Healthy Lives for All, Until the Last Breath: An Interview with Dr. Alex Jadad

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Dr. Alex Jadad

Dr. Alejandro R. Jadad Bechara (Alex Jadad, in short) is a physician, educator, researcher, and public advocate. He is a Professor in the Faculty of Medicine and the Dalla Lana School of Public Health, and holds the Canada Research Chair in eHealth Innovation at the University Health Network and University of Toronto. His mission is to enable people to build full lives through innovative global collaborative efforts enabled by information and communication technologies (ICTs). Alex has been called a "human Internet", as his research and innovation work seeks to identify and connect the best minds, the best knowledge and the best tools across traditional boundaries to eliminate unnecessary suffering and promote maximum levels of joy.

Dr. Jadad is one of the first physicians in the world with a doctorate in health knowledge synthesis, and has developed unique methods to collate and distill high-quality health information for decision-making. His development of the widely used Jadad scale has drastically impacted clinical trial appraisal globally, and his work was instrumental to the development of the Cochrane Collaboration. Furthermore, he spearheaded the creation of the Centre for Global eHealth Innovation – a simulator of the future and a hub for ICT optimization in health care and society – in 2000. He is also spearheading the founding of the Global People-Centred eHealth Innovation Network to promote research, development, education, policy, funding, recognition, and commercialization surrounding ICT use for health and wellness, and the People, Health Equity and Innovation Group to address the needs of the disadvantaged members of society through youth leadership, global multiculturalism promotion, and supportive care to patients and their caregivers. Dr. Jadad's work has been recognized on numerous levels, and his groundbreaking discoveries in e-health innovation, global health and research methodology – among other areas – are world renowned.

The purpose of this interview is to learn about his journey from the time in which he was a medical student, and to explore his views about medical education, medicine, health, the health system, and the future of the species as a whole, in the age of global social networks. More information about his life is available at http://en.wikipedia.org/wiki/Alejandro_R._Jadad_Bechara.

UTMJ: Tell me about yourself and the scope of your work.

AJ: : I am a physician by training and a healer by vocation. My work focuses on figuring out ways in which we humans could have the longest, healthiest, happiest possible lives, full of love, and with no regrets, until our last breath – as part of a planet that doesn't pay the price along the way.

So, I try to blend the high-touch with the high-tech. I try to foster what is really meaningful to us as humans – health, happiness, love – with the support of a global network of collaborators who use information and communication technologies to transcend traditional barriers. This also involves obsessive efforts to eliminate unnecessary suffering. There is a lot of that, most as a result of inequity throughout the world. Inequities are inequalities that could be corrected, and that should be corrected.

UTMJ: What led you to founding the Centre for Global eHealth Innovation, and what does the organization represent?

AJ: I began my real career – that of a curious creature, learning to unlearn – when I was 17. I was already a third year medical student in Colombia, South America, when I realized, thanks to a couple of school kids in a very poor area of Bogotá, how disconnected medicine has become from society at large. They asked me questions about 'basuco', which was a derivate of the coca plant, about which I didn't have a clue. Even though I was a medical student at the top faculty of medicine in the country that was leading the world in the cocaine trade, I did not have a clue about cocaine or this new thing, which soon became known as 'crack'. Before I was 20 years of age, my research on basuco, from a medical perspective was used by governments and United Nations, as there was very little else available. I do not feel that this was a matter of genius; it's just that there was a gap so wide that it was not easily visible. So, from a very early age, I realized that there is a big gap between what people need, want, and expect from medicine and what we call the health system, and what we are offering. My entire career has been devoted to filling that gap. It was cocaine first. The work on cocaine, which is a local anesthetic, helped me become aware that we

know very little about the management of pain. In fact, in Canada, medical students get 3-5 times less training on pain management than vet students! Something similar has been shown in the UK and Australia through analyses of medical school curricula. We seem obsessed with diagnosing and fixing people, which are important when we face curable conditions. But when it comes down to chronic illness or symptoms like pain, which is probably the symptom that we humans fear most, we don't have a clue!

Then, work on pain relief took me to death and dying, which continue to be very neglected. We don't talk about death, we don't talk about dying; we know who dies when and where, but not how. We avoid talking about death in medical schools, and in the healthcare system in general. So I started to look at death and dying issues, joining forces with others to create criteria for a 'good' death anywhere in the world.

And then, the Web exploded! I could sense it coming, when I started playing with what was known as Mosaic and Gopher, before the Web was publicly available – it was only accessible to academics and government agencies at the time. A few years before, in 1990-1991, a patient asked me at the pain unit at Oxford whether I would be keen to get an email message from him about his pain, and I said "sure!" Thus, this patient and I started to peek into another gap, now in the virtual world.

