



The quantified self: closing the gap between general knowledge and particular case?

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Abstract

Rationale, aims and objectives This paper addresses the movements ‘evidence-based’ (EBM) and ‘personalized’ (PM) medicine. The former is being criticized for failing to do justice to clinical complexity and human individuality. The latter aims at tailoring medical knowledge for every patient in a personalized fashion. Instrumental to this effort is the technological development engendering unlimited amounts of data about bodily fragments. The aim of this article is to stimulate a debate about the notion of the body and knowledge in medicine.

Methods An authentic sickness history is used as a vantage point for a more comprehensive account of biomedicine.

Results The analysis of the sickness history demonstrates how biomedical logic guided all approaches in the care for this particular patient. Each problem was identified and treated separately, whereby neglecting the interaction between body parts and systems, and between the woman’s bodily condition and her experiences. The specialists involved seemed to look for phenomena that fit categories of disorders ‘belonging’ to their field. These approaches engendered unintended effects: chronification, poly-pharmacy and multi-morbidity, leading to an unsustainable increase in medical costs.

Conclusions The article elucidates how the status that professionals ascribe to the body has vital implications for what they regard as relevant and how they interpret the information they have collected. On this ground, we challenge both the prevailing and tacitly accepted separation between the physical body and human experience and the view of knowledge underpinning EBM and PM. The growing molecularization of the body veils decisive sources of human illness.

Introduction

The knowledge base underpinning biomedicine draws overwhelmingly on studies that employ methods for documenting separate functions of the human body in the form of numerical data [1,2]. Crucially, such studies are premised on the foundational notion in biomedical logic: information derived by technology is more highly valued (because more accurate and ‘objective’) than information elicited through talk and clinical examination. In short, *the very object of biomedicine is the ‘hidden’ body – the body under the skin* [3].

The data or ‘facts’ that are produced from fragments of the body such as organs, tissues, cells, fluids and systems are made accessible by way of extraction or intrusion. The most common of these are measurements of blood pressure, blood glucose or lipids, a

variety of hormones, blood cells and antibodies to microorganisms, heart rate, lung or brain function, and substances contained in secrets or discharges from the body, such as urine, stools and sputum. These measurements, these biological ‘data’, are interpreted and judged with regard to their pathological significance according to a norm, a standard, an ‘average’ value of the functions or substances in question.

Mean values derived from measurements inform clinicians in their daily work and constitute the very framework for all research. The gold standard of presumably non-biased research is claimed to be the method, randomized controlled trial. This method’s central rules are designed for seeking the most homogeneous, unambiguous and controllable conditions for research allowing an exact conclusion concerning certain predefined variables. Such variables are typically numerically defined and presumably separate

'entities', in most cases, biological substrates or chemical substances. The most salient premises for the validity of this method are some core assumptions: (1) that parts or fragments can be separated from the body without changing their characteristics; (2) that bodies are equal entities allowing numerical approaches provided certain common criteria; (3) that patients having been diagnosed with 'the same' disease make a homogeneous group; and (4) that trials which accord to these methodological criteria yield generalizable results which are representative for the entire population. This knowledge about the average human body, its defined and classified diseases, and the appropriate attendant interventions inform the basis of contemporary biomedical, clinical practice condensed and manifest in evidence-based medicine (EBM), and formulated in guidelines for clinical application related to each disease [4]. This 'production' of guidelines has, by now, developed into a separate branch in biomedical research, manifest in guidelines for how to conceptualize guidelines, and in a subsequent catalogue of not only hundreds of disease-related but also numerous symptom-related guidelines for interventions on isolated 'variables' such as blood pressure or on single substrates such as cholesterol [4,5].

The spectrum of what can be extracted – and analysed – includes by now billions of data points. Modern genetics and epigenetics have pushed the numbers even higher after the sequencing of the human genome, in short 'genomics', had been completed. Following the same model, other structural elements were and are about to be approached in the same manner. This increasing number of '-omics' comprises the epigenome, the methylome, the transcriptome, the proteome, etc. [6]; the analyses of which gradually add to a seemingly complete mirror of the 'molecularized' self [7],¹ recently meta-commented as 'the narcissome' [8]. This chase for the truth about a person's health in ever more fragmented substrates of the body reflects the deeply rooted belief characteristic of reductionism: the truth about the whole resides in – and can only be unraveled by scrutinizing – parts. This approach will inevitably confirm and fortify a view of the body as extrinsic to the self and strengthen the intimate connection – typical of biomedicine – between knowledge generation and technology. Historically, the diagnostic issue has increasingly become one of accuracy [9,10]. To see without instruments and touch the patient directly is, from a biomedical point of view, inferior. The result of this 'deeper-down-inside-the body' orientation is that relevant phenomena are removed from their personal and social context [11]. Since biomedicine strips the body of its social context at the outset, connections between illness and the persons' life and struggles cannot be established.

