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Patient Narratives of Hope in Stem Cell Technologies: Trust in Biomedicine and the Body's Natural Ability to Heal Itself

ABSTRACT

The scholarship on patient hope in biomedical technologies describes two narratives of hope: the biomedical and the individual. The biomedical narrative represents patients' beliefs that the institution of science will eventually produce treatment for their disease, whereas the individual narrative represents patients' beliefs that they can alter their prognosis through affective and behavioral modifications. The distinct analytical categories of "biomedical" and "individual," however, fail to account for the fact that patient hope has been found to be much more complex. Building upon extant literature, we contribute to the understanding of the complexity of patient hope in biomedical technologies by examining a case that highlights interdependencies between the biomedical and individual narratives: hope in stem cell technologies (SCTs). We draw upon interviews with patients with Parkinson's Disease, and find two narratives of hope: a biomedical narrative, as captured above, and an additional hybrid narrative, which we call a *nature narrative*. The nature narrative reflects patients' beliefs that scientists will eventually create SCTs that will allow their individual body to naturally heal itself, which combines a biomedical and an individual narrative.

KEYWORDS

bioethics; technology in healthcare; risk and health

INTRODUCTION

The social science literature on the hope and expectations of medical cures has long recognized that hope is embedded in the modern healthcare system, including both the values and practices of biomedicine, as well as those of patient participation (Petersen and Seear 2011). A prominent strategy for analyzing patient hope has been to contextualize it within what Delvecchio-Good et al. (1990) coined the “political economy of hope,” which refers to the complex management of hope by myriad agents vested in the funding, promotion and/or proliferation of biomedical technologies, including biotech companies, the media, researchers, practitioners, politicians, advocacy groups, and investors (Rettig et al. 2007; Rose and Novas 2005; Petersen and Seear 2011; Petersen et al. 2017; Metzler and Just 2017).

This research describes two narratives of hope: the biomedical and the individual. A *biomedical narrative* is premised on a person’s trust in the eventual efficacy of biomedical innovation (Metzler and Just 2017). The biomedical narrative is characterized by a fundamental, sometimes taken-for-granted belief that biomedical treatments will yield beneficial—even curative—results in the future, regardless of when that future might arrive (Moreira and Palladino 2005; Petersen and Seear 2011). The biomedical narrative can be succinctly summarized as hope in the institution of science.

Scholars have also articulated an *individual (or illness) narrative* in contrast to the *biomedical narrative* (Metzler and Just 2017). The individual narrative is characterized by a person’s belief that they can improve their health condition through individual effort, either through affective or behavioral measures (Petersen 2015; Delvecchio-Good et al. 1990); for example, “practicing self-care and positive thinking” (Metzler and Just 2017: 484). Through this agent-filled individual narrative of hope, as Brown (2015: 125) explains, “hope is credited with

the vitalistic power to animate life, having causal and elemental corporeal agency.” Expressing individual narratives of hope are therefore linked to the exercise of choice, personal control, and empowerment (Petersen and Wilkinson 2015), enabling patients to build a self-identity as an active agent (Petersen et al. 2014), in a culture which rewards individual agency. The individual narrative can be succinctly summarized as hope in the self.

The distinct analytical categories of “biomedical” and “individual,” however, fail to account for the fact that patient hope has been found to be much more complex. The desire to more fully understand the complexity of patient hope has generated a large body of work which analyzes how patients actually experience hope—what Brown and de Graaf (2015:221) call the “empirical messiness of hope.” This literature demonstrates that narratives of hope are highly contingent upon the social context under which they arise, and that patients often use them in tandem (Borup et al. 2006; Brown 2003; Brown 2015; Brown and Michael 2003; Metzler and Just 2017; Prasad 2015).

Some researchers demonstrate this messiness by describing patient hope as multifaceted, fragile, and context-specific. We know, for example, that stem cell tourists actively struggle with uncertain and ambiguous hope, rather than follow blind or volitional hope (Prasad 2015). Brown and de Graaf (2015) similarly find that hopeful advanced-cancer patients actively navigate between present and future hopes, being both realistic and positive, and craft adaptable hopes that are simultaneously specific and ambiguous. Research shows that patient hope can be shaped by space, where distance from the source of knowledge production is positively correlated to promissory declarations (Brown 2003), shaped by individual proximity to knowledge production and one’s ability to see researcher uncertainties (Brown and Michael 2003; Borup et al. 2006),

and shaped by temporality, where one's present hope is shaped by the trajectories of past promises and disappointments (Borup et al. 2006).