These big gaps between what people need, what people want and what people expect from the system and our inability to pay attention to them, led to the creation of the Centre for Global eHealth Innovation, which is in essence, a place that is designed with change in mind, because the only thing that we can anticipate is change. It is a place where we can imagine the future – a future where we would all like to live, and that we might be able to create, collaboratively. So we have a facility where we can simulate almost any set of circumstances where we could improve our health and actually build them, collaborating with people from different disciplines, and putting the person, and the community at the centre (and lead) of the change process. This organization creates an opportunity to close the gap, that gap that has fed my career, sadly, between what we as members of society want and need to achieve optimal levels of health, and what we get, in the age of the Internet and social networks.

UTMJ: How do you define health and illness, and what is the role of technology in addressing the two?

AJ: Nothing important can be defined. Try to define a chair – as Wittgenstein, the philosopher, invited us to do. What is a chair?

UTMJ: A surface with 4 legs that someone sits on?

AJ: But this one (*he pointed*) has 5; the one on which you are sitting.

UTMJ: That is true.

AJ: Then what's a chair?

UTMJ: Something that is used to sit on.

AJ: For the record, I am sitting on the floor. Is this a chair?

UTMJ: No.

AJ: Then what's a chair? We cannot define pretty much anything. So don't try to define things. Defining things requires precise language, to describe an entity in a way that everyone would accept and that would include all instances of the entity. So, I asked this question to myself in the year 2008 when I thought I had colon cancer. I realized that even if I had colon cancer, I wanted to be healthy. But to be healthy, I needed to know what health means. I was shocked to think that 20 years of university education made me unable to answer the question 'what is health?' What do I mean by health, and how do I know when I am healthy?

I was very good at diagnosing diseases, and I was rewarded for diagnosing disease, and trying to treat it. But in horror, I realized that I did not know what health means. I checked the definition (and they called it a definition), that was used for the creation of the World Health Organization in 1948, and it still reads, 'health is a state of complete physical, mental and social well-being, and not just the absence of disease or infirmity'. But who can claim to have complete physical, mental, and social wellbeing? You are tired, you did not sleep well last night, and so you are not healthy. You probably have cavities – the prevalence of tooth cavities is huge (it is the most prevalent chronic disease in the world, a fact that is often ignored). Most people in society have visual problems. Even if your shoulder aches a little bit, you do not have complete physical wellbeing. If you have to wear glasses, you don't have complete physical wellbeing. So in essence, that definition makes us all 'not healthy', and makes health impossible to reach. So we medicalized our lives, to our advantage of course. In the year 2008, when we were celebrating the 60th birthday of the World Health Organization, I had the privilege to invite the world to participate in a global conversation about the meaning of health, and we used technology for that.

The British Medical Journal supported this conversation, and 3 years later, we proposed what is, rather than a definition, a conceptualization of health. When you conceptualize something, you try to de-

scribe it approximately with what it intends to achieve or with what it makes you feel or with some features that would allow you to recognize it – it is a very dynamic thing. The concept of health we are proposing is the ability to adapt and to self-manage when we are facing physical, mental, and social challenges, as individuals or communities. That implies preventing the preventable, treating the treatable, and transcending the inevitable. If you have a chronic disease, by default, it is incurable. We have discovered that having an illness or disease and being healthy are not incompatible things. 90% of people with diabetes consider themselves to be healthy, for example. Two-thirds of people with incurable cancer have been shown to consider themselves healthy – that their health is good, very good, or excellent.

We really don't know what disease or illness mean. We haven't devoted enough attention to this – who is to decide what is an illness or a disease? Traditionally, it has been the medical profession, which has decided what is abnormal.

Havi Carel, a philosopher in the UK, who was diagnosed with a very serious disease at an early age, proposes at least 3 approaches to the conceptualization of illness. She proposes to take into account the biological or medical aspects – the naturalist perspective – criteria proposed by people who are experts in medicine about what is abnormal – we need to be very careful about that. Psychiatry is a clear example – how we decide when something is a mental disease is one of the most contentious things. So we need to be very, very careful – even with cancer. Cancer does not seem to be just a disease; it seems to be at least 250 different conditions. The more we dig into the biology of the tumours, the more we realize that using the word 'cancer' is very similar to using the word 'infection'. "Oh I have an infection!" What does it mean? You can have a cold, pimples, or Ebola – all are infections! Saying, "I have cancer" – what does it mean? When we stop to think about what illness is, we realize that we haven't stopped to think about what we mean, or should mean, by it today. So Havi Carel says, yes there is a biological aspect to illness.