Average patient, individual patient or particular person?

Personalized medicine (PM) [12,13] is presented as an alternative to interventions based upon knowledge of the 'average' patient, also named 'the one size fits all' model, and its version of individual specificity is met with both enthusiasm and critique. Proponents maintain that PM represents a paradigmatic change in

medicine, while critics underscore that individualization has always been stressed in medicine, but its meaning has changed through the years. Some critics argue that the result is solely new forms of sub-populations rather than individual differences [13], others question the widespread conception of the universal material body and the lack of genuine interest for socio-cultural considerations when it comes to understanding human suffering and morbidity [7].

We wish to emphasize that individualization has always been an *ideal* in medicine and in health care more generally. Moreover, we recognize that a meticulously differentiated data profile, as described in PM, may quite precisely depict specific, quantifiable elements of an individual. Still, this approach represents an extremely narrow notion of personhood (a 'person' being someone embedded in and informed by socio-cultural context) since it neglects human relations and experiential sociality. The prevailing framework of the human body has, to an astonishingly limited degree, been problematized in medical research and clinical practice. The human body is conceptualized partly in physicalistic terms, still inspired by physics as the ideal scientific discipline, partly as a biological organism, inspired by the change in what is conceived of as the scientific ideal in recent decades [1–4].

Fragmented data veil the socio-cultural context

Epidemiological research has documented both an uneven distribution of sickness, of patterns of diseases and of premature death in most societies [14–17]. Ample evidence testifies that context phenomena such as socio-economic conditions (i.e. level of education, social class, housing and social network) are highly relevant premises for good health and a long life [18–21]. Social gradients in health have been increasingly studied – and documented – during the last decade, confirming the same pattern in every society and among societies: deprived populations (e.g. due to war, social crisis, famine, corruption, political instability or dictatorship) or certain deprived strata of populations (e.g. due to racism, sexism, ethnic discrimination or marginalization) suffer more and more from complex diseases and premature death than people in egalitarian and politically stable societies [22–27]. But even in these societies, social gradients cut invisible lines between areas of the country, through cities and even between neighbourhoods. Population statistics of the city of Oslo, for example, the capital of affluent, stable, egalitarian and democratic Norway with one of the world's highest average level of education, income, housing and employment show that life expectancy differs by a decade between inhabitants of inner city east and outer city west, in general, and for males in particular [28]. Being a male dweller in Oslo inner-east is simply not healthy. The reason for this cannot be deduced from measuring his body functions. The 'causes of the causes', as Sir Michael Marmot has termed this phenomenon [29], are the unevenly distributed living conditions and different existential premises for people leading their lives in different socio-cultural contexts.

We claim that unevenly distributed disease occurrence can serve as a two-sided magnifying glass. On the one hand, possible or probable *social preconditions* can be examined. This would require recognition of the interconnectedness between structures

¹ The notion of the increasing molecularization of life in an even wider sense has been explored and commented upon in Braun, B. (2007) Biopolitics of the molecularization of life. *Cultural Geographies*, 14, 6–28.

and agency. It is not enough to scrutinize structural conditions; people's habits and way of life should also be included [30]. On the other hand, one may explore in what way *biomedicine and clinical practice* itself may contribute to social inequalities of health and illness.

Since social life and socio-culturally constituted roles and values inform personal health directly and indirectly, issues of power, resources and autonomy, and their opposite – powerlessness, deprivation and dependency – are at stake. Being and feeling overpowered may be lethal in itself [14,22,26], and it does not inspire self-respect. Consequently, people who are not met with respect are prone to act in ways that are not conducive to good health [31].