Other researchers demonstrate this messiness by describing how patient hope can be a complex combination of both narratives. In other words, patients can experience them relationally, rather than in isolation. In their study of Parkinson's Disease patients, for example, Metzler and Just (2017: 496) find patient hope in individual behavior that is enabled by a "confidence that better therapies would eventually arrive." That is, they find that patient hope reflects a relationship between an individual and biomedical narrative. Hope, therefore, cannot be reduced to either hope in self or hope in science, as a person draws upon both narratives in their articulation of hope.

Building upon the extant literature, in this article we contribute to our understanding of the complexity of patient hope by examining a case that highlights interdependencies between the biomedical and individual narratives: patient hope in stem cell technologies (SCTs). Stem cells are created by re-programming existing cells—be they someone's skin cells or cells derived from human embryos—and coaxing them into reverting to a stem cell, which is a cell that is primordial to more specific cells. This primordial stem cell can then, in principle, be further coaxed into becoming a specific type of cell needed to restore human function. In the case examined in this paper, the hope is that the stem cell could be coaxed to become a certain type of brain cell which would replace those damaged by Parkinson's Disease. SCTs are hoped to lead to treatments for a host of ailments (Henchcliffe and Parmar 2018).

Like Metzler and Just (2017) and others (Brown 2015; Brown and de Graaf 2015), our findings help disrupt a dichotomy between biomedical and individual narratives of hope by demonstrating how, in practice, patients rely on a narrative of hope that is simultaneously

connected to both. We find two narratives of hope: the first is a narrative of hope premised on a biomedical understanding; the second is a hybrid narrative of hope premised on biomedical technologies freeing the individual body to naturally heal itself, which we call the *nature narrative*. The nature narrative departs from individual narratives in the literature, because unlike typical individual narratives where healing is presumed to be due to individual agency, such as positive thinking or a healthy lifestyle, the nature narrative empowers the individual *via* biomedical innovation.

Our findings draw upon in-depth interview data from a study with 27 patients with Parkinson's Disease (PD) about their understandings of stem cell (SC) technologies and clinical trials, and an analysis of their expressed hope in SCs to cure or ameliorate the symptoms of PD. In our findings, we first describe the biomedical narrative. Respondents in our sample actively trust in institutional biomedical processes to discover treatments and believe that these processes will eventually prevail. This finding was expected, as previous research has shown that patients who are hopeful typically espouse trust in science (Moreira and Palladino 2005; Petersen and Seear 2011). Furthermore, to the extent that respondents expressed hope we expected to find a biomedical narrative because we explicitly asked about hope in a biomedical technology (as opposed to hope in individual agency or hope in general). We show this narrative not only because it appears to be a prominent and separate narrative, but also because showing it in use allows us to better interpret our second finding.

Our second finding describes an additional—hybrid—narrative of hope that we observe, the *nature narrative*. This narrative captures respondents' beliefs that stem cells are more “natural” and that as a natural intervention, SCTs are more likely to succeed compared to less “natural” biomedical interventions. We refer to the nature narrative as a hybrid narrative because

it simultaneously draws strength from biomedical and individual narratives of hope. On the one hand, the nature narrative as espoused by respondents actively trusts in a biomedical technology to enable the body to engage in a more natural healing process. On the other hand, it rests on the premise that the individual body has an ability to self-heal, which respondents both prefer and believe to be more efficacious than other biomedical interventions, like deep brain stimulation or pharmacological medications.

In addition to broadening the empirical literature on the complexities of hope, our findings contribute to our understanding of the public cultural discourse about stem cell science and biomedical innovation. These findings may be of particular use for SC researchers and practitioners concerned with ameliorating the pernicious consequences of hyped, yet unproven, medical technologies, such as stem cell tourism (Moreira and Palladino 2005; Petersen and Seear 2011; Prasad 2015; Petersen et al. 2017).

DATA AND METHODS

One of the targets of SC therapies is Parkinson's Disease (PD) (Henchcliffe and Parmar 2018). Between January and December 2018, we recruited 27 respondents for in-depth interviews from four sources: one from one of the largest medical practices that treats PD in the region; two from a local PD association website; and twenty-four from a few PD support groups in Southern California. The logic guiding this sample construction was that these would be the populations from which biomedical researchers running a phase I clinical trial would recruit. This research was approved by the Human Research Protections Program of the senior author's university, project #172081.

