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Observations of health and illness from the perspective of the lay experiences: A review of previous studies and plans for the future

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Abstract---This article reviews and evaluates the literature on health and illness produced over the last 20 years that has added to our knowledge of lay experiences of health & illness. From an “outsider” viewpoint, as expressed in the Parsonian idea of the “sick role,” comes a crucial and welcome transition to one that examines the experiences of individuals in their everyday lives. Early work by “Bury (1982), Charmaz (1983), and Williams (1984)” has been highlighted for their role in laying the groundwork for a more nuanced understanding of lay experiences that takes into account both micro-and macro-contextual effects. As well as pointing out ‘uncharted territory’ and “the ‘missing voices’ in the medical sociology literature, the paper looks to the future and the past. According to some recently published work in the Web of Science, Scopus, and Google Scholar journals that have opened the way to what may be 21st-century health and illness. The paper concludes with a plea for medical sociologists to be more open to new and unconventional theoretical & methodological perspectives.”

Keywords---Biographical Disruption, Health, Illness, Lay Experiences, and Self Loss.

Introduction

Glancing back in history

Begin with Wallach Bologh’s [1] writings, who criticized “the values and assumptions inherent in the medical system” in an early contribution to the literature on the subject. Based on prior research (e.g., Friedson (1970) [2]; Illich 1976 [3]; Bell, S. E. (1987) [4]. Rosenfeld, D. (2006) [5] Fourie, R. J., & Murphy, M. (2011) [6]), she makes the argument that contemporary Medicine dehumanizes and objectifies patients, separating the ego from the body. Because “modern Medicine tends to disregard the patient as anything but an owner of his or her own body or condition,” she

contends [7]. Medical professionals have too much power and control over their patients, resulting in patients being reduced to the status of “an object or body without intellect,” as she puts it in her book, ‘Patients as Non-Humans.’ While Wallach Bologh’s criticisms of the medical establishment may have had some merit, his ideas seem archaic and even stupid. So she thinks that asking patients about their purportedly alienating experiences is not essential to comprehend their perspectives and ideas. Similarly, she suggests that the medical system is solely responsible for the patient’s feeling of self and body during sickness (rather than other contextual circumstances).

Wallach Bologh’s writing may seem a bit insensitive to focus on in this manner. Researchers have chosen to utilize her example because it provides a valuable platform to highlight how “our understandings of lay experiences with health and illness have expanded since her work was released. There are many innovative and exciting ways in which contributors to the subject have progressive ideas and work related to the experiences of lay people in the context of health and illness.” Still, researchers don’t want to give the impression that these articles were written independently of other medical sociology research. Because of the enormous amount of work that has been published in this field over the previous two decades, this has been a difficult task. However, the passage of time since some of the most innovative publications was also written has presented a bigger problem. Medical sociology has incorporated many terms and “ideas developed in the publications’ early years” into its vocabulary, making them nearly commonplace to the modern reader. As a result, to truly understand the writers’ long-term contributions, “one must remember what occurred before (and not just after) the publication of this early work.”

The variety of papers published throughout the 20 years of the different Journals is promptly evident. People with various diseases (although predominantly chronic diseases, which we will return to later) have been given a “window into their lifeworlds, at multiple stages of sickness, and in various circumstances through these studies. A few examples of publications that have examined the experiences of people” with a variety of illnesses and disabilities include insulin-dependent diabetes (Gledhill, J. et al.: 2000[8] and Schwarzer, R et al.: 2011[9]), cystic fibrosis (Bernttsson, L. et al.: 2007[10]), and Parkinson’s disease (Brod, M. et al.: 1998)[11]. Cancer (Livneh, H. et al.:2004)[12] & paraplegia (Yoshida 1993)[13] and have been addressed with a “variety of issues, including experiences of stigmatization (natural & expected), ambiguity & worry, and the strategies used to avoid and neutralize these experiences (e.g., Garneau, C. R.:2012[14], and Davidson: 2000[15]). Experiences of discrimination and isolation in and outside of the workplace (Julia, L; 2003[16], Krings, F.et al.:2014[17] and Osseo-Asare, A., et al., 2018[18]), and experiences of adapting to, and living with, different types of medical technologies” (e.g., O’Brien, M. E.:2000[19], Atkin and Ahmad:2000[20], and Free, M. J.: 2004[21]). Studies in these journals have mostly relied on qualitative methodologies (primarily in-depth interviews) and placed a high value on detailed descriptions of the experiences of patients (see “Williams, 2000)[22]. As such, they have contributed to a more significant conceptual movement in medical sociology away from the ‘external viewpoint,’ exemplified by the Parsonsonian idea of the ‘sick role’ (Parsons: 1951)[23], and toward an ‘insider perspective,’ concerned with patients’ subjective

experiences outside (as well as inside) the medical environment (see Conrad 1990)^[24].”