Likewise, socio-culturally or politically legitimized differences may represent concealed sources of unevenly distributed health problems and premature deaths. The constant experience of being treated in an 'unfair' manner was, however, a strong predictor for chronic cardiac disease in the Whitehall II study [32]. And the influence of a position of lower professional rank in the strictly hierarchically structured Whitehall quarters was strongly associated with other types of health problems such as type 2 diabetes [33] and obesity [34].

The detrimental effect on health of feeling powerless, dependent, subjected to external force or will, have, in general, been documented beyond doubt during the last decade. This effect is even more pronounced if such experiences have been an intrinsic part of childhood or adolescence [35–37]. An early 'overload' of a person's stress response system, resulting in chronic distress, has been shown to increase this person's risk for developing each of the most serious chronic diseases and to reduce her or his life expectancy by decades [38–41]. However, due to the very nature of sources of chronic distress, embedded in social structures and personal relationships as they are, these 'causes of the causes' [29] of chronic illness typically remain unidentified. The very concept of the body, the depersonalized, context-free, standard body and the average measures, renders biomedicine insensitive to other phenomena than those directly and technologically extracted from the body. Since these extracts not only are delimited as to certain characteristics (technical 'visibility', type of material, size of sample) but also precisely localized on the biomedical map of the body, they allow for the degree of exactitude and for numerical precision that meets the naturalist search for accuracy in the paramount strive for unambiguity.

Judith Janson: an authentic case

Once more, we wish to emphasize: we are aware that individualization has always been an *ideal* in medicine and in health care more generally. However, one can never take for granted that there is correspondence between practice and ideals. To elucidate the relationship between ideals and real-life practice is therefore an important empirical task. It requires, however, a methodical approach, which departs significantly from the dominant views of what counts as appropriate research in medical quarters. From our experiences as clinicians and researchers for several decades, we are well aware of the fact that several clinicians practise in ways that do *not* accord with the ideals of biomedicine. We therefore support Schwartz and Wiggins when they pointed to a paradoxical feature of medical practice [42]. They argued that the *human*

aspect of medical practice is secured only when doctors are able to act in inconsistent ways, by availing themselves also of knowledge that from a biomedical point of view is unscientific. According to these authors, doctors would 'do harm' if they adhered strictly to biomedical logic and we should therefore appreciate doctors' ability to be inconsistent.

Still, there is a step ahead: aiming at individualizing the biomedical knowledge of the average body in encounters with the individual patient may provide possibilities for tailoring the medical measures taken. This, however, does not suffice to do justice to the health problems that spring from a particular person's lifetime experiences. In this context, we have chosen to analyse a case that saliently illustrates the tenacity of biomedical logic. In the following story, we have braided personal accounts of a woman with regard to that and how she was molested as a child – which was never recognized by her doctors or dentists during the first five decades of her sickness history – and a condensate of parts of her patient record which author A. L. K. had been given access to while performing a research project.²

A male neighbour raped Judith when she was 11 years old. Throughout the next year, the man provided his friends with frequent opportunities to abuse the girl through forced oral penetration. At the age of 12, she was admitted to a hospital suffering from severe abdominal pain, jaundice and pancreatitis. The surgeons concluded that the cause was a gallstone and decided to perform a cholecystectomy. The intervention did not relieve her abdominal pain, which continued unabated into adulthood. While still a teenager, the condition of her teeth deteriorated and she developed severe dental fear. At age 15, she attempted suicide and was admitted to a psychiatric unit. Also, she developed asthma and was diagnosed with anxiety disorder. Her attacks of anxiety were always accompanied by nausea, which very often led to vomiting. While still a teenager, she developed serious eating disorders, expressed in alternating phases of anorexia and bulimia. Since she experienced that she could sometimes control both her nausea and her vomiting by eating, she soon became grossly overweight. Beginning in early adulthood, she abused alcohol and, on several occasions, was involuntarily committed to a psychiatric unit subsequent to intoxications. There, she was medicated with various psychotropic drugs and, once, tried to hang herself. Her bad teeth caused a variety of eating problems and much oral pain. The expense of innumerable dental interventions, including implantations, resulted in her running up huge debts. Now in her early sixties, she is diagnosed with irritable bowel syndrome, type-2 diabetes, hypertension and hyperlipemia. In addition, she suffers from atopic eczema and arthritic pain, probably side effects of long-term medication for her chronic diseases.

