

February 2014

Book Review: Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness

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Recommended Citation

Attell, Brandon K. (2014) "Book Review: Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness," *The Journal of Public and Professional Sociology*. Vol. 6 : Iss. 1 , Article 5. Available at: <https://digitalcommons.kennesaw.edu/jpps/vol6/iss1/5>

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Cover Page Footnote

The author would like to thank Laura Overstreet for recommending this book.

At some point or another everyone becomes sick, and for many this means an encounter with a physician. With this encounter, the individual becomes the patient and typically some sort of a relationship is forged with the doctor. For most, this relationship is minimal at best, but for those who live with chronic illness the doctor-patient relationship is of crucial importance.

Recently, in an effort to better understand the doctor-patient relationship, I read *Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness* (hereto referred to as *DATRE*). As the title implies, this piece of non-fiction was co-authored by both a doctor and a patient, providing the reader with unique insight and perspective into the realm of chronic illness. Alida Brill, the patient, is a self-acclaimed feminist social critic and long-time sufferer of an atypical form Wegener's Granulomatosis. Michael Lockshin, the doctor, is held in high regard as a world-renowned rheumatologist and expert on working with individuals living with chronic illness.

By composing *DATRE* with alternating letters to the reader, Brill and Lockshin craft a unique conversational tone that spans many topics. Indeed, one of the most admirable characteristics of the work is its call to a general audience. Anyone would greatly appreciate the ease of readability that is present. Scholars in the field of chronic illness would benefit from the read as well, due to its approachability and frankness of the topics covered.

There is no specific thesis of the work per say, but rather a practical discussion of issues that are relevant to experiencing chronic illness. These issues include: uncertainty and the false power of illness, illness as an adventure of discovery, the day-to-day life of living with illness, impersonalization and the bureaucracy of health care, social epidemiology, and of course, the doctor-patient relationship, to name a few.

Analysis

In a broader context beyond the illness experience and the doctor-patient relationship, *DATRE* is, at its core, a true work on human socialization. What we see by reading and examining the text is that a multitude of the aspects of this discipline emerge into the day-to-day happenings of living with chronic illness.

For example, one fundamental aspect of human socialization is the dimension of time. Some people live by clock time, while others live by event time. Likewise, we also know that some live in terms of either a linear or felt time. But how does this relate to chronic illness? Brill and Lockshin explain that when living with chronic illness, one struggles with how to define time and carry out one's life. When things are going well (i.e., illness is in remission), we tend to live in a linear time (Brill and Lockshin, 2009, p. 8). But yet, when we encounter a medical crisis, we live in an immediate and emergent "now" time (Brill and Lockshin, 2009, p. 8).

In a similar light, Brill and Lockshin highlight the importance of the notion of a developmental perspective. Popularized by Erikson and Piaget, a developmental perspective focuses on experiences and change across one's life course. With chronic illness, we see that a developmental perspective is extremely important. For example, the experiences that one has with the medical world as a child immediately shapes how they will react to future experiences with the health care institution (Brill and Lockshin, 2009, p. 35-46, 55-59). Also, doctors frequently face a crossroad of choosing whether or not to do what is good for their patient in the long run, and in turn harmful for them now, or doing something good for them now and harmful in the long run (Brill and Lockshin, 2009, p. 169-178).

On a different, but equally important note, living with chronic illness often results in role strain. For example, while living with chronic illness Brill has faced the loss of a loved one (Brill and Lockshin, 2009, p. 116) and the loss of a prestigious job (Brill and Lockshin, 2009, p. 197), due to her constant struggles with maintaining life as a sick person. Furthermore, there also comes a point where she is sick herself, and must take care of her equally sick parents (Brill and Lockshin, 2009, p. 217-225).

But let there be no mistake in knowing that doctors also experience role strain. It becomes abundantly clear that throughout the text, Lockshin constantly struggles with dealing with the many roles he leads as a doctor, friend, and husband. It is painfully obvious that the many calls from patients that Lockshin receives at his personal home causes undue stress on the relationship between him and his wife (Brill and Lockshin, 2009, p. 181-187).

As this is a book centered on living with chronic illness, it comes to no surprise that much of the text also focuses on interactions with the social institution of health care. It goes without saying that the health care system in America is widely criticized for a multitude of reasons. In this regard, *DATRE* speaks to two important issues. These are the impersonalization and bureaucracy of the hospital, and the treatment of social classes in the health care institution.