Respondents were told we were interested in talking about their attitudes toward and understanding of SC clinical trials and they signed a written informed consent form. The 27 face-to-face interviews averaged 62 minutes in length, with a minimum of 35 minutes and a maximum of 103 minutes. Respondents were all white except two Asian Americans, and 30 percent were women. While one respondent did not state their age, 15% were in their 50s, 37% in their 60s, 30% in their 70s and 15% in their 80s, as would be expected in a population of people with PD (Nalls et al. 2015: 851). All respondents lived in California, which is important because a few years previously there had been an extensive public campaign to have the state of California fund SC research named Proposition 71, which many see as a source of the biomedical narrative of hope, hope that is directly connected to trust in science (Cho and Magnus 2007).

The sample is likely overly exposed and attuned to the biomedical narrative of hope. This over exposure is because more education likely means more exposure to science (Evans 2011: 720), and the sample is very well educated: 19% had a high school degree, 29% an undergraduate degree, 41% a professional degree of higher (11% did not state their education level). In addition, given that most of the interviewees were part of a support group, they are probably more aware of PD research and scientific research in general than the average person with PD. We used a fixed interview guide but with open-ended follow-ups to each question so as to ensure we understood each respondent's views. All of the interviews were transcribed except one, where the respondent did not want to be recorded.

Despite this group being more educated on biomedical research and technologies, a typical methodological problem in the social science of emerging technologies is that since the technologies do not yet exist, people cannot know enough to have established views. There is no

direct solution to this problem. The response we took was to ask a slightly different question, where instead of obtaining the view of respondents who potentially know nothing about SCs, we evaluated their response after exposure to a brief description like one they would encounter when hearing of the technology for the first time. Therefore, early in the interview, after asking respondents about their medical condition and what they know about SCs, we provided them with the slightly shortened text from a Mayo Clinic webpage explaining stem cells (Mayo Clinic 2018).

This Mayo Clinic text is the sort of short text people would initially read to see if they were interested in participating in a clinical trial, although obviously before agreeing to be in the trial most people would seek out additional information. The text described four sources of stem cells: from embryos, from adult stem cells found in bone marrow or fat, from adult cells reprogrammed to be like embryonic stem cells, and perinatal stem cells taken from amniotic fluid. We did not find that respondent hope was contingent on the source of the SCs. We can conceive of the interview responses as the ideas that are triggered from a brief description combined with their pre-existing knowledge. The responses were inductively coded using the NVivo software package, and the findings were discussed by the three authors and subsequently modified; all names utilized in the results section that follow are pseudonyms.

Finally, it is worth noting that like other scholars before us, even as we try to disrupt a bifurcation between the two narratives, the contingencies of hope that scholars discuss often keep biomedical and individual narratives as distinct categories; this is both an artifact of the binary distinction respondents make and the analytical leverage attendant to categorization. As a result, describing patient hope as a relationship between both narratives can still perpetuate and overstate a binary between “science” and “self.” We recognize that by starting our findings with

a section purely devoted to the biomedical narrative of hope, we may be perpetuating a false binary between science and self. But, as stated in the introduction, because our interview questions asked respondents about SC technologies, to the extent that we found hope in SCTs we would expect a biomedical narrative. In fact, we did find that respondents expressed hope in SCTs and as expected, this narrative was distinctly biomedical. Ultimately, the presentation of our findings reflects what we believe our data reveal: PD patients express hope in SCTs first because they trust in science in general (biomedical), and second because they trust in science to unleash the natural power of the body's stem cell (hybrid nature narrative).

FINDINGS

From the interviews with the 27 Parkinson's Disease (PD) patients, we find that most respondents describe having hope in the scientific process by which stem cell technologies (SCTs) are developed, and the naturalness of SCs, themselves. We describe these findings as two narratives of hope: a biomedical narrative and what we call a hybrid nature narrative. In what follows, we present the results from coding the section of the interviews that ask the respondent what a SC is and the section that asks them to compare the potential of SC treatments to other ways of treating disease. The starting questions in the interview were: "What do you think a SC is?;" "What do you think it is about SCs that makes scientists so hopeful that they will heal diseases?"; "Imagine scientists are working on a cure that uses drugs to regenerate the neurons lost due to Parkinson's Disease. And, scientists are working on a cure using stem cells. Which do you think is more likely to succeed?"; "Are SC treatments different from ordinary medical treatments? How so?" While these questions presuppose hope, they were designed to evaluate

how PD patients describe their hope (or lack thereof) in SC therapies, without delimiting the discussion.