But then there is a societal aspect to illness – how we as a community consider things to be normal or abnormal. There are situations like back pain – back pain in other cultures is not an illness or attention deficit disorder or hyperactivity – that do not exist, or are not accepted as an illness in other parts of the world. That does not mean that they are not diseases – but that they are socially determined. Havi Carel insists that at the end of the day we have ignored the phenomenological aspects of our health – how it feels to the person, the lived experience. That is why we are emphasizing a lot on the self-reports of health status. We are asking people, "In general, how would you rate or judge your health?" If you feel that your health is good, very good, or excellent, then you are healthy! If you have the label of a disease or more than one disease, it is our responsibility as health professionals to acknowledge this, to honour this, and to enable you to remain healthy. If you have a disease that could be treated, we should treat it, of course. As this is not the case in most instances, we must look beyond the biological and medical aspects of an illness as the main drivers of the decisions we make.

UTMJ: What role can information and communication technology play in transforming medical education and healthcare?

AJ: Well, it depends on us. What do we want to be? What is our essence? What is really the role of a physician in the 21st century? What are those things that only we as physicians can do that no other group can just as well or better? When we think in those terms, it gets very uncomfortable for us. What justifies our existence in society? If we are the people that make diagnoses and fix people, do we need so many years of training? Do you really need to go through medical school for 20 years to do a bypass on a heart? Do you as a member of society prefer to have a group of people who for three years devote themselves to learning about how to put a piece of vein on a heart?

What is the role of hospitals? We haven't thought about this very much either. 'Hospitals' come from the Latin word 'hospes', which refers to a 'guest house'. It is a place where you should feel as comfortable as you feel at home when you cannot be at home because you are not well. What is the role of hospitals? Probably only 5 things – intensive care, major emergencies, major surgeries, exacerbation of complex chronic conditions, and experimental stuff. Everything else should, and could, be happening elsewhere. Hospitals are the most dangerous places in society. Perhaps, most of what is happening in a hospital right now should be happening outside those buildings. Information and communication technologies should be enabling us to achieve optimal levels of health by avoiding going to those places, or by connecting us with people who could enable us to adapt and self-manage when we could not do it on our own, or with support from our peers and other members of our communities, or with support from community-based professionals.

What kind of medical education do we want? Do we want to train people to be technicians, or to be the storefront for industry to sell their products, or do we want people who are truly enabling the population to achieve maximum levels of health in the sense of the ability to adapt and self-manage when faced with physical, mental, and social challenges? If that is the case, we need to change medical education dramatically. If not, we just need to acknowledge that we are techni-

cians and that we use gadgets to help us do more of the same, which may not be meeting the needs of society. Don't get me wrong – I'm not talking about not treating the treatable – if there is something treatable it should be treated, and for free! That is what people like Archie Cochrane said – every effective treatment must be free. Most of what we are doing is trying to treat untreatable things and throwing therapeutic options at things that are not going to go away, neglecting in our medical education the relief of symptoms, or the social aspects of illness. Loneliness may cause more death amongst old people today than obesity or high blood pressure. Fatigue is the most disabling symptom amongst people with cancer. We know little about how to deal with those important things!

Even more importantly, it seems possible to create and spread health. As ideas, emotions, and behaviours are contagious, health is likely to be transmissible. We have a unique historical opportunity to trigger a pandemic of health. Information and communication technologies could and should play a major role in speeding it up, particularly through the activation of our social networks.

UTMJ: And is there a role here for information and communication technology to play?

AJ: Of course! Because most of the issues require bonding, supporting each other, being with people when they feel most vulnerable, and contributing to improve their capacity and ability to adapt and to self-manage the challenges that life presents. In many cases, technology can also boost our efforts to cure the curable, or to prevent the preventable.

UTMJ: What are the consequences of our overreliance on technology?

AJ: We become more and more like robots, and less and less human. The early industrial titans, perhaps, realized that building robots was too expensive or too complex, so they decided to turn us into robots. I feel that it has been much cheaper, much more effective, to turn humans into robots to perform tasks along production lines, than to build robots that could replace us completely. This has now extended to the service sector, where the "healthcare industry" belongs. Most of us are becoming, or behaving, like robots. The educational system seems to be designed to standardize and to make sure that we conform, and are compliant, and that we go into production line-like activities with division of labour, so we become more and more specialized doing few things, often just one thing, and one thing only without deviating. The consequences of our overreliance on technology is the reduction in our humanity and reinforcement of our transformation into robots and the inability to communicate, to bond, to relieve suffering that goes beyond what could not be fixed with gadgets, within a context that is not really a system, but an inefficient franchise of repair shops which at the end of the day might be the biggest threat to our health.

UTMJ: What has guided your work in global health and eHealth innovation?

