

Science, Technology, Body and Personhood: The Concept of Health Emerging in High-Tech Modern Medicine Practice

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Abstract: In this participatory action research project, we studied the process of practice in high-tech modern medicine as a particularly powerful domain in which integration of science, technology, body and personhood needs to take place. We posit that this integration demands a conceptual evolution of a static concept of health into a concept of health that is based on the ability to adapt and self-manage. There are different level of learning about living with high technology modern medicine, including from the patient perspective learning about own body, learning to live with the machine, learning to live with uncertainties, and, from the physician perspective, to understand the relationship between supporting the patient in developing a new sense of self, for technology to be completely integrated in the patient's life, past, present, future and self and the ownership over the specific critical health decisions with its physiological manifestation and course.

Introduction

In this paper we explore the process of practicing high-tech modern medicine as it is the chronic and acute advanced heart failure practice, often in the setting in critical care, as a particularly powerful domain in which integration of science, technology, body and personhood takes place. Specifically, we investigate how stakeholders (patient, family, healthcare professionals) in Advanced Heart Failure (AdHF) medical encounter negotiate the tensions between formal definitions of health and choice in the actual practice. This study is of a particular interest for the field of the learning sciences because in agreement with Rogers Hall's call (Hall, 2005), it opens up new perspectives between the larger scales of classification systems at the *society/policy level* such as the ones outlined in the Patient Protection and Affordable Care Act 2010 (ACA) (Fineberg, 2012) and the lower scale, such as the level of an individual making informed decisions and of person's choice – *Individual level* (Washington & Lipstein, 2011). This research focuses on the middle level – *practice level* – where people negotiate these tensions in actual practice, the person-in interaction level (Hall, 2005).

Our focus on the practice level where participants are in interactions has important implications in the context of the rich tradition of research on illness in the sociology and anthropology of medicine and medicine education. In the medicine education field, the attention is focused on medical school students and most of the literature centers on General Practice and the application of models of care such as patient centered care (Stewart et al., 2003). In sociology and anthropology of medicine, there is extensive research on chronic illness either at the policy societal level or on the individual level. Patient-centered perspective provides a rich literature on the experience of chronic illness (Pierret, 2003) as biographical disruption (Bury, 1982) and processes of adaptation to a new life (Charmaz, 1995; Pierret, 2003). Yet, this research has been mostly removed from the rich context of the specific disease as an ontological reality of the body with few important exceptions (e.g. Mol, 2002) and from high-tech modern medicine of chronic and acute practice, often in the setting in critical care whose situated specificity of disease it is not reducible into a melting pot of chronic illness (Timmermans & Haas, 2008). The big impact that the field of science studies has had and continues to have in the learning sciences is based on the fundamental focus on practice, showing that in the scientific practice of each discipline, criteria, argumentation, instrumental expertise and methodological sensitivities develop with their own specificity (Knorr-Cetina, 1981; Latour & Woolgar, 1979). We claim that in the context of medical practice, as seen in the study on science in action (Latour, 1987), discipline-dependent knowledges of practice, concepts of care, disease, decision making and self do emerge with their own specificity. The experience of the body and of the self, interacting with physiological constraints and manifestations and the interactions with high technology make participation in the practices a learning experience. This presupposes both: what participants become and how they act as knowers (Roth & Lee, 2007).

We take the situated specificity of disease in the medical practice as the starting and returning point of all our discussion. Specifically, this study is situated in the rich context of AdHF where high technological

advances play a fundamental role in people's lives and practices offering a window on what high-tech modern medicine entails for individuals in their interactions at the practice levels. Specifically, the study is situated in the AdHF context of practice as a preeminent example of high-tech modern medicine with its first implantation of a total artificial heart as a permanent device in 1984 and the first use of a wearable left ventricular assist device in 1994 (Goldstein et al., 1998). This means that 'biographical disruptions' (Bury, 1982) entail integration of technological advances such as being kept alive mechanically, while continuing participation in family, work and social life; unknown 30 years ago. These experiences are novel to patients and their family and unknown to physicians.