However, “the papers that have stood out most in the research history have been those that have developed wider conceptual and analytical frameworks, which have advanced to a standard overview of the (chronic) illness experience.” Four articles, in particular, stand out in this regard: Bury’s (2001)^[25], Doran, N. J. (2007)^[26], Strickland, K. (2014)^[27], Charmaz (1995)^[28] & 2002^[29]), Grabowski, R. M. (2002)^[30], Jakoby, N. R. (2015)^[31] and the study of “loss of self,” as well as Williams (1984)^[32], Garro, L. C. & Mattingly, C. (2000)^[33] & Bateman, A. W. (2021) ‘s^[34] account of “narrative re-construction,” are all examples of authors who have studied “biographical disruption” and “narrative re-construction,” respectively. These will be discussed one by one before the long-term impact is assessed.

The Concept of Biographical Disruption

“Chronic disease as biographical disruption” by Mike Bury^[35] is generally regarded as an essential “turning point in our awareness and conceptualization of lay experiences with (chronic) illness.” It is one of the most regularly referenced publications in research history. Bury’s research is based on interviews with RA patients, emphasizing individuals who have recently been diagnosed with the condition. Taking a cue from Giddens’ (1979) ^[36] idea of “critical situation,” Bury attempts “to move away from descriptive categories and toward broader theoretical issues” in his discussion of chronic disease, which he names a “biographical disruption.” Just as Giddens demonstrates how big events like war may undermine the generally accepted character of society, Doran, N. J. (2007)^[37] illustrates how “the experience of chronic disease can lead to a fundamental reassessment of a person’s biography and self-concept in an equally nuanced and multi-faceted manner.”

Bury’s conceptual framework is rife with disruption at every turn. Arthritic pain and suffering, for example, may “bring about a new awareness of the body and the contingent and precarious aspect of one’s (embodied) existence,” as he explains in his book. To quote him, ‘chronic disease implies an awareness that is generally only reserved for distant possibilities or the fate of others of the realms of agony and suffering, maybe even death. Bury’s informants, most of whom were in their twenties and viewed arthritis as an old-age disease, maybe devastated by an unexpected illness that shatters “plans for the future and marks ‘a biographical transformation from a presumed normal trajectory across the reasonably predictable chronological procedure, to one profoundly abnormal & internally detrimental’.”

Moreover, Strickland K. (2014)^[38] research shows that the advent of sickness changes the “structures of meaning and destroys relationships and material and practical matters. Because arthritis may lead to a rise in physical dependence on others, it can violate rules of reciprocal reciprocity & mutual dependency. For example, The strength of one’s social network (for example, how helpful family and workfellow employees are willing & able to be), as well as one’s capacity to mobilize physical & other resources, may be critical to how the disease is afterward perceived, as suggested by him.”

The Concept of Loss of self

Kathy Charmaz [39], “who published at the same time as Bury, focuses on the experiences of persons with a wide range of chronic illnesses.” Charmaz, a symbolic interactionist, uses the term ‘loss of self’ to describe the sensation of ‘old self-images falling away without a concomitant creation of equally valued new ones’ in her study of ‘extreme’ instances, such as those who were seriously disabled and/or housebound. “Loss of self was a multi-faceted experience for her participants” who, because of their sickness, typically had constrained lifestyles and were socially isolated, dismissed by themselves and others, and experienced the humiliation of being a burden on others eloquently shows.[40][41][42] Among “contributions to our understandings of lay experiences” are the following:

- Suffered people’s viewpoints and day-to-day situations are the primary emphasis of their work in this field, rather than a restricted medicalized notion of suffering as physical distress.
- The author highlights how distinct components of the illness experience might reinforce and magnify one another, leading to a loss of self in one area of her participants’ life frequently spiraling into a loss in another, with catastrophic and perhaps irreparable repercussions.
- People may have poor self-esteem and retreat from social activities due to the stigma associated with chronic illness, as she explores in detail (e.g., quitting work, limiting social engagements).
- A more constrained lifestyle might lead to emotions of self-loathing since there is less possibility for meaningful contact with others.