We will point to central phenomena – and are going to elaborate on a few of them – in Judith's sickness history, such as (1) bodily inscriptions of oral abuse; (2) early loss of self-respect due to other people's disregard of her integrity; and (3) problems arising from lacking certainty as to own boundaries and a right to have these respected.

² The first analysis of the case is reported in detail in Kirkengen, AL. (2001) *Inscribed Bodies*. Dordrecht: Kluwer Academic Publishers. The woman related further information to the first author in recent conversations.

Furthermore, when regarded as a 'case', Judith's history also contains certain clusters of problems or phenomena recently identified as some of the greatest challenges in Western health care. These are (1) patterns of so-called co- or multi-morbidity; (2) poly-pharmacy; and (3) well-known combinations of chronic pain syndromes resistant to medication, and of other so-called 'medically unexplained symptoms' or syndromes [24,43–45]. We shall return to these challenges.

With regard to the bodily impact of frequent and forced oral penetration, Judith's own accounts open insight into a wide spectre of sensations and perceptions, partly presented to the health care system – yet interpreted as signs of particular diseases – and partly untold by herself or unrecognized by relevant others as the effects of previous adverse experiences. Judith would never learn how to swim, and even showering could pose a threat, as she was particularly afraid of water – or anything else – 'running over my mouth', as she related. Being accidentally hit in her lower face by water, would immediately evoke grave panic and according reactions like heart-beat, trembling, sweating, hyperventilating or fading and breathing problems. Only decades after the abuse had terminated (when she for the first time was admitted to the hospital), Judith came to understand that the obstructions diagnosed as asthma were always triggered by perceptions of or associations to being suffocated by 'things' swelling in her mouth. Later, she also realized that she could actually control both her abdominal pain and her eating problems by avoiding all foods with a shape, colour, smell, consistency or taste reminiscent of a penis or of semen. After such massive oral abuse, and given the effects that had indelibly inscribed on her body, her self-perception demanded that she draw a distinct line between her and what she had been forced to endure. Judith also reported that she always dissociated when receiving medical or dental treatment. Only recently has she found the courage to request of her doctors that they, 'Talk to me so I can bear to be present.'

Judith's dental fear and oral pains reflect a gradually emerging and partly recognized, complex pattern of health problems linking chronic pain, periodontal diseases, eating disorders, substance abuse, psychotropic medication, cardiovascular diseases, type 2 diabetes, metabolic syndrome, intoxications, depression, self-harm, dissociation and ideas about and actual attempts at committing suicide – with each other and with early childhood adversity [35–38,40–42,46–52].

Judith's health began to improve slightly when she, in her late forties, began to attend group meetings with incest survivors at a local incest centre. Becoming aware of what had been done to her and how these abusive experiences had affected her bodily self, her self-respect and self-esteem, her health and her subsequent need for health care, enabled her to reduce her sense of shame and her need for alcohol as a self-medication. Her personal statement is that, despite extensive medical attention since her early teens, countless laboratory tests, referrals to somatic and psychiatric hospitals, clinical investigations and extensive poly-medicalization, she has never received medical care appropriate for her personal needs.

The making of a chronic patient

The patient Judith Janson represented ever more clearly a problematic yet highly familiar 'Gestalt' in modern medicine: multi-morbidity. The term denotes that she suffered from several disorders and diseases diagnosed as somatic, psychiatric and so-called func-

tional and viewed as *unrelated* [24,43]. Thereby, we also encounter another core problem in modern medicine, namely poly-pharmacy. The term denotes the necessary use of various drugs for supposedly different diseases or health problems, each of which is prescribed and monitored according to separate guidelines specified for diseases or even risk factors, and developed in specialist medicine based upon clinical evidence for each diagnosis. Poly-pharmacy frequently results in consecutive health problems defined as side effect of singular drugs or engendered by their interaction. Although unintended, these health problems cause ever rising numbers of hospital admissions and even premature death [44].

This situation creates an ultimate challenge to EBM: proper medical approach to multi-morbidity is non-existent and, according to the model's own logic, it can never be generated.