Society Level / Individual-Level: Health, Choice and Decision-Making

Society/Policy Level: In the USA, ACA has authorized the creation of the Patient-Centered Outcomes Research Institute (PCORI). This non-profit organization is entrusted by the Congress to identify national priorities for research and to fund research guided by patient-centered questions that can provide information about the best available evidence to help patients and their health care providers make more informed decisions, better understand the prevention, treatment and care options available to them, and the science that supports those options (Washington & Lipstein, 2011). At the *Individual Level*, providing information to best support understanding and make informed decisions has on one hand contributed to moving the process beyond informed consent, rooting it in the multifaceted and more complex (Dy & Purnell, 2012) frame where all stakeholders involved – patient, caregivers and health professionals – work together (Charles et al., 1997), each bringing a complementary and necessary perspective to decision support (Elwyn et al., 2010). At the same time, it is based on normatives of autonomy, individuality and effectiveness which entail responsibility, and accountability for the consequences of people decision (O'Neill, 2002).

Practice Level: How are these concepts of choice, individuality, responsibility and autonomy negotiated in the context of high-tech modern medicine (Timmermans & Haas, 2008) in which AdHF practice unfolds? We address this question in our study

Methods

This study is part of an ethnographic and participatory research project (2011-2013) conducted in a large University Medical Center in California (Raia and Deng, in press).

Data Collected and Analysis

The data have been collected in three stages:

Stage.1:*Narratives.* We conducted exploratory interviews of stakeholders and 1 hour to 2 hour-long open-ended interviews of participant patients and their family to collect their narratives on the experiences in advanced heart failure.

Stage 2. *Medical Encounter Recordings.* Three recruited AdHF cardiologists were audio- and video-recorded in their AdHF medical encounters with their patients (N=25). Of the 25 patients in the study, 18 patients and their family were recorded in their medical encounters with the participating physician for a period of 1-2 years AdHF Medical encounters were audiotaped in *in-patient* medical rounds and audio and videotaped in *out-patient* clinic medical encounters:i) In *in-patient* medical rounds medical encounters AdHF cardiologists are audio-recorded while on rounds in the hospital on AdHF patients who are hospitalized (AdHF in-patients). These patients are often admitted or transferred from a regional hospital into the larger hospital in an advanced decompensated and often life-threatening condition. It is during these hospital rounds that AdHF cardiologists sometimes meet the patients and their caregiver(s) for the first time. Often, it is during the stay in the hospital that patient and caregivers are faced with fundamental decision making of heart transplantation or mechanical circulatory support implantation. Each patient is in a single-bed room. In the Cardiothoracic Intensive Care Unit (CTICU) patients are recovering from cardiothoracic surgery for either an assist mechanical circulatory support device implantation or heart transplantation; in Coronary Care Unit (CCU) and Cardiac Observation Unit (COU) patients are under observation and often listed for heart transplantation. In-patient medical rounds are structured so that the attending AdHF cardiologist, the physician on call responsible for the hospitalized patients, walks from unit to unit visiting each patient in her/his hospital room. ii) Out-patient clinic medical encounters- In these encounters, AdHF patient, not more hospitalized or not yet hospitalized, come in the hospital for a medical appointment and meet with the AdHF cardiologist in examination rooms.

Stage 3. *Co-Generative dialoguing (CoGen)* (Elder and Levin, 1991). AdHF cardiologists, whose interactions have been recorded in Stage 2, participate in weekly audio/video-recording viewing sessions as part of the research team. These research encounters (Stage 2) are videotaped (. The diverse perspectives of participating in the study and the researchers are shared, reflected upon and elaborated allowing all to develop and understanding of the issue at stake. In these weekly sessions, four AdHF participating cardiologists, together with student researchers and researcher, reviewed the taped medical encounters in which they participated and discuss the elements that emerged to be important to them. Reviewing together the data in

CoGen session allowed to unfold a richer perspective on the *practice* of high-tech modern and amongst other things to address questions most relevant to practice, depending on the clinical circumstances and on the physician's stance and knowledge at specific times in the medical encounters (Wirtz et al., 2006). It also allowed checking for validity of the emerging patterns identified in this study. As in the tradition of participatory research we all co-author in this paper. Data from Stage 2 medical encounters data was transcribed by student researchers co-authors and the first author of this paper and checked for agreement.