The Concept of Narrative Reconstruction

Gareth Williams (1984), Garro, L. C., & Mattingly, C. (2000), and Bateman, A. W.(2021) pioneer the idea of ‘narrative re-construction to characterize the conceptual techniques individuals use to establish an orderly, coherent, and stable narrative in the aftermath of the ‘biographically disruptive’ event of illness onset. Instead of interviewing folks who have just been diagnosed with RA, Williams seeks out “seasoned professionals” to learn about the long-term consequences of chronic illness on people’s self-perceptions. The authors’ research aims to discover why their participants opted to focus on certain models to explain the start of their condition. In contrast, alternative explanatory models were as plausible. Williams and Garro, L. C. develops a notion of the story as creating “social reality.” Their investigation shows that people’s narratives of causation don’t only focus on the assumption that there is a disease or an etiology but rather on the creative effort “to find a proper and meaningful place for the sickness in their life. Indeed, researchers’ interviewees commonly alluded to important occurrences in their pasts, such as a death in the family or a negative/exploitative job experience,” to explain their present (diseased) conditions. As authors imply, they did this to give their tales a moral (and sometimes explicitly “political” component). As a result, the authors’ research shows how narrative re-construction may “be used to ‘reconstitute and mend ruptures between body, self, and the world by connecting and interpreting diverse biography components to realign present and past and self and society.” Because of this pre-eminence, Bateman [43] might be credited for calling for “sociological research to study the positive measures individuals take in

response to chronic disease rather than merely concentrating on the challenges they confront.”

To fully grasp people’s experiences of illness and how they ‘live with’ it, it is critical to look at their personal histories and the contexts in which they occurred, and their current and past environments. Williams, Bury, Charmaz, Garro, Bateman, Strickland, Doran, and Jacoby’s papers have all done just that by “highlighting the overlapping and interdependent nature of present and past and the past present.” That’s because of the work of people like Corbin and Strauss (1987)^[44], as well as the work of people like Calnan and M. (1988)^[45]. A slew of groundbreaking studies, including those by Pierret, J. (2003)^[46]; Lewis, T. T. et al. (2015)^[47]; and Tomoaia-Cotisel, A et al. (2013)^[48], have been made possible by the journal’s pioneering work in identifying the macro-and micro-contextual factors that shape people’s “experiences of illness (and, to a lesser extent, health). As I will demonstrate, this research has been primarily focused on the effect and impact of time, location, and interactions with others (e.g., family ties, relationships with coworkers) on individual experiences of health & illness.”

Reconsidering ‘biographical disruption’ in terms of age, time, and biographies

Biographical disruption has been revisited and critically reappraised in various studies published in the Journals that have tried to reinterpret Bury’s idea of biographical disruption. At the outset of his research, Bury noted that his informants (most of who were in their twenties and thirties at the time of their diagnosis) were young, so the start of the condition had a disruptive effect on them. Studies by Pound P et al. (1998)^[49], Sanders et al. (2002)^[50], and Godfrey, M., & Townsend, J. (2008)^[51] all of which deal “with illness experiences in ‘older age,’ have all developed the idea that a disease can be experienced as more or less disruptive depending on the point in the life course at which it first manifests.” Sanders et al.’s research looks at how osteoarthritis (OA) impacts the lives of older individuals, a condition that, “like RA, is seen as normal and inevitable” by the general public as people age. For individuals in Sanders et al. (2002)^[52], ‘s research “(who were on average considerably older), the symptoms of OA” were seen as an “integral” part of their lives. Still, for those in Bury’s study, the development of RA was seen as a sudden attack on the self. There was a shift in perspective from one where illness was seen as disruptive to one where illness was seen more as a ‘biographically expected’ occurrence.

Similarly, “Pound et al. (1998), in their study of stroke” survivors from the East End of London’s working-class, drew attention to how their informants’ age and life experiences seemed to regulate their perceptions and reactions to their disease. According to Godfrey et al., the stroke significantly influenced their participants’ lives—such as how they moved, spoke, bathed, and clothed themselves—but “it was not typically seen as an unusual (i.e., biographically disrupting) occurrence. Many, on the other hand, regarded stroke as a ‘typical crisis’ in their ‘hard-earned life’ (Faircloth R.S. et al. 2004^[53] & Hughner et al., 2004^[54]), which they were already acquainted with the realms of pain, suffering, and death (Rosenfield, D.2006)^[55], due to their age, histories, and exposure to events such as World War II.”