Medical artefacts backfire

Medically unexplained syndromes, chronic pain, multi-morbidity and poly-pharmacy are issues of increasing concern in medical quarters as in the health care sector more generally, and they demonstrate ever more clearly the limitations of modern medicine. A stream of documentations from the neurosciences and from psycho-neuro-endocrino-immunology indicates with increasing strength that personal, lifetime experiences, in other words strictly subjective phenomena loaded with values and endowed with socio-cultural meaning, affect the human body down to the cellular level. The empirical weight of these data, brought about by traditionally judged first-rank methodology, creates a paradox: *it invalidates its own premises*, the mind-body-schism, the fundamental biomedical theory of mind and matter as separate and different. Updated evidence from naturalist informed research points to a contrasting way of thinking: mind impacts on matter; mind matters.

This documentation dismantles the over-simplification inherent in medical attempts to, for example, explain the previously mentioned social gradients of disease. Denoting an uneven distribution of sickness in populations and strata of these, social gradients traditionally have been 'explained' with unfavourable lifestyle in groups or subcultures of any given society, and, as such, a result of 'choice' on group or individual level. Representing a considerable range of serious health problems such as hypertension, diabetes, hypercholesterolemia, metabolic syndrome, obesity, chronic lung diseases and cardiovascular disease, the phenomenon of social gradient of disease coincides with multi-morbidity, poly-pharmacy, high-risk profile, medically unexplained syndromes and disability. Still, medicine responds traditionally: diagnosing and treating each condition in every individual while failing to address socio-culturally constituted conditions engendering or fuelling the unevenly distributed problems. This approach, based upon measurements of bodily extracts or visualization of the body's insides, although increasingly recognized as inadequate, is consistently considered 'the best measure' and is still regarded as most valid due to its medically constructed 'evidence'. Furthermore, the movements of EBM and PM, relying upon ever greater numbers of fragmented data, grow rapidly and gain credibility precisely due to their use of traditional measures for data production about the individual body, promising accurate calculations of 'personal' risk and tailored disease prevention.

Meanwhile, health care systems in all Western countries, although absorbing ever more resources, do not 'produce' more

health but rather chronicity and premature disability. The skyrocketing costs have been sought limited by means of a rapidly growing administrative control system, structured according to the principles of the market and designed to secure production, the model called new public management (NPM).³ However, the technology-driven development in biomedicine, in principle unlimited, fuels a likewise unlimited growth of controlling administration, involving doctors in producing information meant to allow for control of their desired and stipulated 'productivity'. This spiralling development, interfering between doctors and patients because absorbing active working time at the costs of proximity to the patients has, for example, led to a protest movement among Norwegian doctors across specialties [53], who reclaim their right to serve primarily the patients instead of the system/administration. The protest does not, however, include a critique of biomedicine and its fundamental assumptions. Given this shortcoming, it risks, although based on good intentions, to succeed in nothing but piecemeal revisions.

It goes without saying that NPM encompasses a host of organizational and institutional issues, which have significant impact on medical and health care practice and therefore need to be scrutinized. These issues, however, must be seen in connection with the theoretical framework underpinning biomedicine and the entire health care system in order to secure both a human practice and to keep the costs in the health care sector at a sustainable level.⁴

Conclusion

We have reflected upon recent movements in biomedicine, EBM and PM, which aim at improving medical knowledge production and clinical practice in the face of rising costs and tasks in the health care systems of all Western societies. However, the most central challenges – multi-morbidity, complex chronic disorders and subsequent medicalization engendering poly-pharmacy – seem to evade the approach of these movements. By means of juxtaposing EBM and PM with the authentic, lifelong sickness history of a woman representing these challenges, we have shown that the assumedly appropriate medical treatments were not only useless, but had, in fact, detrimental effects. Moreover, we have tried to demonstrate that the origin of her sickness was of a kind that can never be disclosed by employing a biomedical rationale. In line with this, we claim that molecularizing the self with the increasing fragmentation of the human body cannot but fail to grasp the embodied impact of adverse living conditions. Consequently, a total re-orientation in medicine is needed.

³ We are aware of the extended literature about NPM dealing with organizational issues and the problems inherent in applying a system designed for control of productivity in the realm of economy and bureaucracy to a field concerned with health, disease and human suffering, but we cannot elaborate on this topic within the frame of the present paper.

⁴ As to economics, not only the health care sector is grossly affected, but society at large. Interested readers may find extensive documentation provided by James Heckman and co-authors [54,55].

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