Major Findings, Conclusions, and Implications

When a patient and family member are confronted by choices of heart transplantation or mechanical circulatory support device implantation, to make a decision, they must accept that a substitution of a malfunctioning organ (in the first option) or a substitution of the pumping function (in the second option) is possible. This requires one's body or loved one's body to be seen as *conspicuous* (Heidegger, 1962) in its malfunctioning. This gaze on the properties and natural function of the body parts, not as a whole 'me,' moves to consider it as an instrument that has failed to do its job, with malfunctioning or broken-down part(s). In this, according to Heidegger, *familiarity* with what was known has broken down (Heidegger, 1962). But what happened when a patient wakes up from the surgery and finds him/herself with a heart transplantation or mechanical circulatory support device implantation?

The following excerpts two encounters between one of the participant-researcher doctors and Mr. J, a 33 year old patient, constitutes a representative example.

Context: Mr. J is in his thirties and always been physically very active. His condition of AdHF developed about ten years ago but at the moment has dramatically deteriorated. He is emergently hospitalized and resuscitated after having suffered a sudden death due to lethal arrhythmia. Mr. J accepts to be a candidate for heart transplant with the only alternative choice to die possibly very soon from another episode of fast chaotic heart rate for which he has been hospitalized. He is listed on the highest emergency category in the USA national list for heart transplant but, based on the unpredictable course of a reoccurring fast chaotic heart rate the AdHF health professional team had suggested an implantation of BiVAD (a mechanical circulatory support device) as a bridge to transplantation, if another of these episodes with loss of conscience were to occur. Mr. J remained hospitalized in intensive care in Cardiac Observation Unit under close monitoring and the lethal arrhythmia followed much sooner than expected. Mr. J is just recovering from the BiVAD implantation surgery in the CTICU, when Dr. D enters. The plan for Mr. J is to completely recover from the BiVAD surgery and be discharged from the hospital to qualify again to be a candidate for heart transplant in accordance with the USA national directives for heart transplantation listing. Because of the BiVAD implantation, Mr. J also needs to have two trained caregivers who can assist him living with the assist devise. Dr. D and Mr. J meet for the second time now.

Encounter 9

- 1 Dr. D: Hello young man!
- 2 How is life?
- 3 Mr. J: I'm fine
- 4 (3 sec pause)

Three second is a long silence as as long silences are reported to cluster around the one-second interval (0.9–1.2 s) (Jefferson, 1989). Here the doctor is waiting for the Mr. J to continue talking –as he usually does, but Mr. J does not. Silence. If we compare it with another day, we see that Mr. Jay respond differently to the doctor salute:

Encounter 10

- 1 Dr. D: Hi young man
- 2 Mr. J: Hi!
- 3 Dr. D: How is life?
- 4 Mr. J: Getting better. Had a nice breakfast.
- 5 Dr. D: I saw you (3 s)
- 6 Mr. J: Got the eggs
- 7 Got the turkey sandwich
- 8 Got a nice little fruit cup
- 9 My feet are starting to feel a little bit better

As Dr. D. describes in CoGen, entering the room on Day 9, he expected to see Mr. J to be “sitting up in the middle of bed and despite adversity: “a handsome young man with his long hair looking like a Jesus full of

inner life, vision energy and dignity holding on each side his two pumps,” Dr. D gesturing the expected Mr. J’s position gives an impression he is expecting to see somebody in charge: “a victorious young men” “Yes! Having survived a major heart attack, being resuscitated, and undergone a major heart surgery, he should be in the same framework as I am” and in this framework “*just* fine is not a good start after a major surgery” because “*just* I’m fine” does not grasp the immensity of what just happened, what Mr. J went through

