

Response to “IPLEX and the Telephone Game”: Conflicting Paradigms

Mihaly Lenart¹

Blaming the Victim

The title refers to the paper (1) by Bedlack, Silani, and Cudkowicz (in the following “authors”). It takes a critical view at the communication among ALS patients (PALS) and their caregivers, in particular at the spreading of rumors and misconceptions about ALS treatments, specifically with IPLEX. Given the authors’ concern, my question to them is this:

If you are on death row facing also years of torture, and suddenly you are given a gleam of hope to delay the inevitable or even escape by following unproven directions, what would you do?

This is namely the dilemma of PALS! They ask the medical community: What are you offering us other than palliative care? Can you tell us anything encouraging other than making vague promises that in some distant future we will have an early detection of ALS, effective treatment of symptoms, or even a cure? The answer is disheartening: ALS is “a dreadful, terminal, neurodegenerative disease to which no cure has been found so far” (1), not even a symptomatic treatment, and all that PALS can hope for now is to slow down the progression of their illness. Given this answer by the medical community, is it then surprising that PALS are keen to listen to other, more optimistic messages, regardless where they come from and how reliable they are? Who can blame them for turning to each other for help, organizing support groups to exchange news, stories, and ideas? Who can blame them if they reach even for the thinnest thread of hope, or believe in unverifiable promises? Who is to blame if they are fed up with disappointing statistics and listen instead to promising anecdotes? Who can blame them for amplifying and/or distorting rare success stories? Who can blame them even for gullibility?

Changing Focus

I understand the reservation of the authors and agree—to a certain degree—with their assessment regarding the danger and potential harm of misleading information, but one also needs to understand the desperation of PALS that is fertile soil for myths and false hopes. I grant the positive intentions of the authors, yet it is hard to sympathize with their grumbling about the “the telephone game” of PALS, as recognizing myth, fiction, imagination, or confabulation is not easy, especially if your vision is blurred by desperation. The authors don’t blame anyone explicitly, but they do indirectly by expressing concern about the fast spreading information that gets distorted and misinterpreted by the online grassroots community of PALS. They also seem to be concerned about internet communication fostering unfounded rumors and gossips, in particular about “[I]etters and petitions [...] circulated online” (1) or online chat rooms, such as PatientsLikeMe.com. However, only Luddites would blame the internet, and spreading misleading information that gets more misleading and distorted at every turn is only a symptom. The real problem that should be addressed instead is the divide between the medical community and that of PALS created by the different paradigm each one lives by.

Authors’ Paradigm

The paradigm of the medical community can be characterized by a sign that I once saw in a medical office. It said: “*Let’s first establish who the doctor is here and who the patient.*” The authors obviously share this view of medical authority, as they find solace in the fact “that most patients have tremendous

¹ lenartm@gmail.com

respect for the opinion of their treating physician and health care provider” (1). They suggest that only medical doctors and scientists have the knowledge and wisdom to decide what is best for the patient. They look down on the PALS community as a group of laymen or amateur scientists who often don’t understand the subject and won’t appreciate or respect the rules of scientific research. For example, the authors write disparagingly about a study conducted by the PALS community: “Those who wanted to experiment on themselves [with lithium] found physicians to prescribe it, and even found an online forum for entering their data (2). Now these lithium ‘data’ (none of which are validated or controlled) have been analyzed and there is reportedly no obvious beneficial effect, which has prompted calls to cease further study of lithium (3)” (1). The authors are concerned that “this type of misinformation [...] could negatively influence enrollment in ongoing and future clinical trials in ALS and slow the development of effective treatments for ALS” (1). It means that trials are the exclusive domain of medical authority and meddling with ALS research by PALS harms the struggle of the medical community. The authors also believe in objectivity that the authors do but PALS don’t have, as they complain that “few objective data [...] are available at this time [about IPLEX treatments of PALS],” or that “[n]o objective confirmation of these symptomatic improvements [reported by a specific patient after an IPLEX treatment] was provided” (1).

This (positivist, objectivist, or modernist) view or paradigm is based on the premise that knowledge is “out” there, independent of the knower, ready to be discovered and be transferred into people’s heads. It is “a commodity that can be communicated” (4). Presupposed in this view is that there is one true *reality* “out” there, which exists independently of the observer. Furthermore, we have access to this reality, and we can fragment, study, predict, and control it (5; 6). The traditional scientist’s goal is to find the *truth*.

Paradigm Change

The above described traditional paradigm is, however, plagued with contradictions. As von Glasersfeld (4) points out, while trying to access reality, we have been caught in an age long dilemma: On one hand truth is (traditionally) defined as “the perfect match, the flawless representation” of reality (p. 4), but on the other hand, we *all* live in a closed world defined by genetic, social, cultural, and other constraints. *Who then, is to judge “the perfect match with reality”?* To answer this question, Western philosophy has overwhelmingly made the assumption that given the right tools, *pure reason* is able to transcend all constraints and the confines of the human body. Therefore, in traditional science, emotions, and more generally our body, are obstacles to pure reason. As a consequence, the only valid research methods are *quantitative*, in terms of “objective” data. “Measurement!” –writes Pert– “It is the very foundation of the modern scientific method, the means by which the material world is admitted into existence. Unless we can measure something, science won’t concede it exists, which is why science refuses to deal with such ‘nonthings’ as the emotions, the mind, the soul, or the spirit” (7, p. 21).