Because many of their participants had previously suffered from other underlying health conditions, they found that stroke did not force them to lead a too 'disruptive' life. "In their interview research of asymptomatic HIV-positive males" exposed to homosexual sex or medical treatment for hemophilia, Carricaburu and Pierret (1995)^[56] made a similar finding. In contrast to individuals infected due to homosexual sex, many hemophiliacs regarded and "experienced HIV as a type of 'biographical reinforcement'" according to the researchers. As a result, these men's lives and biographies were structured around a disease trajectory even before being infected with HIV. Even though they were informed that they had an irreversible hereditary condition, some opted not to marry or have children due to this knowledge. These guys were already accustomed to dealing with the uncertainty that comes with hemorrhages, and many of them had even given up potentially "risky" pursuits like sports and travel. Since becoming infected with HIV prompted Carricaburu and Pierret to enhance precautions, 'there was no disturbance.' Haemophilia has been shown to be a deadly disease. To sum up, the research presented here shows how critical it is to consider an individual's whole biographies, not simply the age at which they first became ill.

Macro-context: Social and Demographic Effects

Even while much emphasis has been paid to people's ages and histories, several studies have highlighted the relevance of other (but sometimes related) social and demographic determinants on how sickness is perceived and understood. As an example, Bendelow (1993)^[57], Miriam, K. (2007)^[58], and Dickens, D. D., & Chavez, E. L. (2018)^[59] use a phenomenological method to investigate how individuals experience and understand the pain in the context of their everyday lives, focusing on the role of gendered norms and stereotypes as a critical factor. A superficial level of her research points to differences in societal expectations on the capacity of males (and females, in particular) to deal with the pain of childbirth and reproduction. By drawing on concepts such as Freund's (1990)^[60] 'expressive body' and more general ideas about how social categories modify embodied experiences, Fernandez, A. V. (2020)^[61] 's study opens new avenues of inquiry into the relationship between gendered expectations, stereotypes, and actual lived experiences for women and men alike. Nettleton, S. (2021)^[62]'s A significant focus of her research is on how various types of pain are seen and 'lived out' by people based on their "experience of being in a body and being a gendered body in a hierarchically organized gender-differentiated environment."

Instead of focusing on the (possible) influence of (culturally defined) "gendered norms and stereotypes, Ville et al. (1994)^[63] explore how the current historical and socio-political environment may also be relevant to how sickness and disability are perceived. This research compares the experiences of three unique participant groups: persons with paraplegia, people with the severe sequel of poliomyelitis, and a group without any physical disability, to understand how people with physical impairments see themselves. There was a wide variety of self-identities among the non-disabled and paraplegic individuals in their research." Still, those with poliomyelitis were more likely to identify themselves as "self-controlled" and "conscientious." For a deeper understanding of these disparities, the authors effectively explain the need to trace the origins of the handicap back to its social and political environment. Participants with paraplegia who had just been

handicapped were able to encounter a variety of positive perceptions of disability since their sickness started in an activist-influenced location.

On the other hand, people with poliomyelitis acquired their disability at a time in history (the 1950s) characterized by the prevalence of the rehabilitation paradigm. Conformity to social norms was emphasized in this model, and Ville et al. indicate that this resulted in a more homogenized self-image among those who were affected. The research by d'Houtaud and field [64] opens some possibilities for thinking about how experiences of illness/disability may differ depending on one's socioeconomic status.

Micro-contextual Impacts on the Self

An essential part of understanding how the disease is "lived" and "negotiated" in people's everyday lives is to look at micro variables (e.g., family and other interpersonal interactions), which have been extensively studied by Radley (1989)[65]. After conducting "an interview study with male coronary patients and their partners," Radley found that his participants dealt with their illness varied significantly. While some made lifestyle changes to accommodate their illness, others "carried on as if the coronary episode had never occurred (for example, returning to work at the soonest possible opportunity). However, he acknowledges the importance of aspects such as a person's work; his research focuses on the effect and impact of a couple's relationship." For example, Radley finds that couples with a more conventional marriage are less likely than those with more flexible roles to adjust to the impacts of sickness (e.g., increased tiredness).

In "Pinder's (1995)[66] research of the employment experiences of persons with arthritis," the importance of connections is shown both as a barrier and as a resource in the struggle to live with a chronic condition. Several factors may affect whether or not someone with arthritis can maintain employment. These factors include their personal limitations and those imposed by their employers and coworkers' distinctive behaviors and attitudes ("for example, whether or not a manager is willing to accommodate flexible working hours)." It is thus fair to say that the findings support Bury's conclusions that the experiences and outcomes of illness are influenced by 'external' resources (interpersonal, structural, and material). Hart (2001)[67] makes an excellent case for the importance of what she refers to "as 'system-induced setbacks' in stroke recovery." According to this research, delays in stroke recovery that seem to be the consequence of "a problem with the patient's health and social care systems" may be caused by a lack of coordination between these systems. The medical context should not be pushed too far to the sidelines in the study of sickness, as Hart reminds us in this way.