AJ: The feeling that we are part of a species that is accelerating its own extinction, that global health refers to our ability to adapt and self-manage as members of a species facing challenges as a group – as a super-organism in trouble – one that should be considered very much part of the planet, not a separate entity trying to control it. We are experiencing an existential crisis, from the individual to the planetary levels. The air we breathe, the atmosphere, as Buddhists tell us repeatedly, is really our external organ. The water we drink too. We must cherish them, because they are us. We are truly one.

There are many sources of unnecessary suffering that are present everywhere in the world, and that should also be regarded as key drivers of global health activities. Gender inequity is a big one, for sure. Being a woman, for instance, might be the greatest risk factor for violence in the world. Income disparity is a big issue of global health, and it is growing. Early in 2014, it was reported that 85 people had accumulated more money than 3.5 billion people. We have been putting more emphasis and value on the symbol of wealth than on the actual wealth that money represents. One billion people are hungry today, despite our capacity to produce enough food for every human. This is global health too. That one billion people don't have shelter, even though we have space, raw materials, knowledge, and energy to secure a roof for everyone in the world. By the way, at a hyperlocal level, tens of thousands of children in Toronto go every day to school without breakfast. Why? In a country that wastes food worth much more than what would be required to eliminate hunger in the entire world every year – there is no reason. So hunger is not just a problem of India, where 250 million people don't have enough to eat. We have problems of hunger in a country like Canada. Gender inequity – there is no country in the world that has same conditions for men and women. Not a single one – Iceland has the top index of gender equity and women make less money than men for the same type of work. All of these issues have a lot to do with global health.

So yes, we have challenges with traditionally preventable infectious diseases in most marginalized parts of the world, but in financially rich areas we are facing dangerous infections too, mostly caused by antibiotic-resistant bacteria. Antibiotic resistance and the fact that there have been no new families of available antibiotics since the late 80s (mostly because they are not

commercially attractive to pharmaceutical companies), while existing ones are abused may send us to a time (which ended in the early 20th century) when infections were the main cause of death for humans. That is global health. So global health for me, is an effort for us humans to act as members of a species at risk of extinction, and to figure out a way in which we could join forces so we can increase our collective capacity to adapt and self-manage in the face of all these challenges as part of a sustainable planet that needs to be healthy too! We must also look as deep as possible. We need to think and deliberate about the underlying causes for these sources of suffering. Why do we invest so little effort in prevention? Why do we have malaria now in Africa, Asia, and Latin America, and no longer in the United States or Europe? Inevitably, we must start thinking about economics and politics.

UTMJ: What is one piece of advice you would like to share with medical professionals and students?

AJ: I don't give advice or recommendations ever. I provide suggestions. One I would like to share is to be urgently patient, to think deliberately before acting, and to ask questions - Why? What if? So What? - As often as possible. Because we are facing huge challenges, while risking to become willfully blind, most of the time, to the big issues. We are concentrating on what is easy – let's diagnose and fix things. We are paying a huge price – we are becoming less and less relevant in society, people are considering us increasingly as technicians who don't care.

We are suffering – our emotional lives are shattered. The level of burnout among physicians is very high, even from the early years of medical school. The rates of suicide amongst female physicians are multiples of the rates of suicide amongst non-physician members of society. Suicide is a leading cause of death amongst medical students, if not the first one now. We are not a happy bunch. We are becoming sad, burnt out, disconnected from society, and trained to do things that have less and less value in terms of health, and more and more value in terms of the sophistication of our understanding of the smaller aspects of our bodies, but less and less able to deal with health in the broader sense – the ability to adapt and self-manage, as essential to a full life. We need to stop, think and question our most cherished assumptions and beliefs, and join forces with other members of society. Many faculty members, like me, are willing to work with you to find better ways to deal with these types of issues.

The rate of burnout among residents is up to 75%, and amongst medical students is about 50%. Most medical students feel powerless to change anything – so you have to conform, because you want to get your clerkship in a good place and then you conform because you want to get a certain residency. So you keep conforming all your lives, and when you come out at the end you don't remember why you went into medicine in the first place. Most of us said it was because we want to help people. Our ability to help people, in my case, to adapt and self-manage and to deal with the challenges of life, sometimes to cure when problems can be cured, preventing what could be prevented, and transcending, consoling, supporting, providing as much relief to suffering whenever possible is probably more important than anything – and we are neglecting all those things. Other major issues that we do not discuss as often or as seriously as we must, and that might be as important as they are ridiculed and undervalued in medical education and medicine in general, are love and happiness. You might want to discuss them in detail on a future occasion.

UTMJ: Are there opportunities to get involved with global health and e-health innovation for medical students and professionals?

AJ: Many! So please let me know if you are interested in any of the issues we have discussed today, and I would be more than happy to have a good conversation about efforts to tackle them, together with many interesting people in Toronto, Canada and beyond, who believe that it is possible for us all to live a full life as sentient parts of a flourishing planet.

UTMJ: Thank you very much!