In contrast, the so-called constructivist philosophies (originated with Piaget) have adopted a concept of knowledge that is *not* based on any belief in an accessible objective reality. In the constructivist view, knowing is not matching reality, but rather finding a *fit* with observations. Constructivist knowledge “is knowledge that human reason derives from experience. It does not represent a picture of the ‘real’ world but provides structure and organization to experience. As such it has an all-important function: It enables us to solve experiential problems” (4, p. 5).

The traditional image of a scientist is a “cool, detached, solitary genius, the one who has the answers that others don’t have, as if the truth could be owned” (7, p. 315). For example, Gergen (8) mentions the work of (renown sociologists) Bruno Latour and Stephen Woolgar, who observed scientists at work at the Salk Institute of Biological Studies. After months of observation, they concluded that “what counts as objective truth is not the result of rationally subjecting hypotheses to empirical test, but emerges

from a network of social agreements” (p. 93). Thus, if the narratives of PALS are myths, then the *objectivity* of experiments and data is also a myth, for the questions scientists ask themselves, the theories they formulate, and the choice of tools and methods to prove theories (assumptions) are inherently subjective or biased in the sense that they all depend on the intentions and values of the experimenter. Due to the complexity of medical problems, the large variety of symptoms and characteristics, medical science in general and ALS research in particular is especially prone to such bias. Scientists commonly use quantitative methods, in particular mathematical models, to claim objectivity. Yet, these methods only obscure bias. The medical and PALS community have different biases, as they have different perspectives. While the medical community is concerned about helping the entire group of PALS and has a long-range perspective, individual PALS are fighting for their own immediate survival. Problems arise when there is a lack of mutual understanding and acceptance of the biases of the other.

Implications

The PALS community is questioning now medical authority and demanding more involvement in ALS-related activities as equals. The proactive awareness of the PALS community was triggered by free access to information and the unprecedented democracy of the internet: “the *information boundaries* that previously existed have been gradually breaking down; more patients and their families have become more aggressive in determining their own treatments” (10). Patients want to take control of their lives by networking and learning. PALS and their caretakers want to play increasingly an active role in the information exchange and the decision making process. The paper referenced in title (1) confirms that information is already flowing in both directions: from the medical community to PALS and vice-versa. However, this is not an exchange between equals, as the “three well-intentioned researchers” (10) feel to be the authorities in this relationship, the ones with the proper knowledge and right judgment. And they do it by “denouncing or at least severely minimizing a grass roots approach for the use of a biotech treatment [i.e., IPLEX]” (10).

Admittedly, the free-flow of information has pitfalls, such as “possibly erroneous information transmitted, inappropriate use of otherwise good information [...], a lynch-mob mentality that possibly forces the medical establishment to embrace or at least reluctantly provide such treatment” (10). Yet, discrediting or distrusting the PALS community kills free communication. The authors intend to “do a better job distributing information to PALS on the many benefits of” various patient supports and “educate PALS on how to distinguish myth from reality” (1). Thus, in the authors’ view, it is the medical community that has access to “reality” and has nothing to gain by listening to or working with a community that creates and spreads dangerous myths.

The PALS community also distrusts the medical community, as the priorities on both sides not always overlap. The “small but well-documented case series [that] showed potential slowing of ALS progression on lithium” (1) is an example. According to the authors’ own paradigm, the 13 cases of this study are too insignificant to draw any meaningful conclusion. Yet, it was published and, subsequently, no one in the medical community found necessary to scrutinize its findings. This suggests that the authors of the lithium study (11) were more concerned about “publish-or-perish” than the impact of their paper, i.e., the danger of creating false expectations among PALS. Upon witnessing so much noise about lithium on the internet, why did the medical community keep still? How can the authors criticize the PALS community for initiating and self-conducting a study, if the medical community remained silent while negative experiences with lithium treatment were piling up?

The unfolding story of IPLEX also raises unanswered questions to the dismay of the PALS community. IPLEX treatment of PALS in Italy has been going on for over two years. “In the meantime, Insmad collected data from PALS in Italy treated with IPLEX, and preliminary results have been recently circulated inside AIFA, the ALS experts of the Italian Commission and AISLA” (1). Yet, “[t]hese uncontrolled data have not

been officially released" (1). While the medical community must have been aware of the anxiety and high expectations of PALS about IPLEX, how is it possible that no information has been revealed for two years? Is it then surprising if such secrecy fuels suspicion, guesses, speculations, and myths? Now the authors write: "We *could* [italics mine] accomplish this [i.e. the release of preclinical and early clinical data related to IPLEX] via a letter on behalf of the World Federation of Neurology Research Group on ALS (WFN/ALS), the ALS Research Group (ALSRG), or the European ALS Consortium (EALSC)" (1). Why only now? And, if they are indeed concerned about "separating myth from reality on the internet" (1), why then just "*could*" instead of "*must*"? Also the patent dispute surrounding IPLEX raises questions about priorities, as this, in spite of its numerous complex legal and financial aspects, doesn't seem to bother the authors. Curiously, they are deeply concerned about the communication among PALS regarding ALS treatment, but they disregard the extensive communication about legal and ethical issues prior to the release of IPLEX for PALS.