Day 9 continues

- 5 Dr. D: good
6 So, on Friday a week ago when it came up
7 Friday morning was when we said let’s do
8 the high emergency status heart transplantation listing
9 and maybe we have an organ coming up during the weekend
10 That was also when we first met
11 Mr. J: yeah
12 Dr. D: And then we say ok and Dr. C was already little skeptical
13 and said maybe if anything happens we have to go ahead
14 and this was in the night
15 And so then it was clear
16 we have to recommend the Bi-ventricular Assist Device
17 Dr. D: How did it feel when the question came up now the assist device.
18 You were prepared on Saturday morning
19 you know on the 12th?
20 Mr. J: it was it was a little weird, you know,
21 kind of I mean (3.0 sec pause)
22 It’s just kind of
23 uh, uh a little trippy uhmm
24 hearing something like you know
25 like that
26 It weirded me out with gangliectomy you know
27 you don’t wanna do it (2.0 sec pause)
28 but if it’s really for the best you kind of wanna do it,
29 but it’s just weird to think about it you know (1.48 sec pause)
30 and uhhh I am glad it’s happened you know (3 sec)
31 Dr. D: yeah, yeah
32 It’s a big (1.5 sec pause) thing
33 Mr. J: Yes! (2 sec pause)
34 Very big thing

At line 20, Mr. J starts sharing his experience for the first time. It is an experience of estrangement waking up with the machine as part of one’s own body. This experience is shared by other patients as Mr. J, a few months later, during an interview, recalls feeling “like a scary character in the movies, half man, half machine.”

There are the long silences (1.5 to 3 seconds) in Mr. J’s talk elaborating his experience. These silences are not interrupted by the physician. Dr. D notices also that Mr. James does not name the BiVAD, instead saying it was ‘trippy ... hearing something, you know, like that’ (line 20-25) and that he uses the word ‘weird’ three times (line 20, 26 and 29). It is on this word, ‘weird,’ that Dr. D operates the first transformation, from ‘weird’ into ‘big’ (line 32). Note that the pause of 1.5 seconds (line 32) after Dr. D uses the word ‘big,’ gives space to the word and greater emphasis on the transformation. ‘Yes! It is a very big thing.’

The patient starts talking and from here the doctor slowly moves into a discussion of what is coming in the future to maintain a space where the patient will in time elaborate the experience.

Our data show that accepting a life with heart transplantation or mechanical circulatory support device implantation is not done upon making the decision. It is a complex dynamic oscillatory process of adaptive synchronization. This is based on periods of patient’s anguish and despair, feeling lost in an *unfamiliar* life, and countervailing fluctuation of mood between disappointed expectation and support offered by doctors.

The expectation of the doctor entering Mr. J’s room is to find a person who won a battle against death in pursuing an agreed upon course of action (decision making on mechanical circulatory support device) that allows the patient to continue living his life. When the doctor meets the patient on Day 10 after surgery, there is no correspondence with his expectations. The patient is lost. In the decision-making framework, with normatives of autonomy, individuality and effectiveness, the patient’s reaction is not readable as being lost, but

is either ignored or, worse, is understood as “patient is not grateful for the gift of life and for the healthcare and family efforts in supporting the patient in the difficult decision.”

In high-tech modern medicine making a decision is understood as a process of oscillation between asynchronic state of being “not on the same page” and a return to a synchronic state. The interactional pattern sees the doctor respond ‘on not being on the same page’ with the goal of formulating for the patient possibilities for the future. When a synchronic state is reached in one encounter, the expectation is not that it is maintained, as doctors are observed to respond on this day ‘not being on the same page,’ understating that is a process of integration of science, technology, into a person’s life: a recursive transformation.

The understudying of decision-making in the practice of high-tech modern medicine where at the person level, there is learning to live with the machine and learning to live with uncertainties is an oscillatory process of synchronization fundamentally different from a point of arrival (decision) entailing responsibility, and accountability for the consequences of people decision (O’Neill, 2002). It is not regulated by normative of autonomy and individuality but by the imperative to care.

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