Specifically, Lockshin mentions his disappointment with the fact that his hospital does not allow him to design and decorate his own office (he likes to make things comfortable for the patient, but this ability becomes limited by hospital regulations), as well as the overall starkness of the hospital he works at (Brill and Lockshin, 2009, p. 61-66). Further into the text, we see the importance that social class has on the ways in which individuals are treated in the hospital. We learn of a patient named Carol, who was ultimately the victim of a fatal medical error due to health care professionals not taking her complaints seriously (we learn that her claims were dismissed because of her perceived lower class background) (Brill and Lockshin, 2009, p. 163-168).

Beyond these specific examples that I have given thus far, a respectable feature of *DATRE* is the many facets of sociology that are interwoven throughout the text. These are not specific occurrences that are present within the text, but rather several holistic themes that manifest upon completion of reading the book.

For example, as we read the alternating letters from Brill and Lockshin, we obtain a feeling for the importance of dyadic relationships. Here, the connection is obvious: Brill and Lockshin are bound together by the patient-doctor relationship. By reading between the lines, we gain a sense of how their relationship transcends the popular conception of this particular type of dyad. We see that what they have is a crucial, albeit rare, type of relationship where the doctor and patient have become friends and partners as they “negotiate” life with chronic illness. Brill mentions early on in the book that she immediately knew that Lockshin would be a good doctor because of how he greeted her upon their first meeting in his office. Arguably, Lockshin’s success as a doctor is because of his personality and willingness to connect with his patients on a more than superficial level- something that many doctors could benefit from learning.

However, not all is wonderful with such a relationship. There are several instances in which Brill mentions her lack of control in the relationship. Likewise, Lockshin mentions his frustrations when patients choose not to comply with his orders. These cases allude to the broader social phenomena of power and conflict. Of course, classic Marxist theory relies on the notion of determining who controls the means of production within a given society. But as made evident by *DATRE*, we can still see that dyads, by nature of a two-person relationship, are almost inherently likely to lend themselves to the dichotomous power struggle that Marx spoke of between the bourgeoisie and the proletariat. What is important to note is that the two (Brill and Lockshin) are able to put aside this power struggle and equally appreciate one another for their given strengths and weaknesses.

Furthermore, there is a presence of spirituality that illuminates *DATRE*. Not once do Brill or Lockshin mention their religious preferences, but yet the reader is still left with a sense that the two believe in a greater power. Truth be told, some of the most gripping portions of the book are Brill’s discussion on her contemplations of suicide. By allowing the reader into this intimate portion of her life, we see through Brill the power of having some sort of spiritual connection.

Lastly, there is a sense of a symbolic interactionist approach to living with chronic illness that permeates throughout the text. What I took away from this was that living with chronic illness is, in large part, a subjective experience that we assign meaning to. Whether we decide to let the illness take over our identity or master status is largely up to us.

Evaluation

It is my prediction that *DATRE* is likely to establish itself as a reputable work for generations to come. The alternating compositions between Brill and Lockshin are approachable and very well written. It is admirable that the two have written in such a manner, as it allows the reader to comprehend many intimate aspects of life with chronic illness. Again, here it is important to reiterate that as we hear from both a doctor and patient, we are exposed to a dynamic understanding of the topics that are discussed. We see that at times the two agree and at other times the two disagree. This reveals the humanistic aspect of the issues that are relevant to living with chronic illness.

One of my favorite features of the text is the apparent frankness and honesty regarding the issues that Brill and Lockshin address. For many, issues regarding health and illness are intimate details that most care to keep to themselves. This is certainly not the case with *DATRE*. I imagine that those who are new to living with a chronic illness will appreciate and respect Brill and Lockshin's approach here just as much, if not more, than I did.

Of course, *DATRE* does bring about many new ideas. For example, it shows that doctors and patients can, indeed, have extremely positive and meaningful relationships. It also shows that the issues of dealing with chronic illness are not only pertinent to the patient. If anything, we learn that Lockshin internalizes many of the relationships with his patients, as well as the life-bearing decisions that he is constantly forced to make for his patients' lives.

However, I must say that *DATRE* did make me wonder how this book would have been written if Brill and Lockshin had not formed such a lasting relationship. I do believe that it would be interesting to see a similar work crafted by a patient and doctor who were completely indifferent towards one another.

Conclusion

DATRE is, without doubt, a recommended read for anyone who is interested in aspects related to health or chronic illness. I foresee that those who read the book will have a conversation with themselves as to how they understand the various forms of illness that they have experienced in their own lives, as well as the types of relationships that they have encountered with health care professionals.

References

Brill, Alida and Michael D. Lockshin. 2009. *Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness*. Tucson, Arizona: Schaffner Press.