With an Eye on the Future

Medical sociology has made great strides over the last several decades. A large portion of this development can be ascribed to individuals who have written in the *Journal of Medical Sociology*. "Bury's concern that studies of (chronic) disease experiences should shift away from concentrating on meanings per se to incorporate the influence of larger elements, such as relationships (interpersonal and work), economic concerns, or the current socio-political atmosphere been

addressed. There has been some progress achieved, but the terrain on which health and sickness are defined and experienced is constantly changing, so much work must be done. Therefore, the rest of this article will reflect on potential future empirical and analytical work and bring attention to certain recent pieces published in the journal that opens the door to what may prove to be 21st-century sociology of health and sickness."

Towards Sociology of Health and Healthy Bodies

However, "despite the literature's stated concentration on the sociology of health and sickness, it is remarkable that thus far, its articles have focused on the experiences of illness rather than health." When sickness and other dysfunctions begin to take hold, the "healthy" body is seen as an "absent presence" in daily life, according to Lupton, D. (2012)^[68], and only becomes a conscious focus of attention when the 'healthy' body is no longer perceived as an "absent presence" (see also, Williams, S. J: 2002^[69], Wilcock, A. A.; 2006^[70], Kazdin, A. E., & Rabbitt, S. M; 2013^[71] and White, K. 2016^[72]). To put it another way, studying health is considerably more difficult since the latter are more concrete and tangible. To stay up with the rising "risk society," where "healthy" bodies, rather than "sick" or "diseased," are increasingly becoming the sites of medical attention and treatments, medical sociology research must nonetheless take up this task. Aside from the fact that it's one of only a few articles that begin with "healthy bodies," the Monaghan (2001)^[73] study of bodybuilding subculture stands out as unique due to its thorough analysis that might be used in a variety of different settings and situations. Monaghan's research attempts to discover why people who follow a health-promoting lifestyle like bodybuilding are more likely to participate in risky behaviors like illegal drug usage. He points out that health is increasingly seen in popular culture as a representation rather than an objective reality, with "the appearance of health (achieved via the cultivation of a strong-looking, fat-free physique)" sometimes considered more essential than the accomplishment of health itself. According to Monaghan, 'Risky' bodywork's long-term viability may be attributed to the broad public view of anaerobic activity and the immediate sensory pleasures that arise from the sensation of a 'chemically augmented' body. Therefore, his research focuses on how a "healthy" body that has been actively lived in the present day is inherently dangerous. To return to a point researcher-made earlier, this kind of study helps consider how the "healthy body" may hinder "health promotion messages," particularly those aimed towards "at-risk" persons (those who are now "disease-free"). Aside from that, Monaghan's focus on bodybuilding's sensuous (and hence embodied) aspects highlights how a "healthy body is not always" and is inevitably regarded as an "absent presence" as well. To put it another way, his study provides evidence to back up the claim that good health is more than just the absence of sickness.

Concluding Comments

There is little doubt that the individuals who have written in the different publications of "Health and Illness have contributed significantly to our growing knowledge of lay experiences of health and illness over the last two decades." Bury, Charmaz, Williams, and many more, in particular, "had helped to galvanize a more general insight of individual (illness) experiences that acknowledges the interwoven

and interdependent nature of the body, self, and society as well as the significance of looking at timing, setting, and individual biographies in the context of the illness.” In the past, investigations of “patients’ experiences (when they existed)” were conducted from a medical viewpoint and isolated from the ordinary situations in which individuals live. However, it is essential to remember “that there are still many ‘missing voices’ and ‘uncharted territories in the literature’ that must be explored repeatedly. Aside from predominating over the research of health experiences (which are more elusive), studies of sickness experiences have also mostly focused on patients with chronic rather than acute illnesses. At least in part, this may be because, in medical sociology, research interviews are mostly used to gather data on the “significance” of illness rather than its “consequences” for persons in their everyday lives. Even if one accepts “that the research interview encourages a type of (bodiless) talk about experiences of health & illness, one that has led to calls for ‘sick and healthy’ bodies to be given a higher theoretical and empirical profile in work on lay experiences,” there are solid grounds for arguing that this is the case. An open-minded approach to data gathering techniques and taking on this task, in my view, is the best way forward for the sociology of health & illness that is fit to face the challenges of the next 20 years.

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