Commonly used mathematical models in medicine are statistical ones. While statistics are extremely useful for medical research, sometimes anecdotal evidence is more meaningful for PALS. An ALS patient might care more about the account of a fellow ALS patient who experienced "rapid improvements" than the lack of "objective confirmation of [...] symptomatic improvements" (1). From a PALS point of view, does it really matter whether IPLEX "objectively" and measurably improved the symptoms of someone, or s/he just "felt like [her/his] body was under a seismic shift and IPLEX was jolting the foundation of the disease" (1)? If all IPLEX is doing is creating such feelings, then it is more than anything else the medical community can offer today.

In spite of the medical community's misgivings, PALS are also trying unorthodox methods, such as alternative and Traditional Chinese Medicine, to ease their pains. Without offering any alternatives, how can anyone discourage PALS to try medically unproven methods, as long as they are relatively harmless? If they turn out to be useless, the only possible harm is disappointment. Yet, disappointment is still better than succumbing passively to this devastating illness. As long as there is something to try, there is also hope. As long as there is hope, depression, a common ALS symptom, can be kept at bay. As long as no sufficient experimental data are available, IPLEX is also an unproven treatment. It is a drug that has been thoroughly tested and approved for a different application than ALS by the FDA. Yet, it was found safe, even for infants, and apparently did help a few PALS. Thus, it is another hope to keep PALS going.

Opportunity

The misunderstandings and mistrust are very unfortunate, as there are wonderful people on both sides of the divide who are moved by the unspeakable human tragedy of PALS. Every one of them has the same goal of helping PALS, even if their philosophy and approach are different. Since the medical community has the power and means to influence research and the pharmaceutical industry, I applaud the authors for recognizing that it is the medical community that needs to take the initiative and change. However, where they see problems, I see opportunities. The grassroots organizations of PALS are namely an enormous force to reach and mobilize patients and care givers. And the Internet is a magnificent tool to communicate and distribute information instantaneously. So scientists and pharmaceutical companies have an opportunity to build a large community to work with for collecting information, disseminating data, and ultimately help PALS more effectively. Working closely with the PALS community would also minimize misinformation. PALS and their caregivers are also extremely driven, cooperative, and knowledgeable. They might lack medical knowledge, but they live ALS every single day which is knowledge the medical community doesn't have. Thus, there is an opportunity for change of attitudes and cooperation between the medical community and the grassroots organizations of PALS. All it needs is more openness and trust.

References

1. Bedlack, R S, Silani V, Cudkowicz ME: IPLEX and the Telephone Game: The difficulty in separating myth from reality on the internet, *Amyotrophic Lateral Sclerosis*, 2008, pp1-3
2. Patientslikeme.com [home page on the internet]. The website Patients Like Me; 2005-2008 [cited 2008 November 25]. Treatments section [1 screen]. Available from <http://www.patientslikeme.com/als/treatments/show/777-lithium-carbonate>
3. Wohlsen M: Patient-led drug trials defy medical establishment [monograph on the internet]. Associated Press; 2008 [cited 2008 November 25]. Available from <http://www.google.com/hostednews/ap/article/ALeqM5hoh2DJB0ELSmjikYupXYq9eydSHQD94MPVSG0>.
4. Glasersfeld, E. von: Learning as a Constructive Activity, In Janvier, C. (ed.), *Problems of Representation in the Teaching and Learning of Mathematics*. Lawrence Erlbaum Assoc.: Hillsdale, NJ, pp. 3–18, 1987
5. Lincoln, Y. S. & Guba, E. G.: *Naturalistic inquiry*, Sage Publications: Newbury Park, CA, 1985
6. Hale-Haniff, M. and Pasztor, A.: Co-constructing Subjective Experience: A Constructivist Approach, *Dialogues in Psychology*, 16.0., 1999 <http://hubcap.clemson.edu/psych/Dialogues/dialogues.html>
7. Pert, C. B.: *Molecules of Emotion*, New York: Scribner, 1997
8. Gergen, K. J.: *The Saturated Self*, New York: Basic Books, 1991
9. Bedlack RS, Pastula DM, Welsh E, Pulley D, Cudkowicz M: Scrutinizing enrollment in ALS clinical trials: room for improvement? *Amyotrophic Lateral Sclerosis*. 2008; 9:257-65.
10. Byer, S: Private communication, 2009
11. Fornai F, Longone P, Cafaro L, Kastsiuchenka O, Ferrucci, M, Manca ML, et al. Lithium delays progression of amyotrophic lateral sclerosis. *PNAS*. 2008;105:2052_7.