93, cited in 2006: 21). Mike Oliver (1983), to whom the 'social model' is often credited, proposes this model not against the 'medical' but against what he terms 'the individual model of disability'. And even if Oliver occasionally uses 'individual/medical model' (see ibid.: 50, 55), and though he notes that the individual model 'can be taken to include the medical model' (ibid.: 15), Oliver's seminal essay remains focused largely on the professions that dominate disabled people's lives, such as social work and rehabilitation, welfare bureaucracies and dependency-creating services, *not on medicine* per se. Tom Shakespeare also calls attention to this point: 'Oliver prefers to use the term "personal tragedy theory" or "the individual model", by which he means more than the dominance of doctors or of diagnoses' (2006: 15). Current uses of the concept do not only refer to medicine (despite the adjective 'medical'). As Alison Kafer writes, '[w]hat characterizes the medical model isn't the position of the person (or institution) using it, but the positioning of disability as an

exclusively medical problem', and this relates it to a whole set of institutions and practices not limited to medicine (2013: 5).

3. Tom Shakespeare, who has offered perhaps the most vociferous critiques of the medical model, makes a similar point: 'it is impossible to find anyone who actively espouses the concept' (2006: 18). Here he draws on Kelly and Field's critique of the 'sociological caricature of the medical model', where they write: 'on close examination, it is actually very hard to find this medical model in medical practice. Few practitioners, and no textbooks of any repute, subscribe to uni-directional causal models and invariably interventions are seen in medical practice as contingent and multi-factorial and ultimately based on assessments of probabilities' (Kelly and Field, 1994: 35).

4. While concepts ending with *-isations* are oftentimes launched to critique a process (e.g. medicalisation, normalisation), and rarely have positive connotations, this is not how I use the suffix. Rather, disabilitisation refers to how the emergence of QoL has generated new articulations of disease and disability in ways that weaken both the medical model of disability and biomedical models of disease.

5. There surely were other contemporaneous functional assessments developed during the war and its aftermath, especially in the field of rehabilitation. However, my focus remains on these three instruments because they are just not any classifications of function; but *classifications of function that occupy a certain place in the making of QoL*.

6. The classification includes phases such as 'Patients with organic heart disease able to carry on ordinary physical activity without discomfort' (designating Class I), 'Patients with organic heart disease unable to carry on ordinary physical activity without discomfort' (designating Class II and subdivided into a) 'Activity Slightly Limited'; b) 'Activity Greatly Limited'), and 'Patients with organic heart disease and with

symptoms or signs of heart failure at rest, unable to carry on any physical activity without discomfort' (designating Class III) (Bainton, 1928).

7. This emphasis would be reiterated in the 1939 edition of the book: 'Physical signs may be present or absent; but their presence should not influence the rating' (p.71).

8. For a detailed history of the study, see Timmermann (2012).

9. Rhoads was the Chief of the Medical Division of the Chemical Warfare Service, and became the director of the newly-founded SKI. An official report on chemotherapy states that Rhoads 'reoriented virtually the entire program and staff of the war effort with nitrogen mustards… into the chemotherapy program developing at Sloan-Kettering Institute' (Zubrod *et al.*, 1966: 351).

10. Other researchers testing the agent at the time write: 'the margin of safety in the use of nitrogen mustard [is] quite narrow. The maximal tolerated dose (that which does not cause harmful hemopoietic effects) is usually not much larger than the optimal therapeutic dose' (Goodman *et al.*, 1946: 131).

11. From a contemporary perspective, there are disagreements about whether KPS is to be counted as a QoL instrument or not (see Timmermann, 2012: 8). For instance, in their 1986 review of QoL measures used for malignant cancer, Clark and Fallowfield state: 'whilst useful as a measure of health performance status, [KPS] is not a satisfactory estimation of quality of life' (1986: 165).

12. This is the author's own summary drawn from the table indicating the results of HN-2 treatment.

13. In fact, 'the term *disability*', Mitchell and Snyder note, 'was first coined in the mid-1800s to designate those incapable of work due to injury' (2010: 184).

14. By this, I do not mean that had this shift not occurred, medical perception would have remained limited to the confines of *the* body, thereby attesting to the criticism

embedded within the medical model. As I noted earlier, meticulous ethnographies in STS have compellingly shown that *the* body, to the confines of which medical perception remains 'limited', is not a singular, frictionless object. The body is 'multiple' (Mol, 2002). So is disease and, indeed, disability. The idea that the body, disease and disability can be multiple objects in medicine already defies the simplistic criticism embedded in the concept of the medical model.

15. A (relatively) recent questionnaire developed to assess the QoL of cancer patients; see http://groups.eortc.be/qol/eortc-qlq-c30

16. Certainly, pathology and lesion, ontologically speaking, were not essentialised objects in the first place. To reiterate, from STS, a 'single' pathology can be many different objects depending on which room of the hospital one is in, and who is engaged in what sort of knowledge practice.

17. This criticism of QoL tools has already been raised by Hays *et al.* (2002: S6) and Hahn (2001).

18. For a discussion of how a self-reported diagnostic questionnaire used for Myalgic Encephalomyelitis produces the very subject that it seeks to rate, and how the 'patient' becomes complicit in the process through turning the 'ever-extending gaze' on herself, see Shildrick and Price (1996: 108).

Author biography

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