Biomedical Narrative of Hope

In this section, we describe respondents' biomedical narrative of hope – hope in SCTs that is directly attributed to their belief in the abilities of scientists and scientific institutions. Although respondents are talking about their specific hope in SCs, the narrative is rooted in a general trust in science and a belief that the scientific process will eventually prevail. Most of the respondents perceived SCs as having potential, with varying levels of enthusiasm that SCs would create treatments for their disease. As the excerpts from interviews below will show, the “levels” of enthusiasm are not deductive hope scales, like the psychometric indexes detailed in Brown (2015), but rather inductively generated articulations of hope by the respondents themselves. From our view, even the respondents who seemed to articulate enthusiastic hope were not as *overly* enthusiastic as bioethicists concerned about over-optimism of the healing power of clinical trials (therapeutic misconception) would assume (Kimmelman et al. 2006). For example, when we asked Joshua, “Do you think that stem cells will produce a cure for your disease?” He replied, “Yes, I’m very hopeful that they will. It sounds like they’re on the track to do that.” We asked the same question of Oliver, and he said:

Sounds like, probably. I’m cautiously optimistic... because the preliminary science that’s been done, the little bit I’ve read about it sounds like the basic blocks to create a pluripotent stem cells, being able to match them, to direct their growth to differentiated cells, and – and that the early lab trials of – of implanting those differentiated cells – cells, sounds like it was reasonably successful.

In reply to the same question about whether SCs would result in a cure, Bryn said: “Eventually. I think there could be a lot of twists and turns before it gets to that point; and it might not be for my generation or the next generation but I think it's going to happen.” And, Liz answered: “Yes, I hope so... I just think they have a better shot” than a lot of the other approaches. “Stem cells seem to be something different.” When we asked how many years it will take scientists to develop an approved treatment, Liz said “realistically, at least 10.” In these examples, these respondents actively draw upon a biomedical narrative of hope that hope inheres in the scientific process.

Rather than expressing certain hope in SCTs, most respondents expressed tempered optimism in scientific research. We reported a more positive statement of Oliver above, but elsewhere he said “it seems to have a lot of potential, but I’m always taking it with a grain of salt when it looks miraculous, or it’s – and it still seems to be a couple of years more testing. If they say two, it’ll probably end up as five years. When they say four, it’s probably seven or eight.” Similarly, when asked about her opinion of whether SCs would produce a cure for her disease, Melinda responded “I think they have that potential. The research needs to be done.” In addition, Joshua responded that “I think it needs a lot of work but I think there's potential there,” and Jack’s evaluation of the promise of SCs was “eventually, maybe. But at the rate things are moving, I probably won’t be alive to see it.” As above, respondents seem to exhibit a faith in the institution of science as a whole; as Oliver said, “I trust the scientific process and the regulatory processes.”

Some have deeper adherence to the biomedical narrative. For example, Martha said:

Science has come up with a lot of solutions... when they had other operations, you used to have to take six months to recover. Nowadays you walk out of the operating room and they tell you to start walking around.... But it's a matter of time whether stem cells will be successful, I don't think that it's going to happen overnight.

In our discussion with Jack, after he stated that he thought SCs will “eventually, maybe” produce a cure, we asked “Why do you think that stem cells may produce a cure for Parkinson’s?” Jack responded:

I really believe this. From everything that I've read and I've studied, I really believe that the – I call 'em brain-eating diseases, Alzheimer's, Parkinson's, Lou Gehrig's, I really believe that they – the researchers are right on the cusp of a major, major step forward. It's – it's – it's coming. The – these – they've been working on the brain for 60 years, I guess, close to it, that I know of, and they're just – they've gotta be getting closer.”

Hence, respondents expressed hope in SC therapies rooted in their general and sometimes even taken-for-granted trust in the scientific process to prevail.

Keeping the complexity of patient hope in mind, however, it is important to also emphasize that the existence of hope in the eventualities of science does not mean the absence of critical thought—they were actively engaging with the biomedical narrative. For example, in addition to their stated optimism in SCTs, many respondents also indicated an awareness that there are institutional pressures for biomedical researchers and clinicians to engage in hype. At a later point in the interview, we asked respondents “do you think that claims made by scientists

about stem cells may be exaggerated?” A majority thought that all scientists exaggerate; however, their reasoning for why they may exaggerate differed. Very few thought it was because they were “snake oil salesmen.” As an exception to the majority of respondents’ impressions of why scientists may exaggerate, Abe told us that “There is certainly motivation for that. Scientists aren’t supposed to exaggerate anything, but there have been reports that scientists have jumped the gun in reporting results that are not substantiated.” We asked “What is the motivation for it?” to which Abe replied “fame and fortune, especially fame.”

Others recognized what social scientists would call “hype cycles” (Borup et al. 2006) as necessary for contemporary biomedical development. For example, Oliver replied to our follow-up question about why scientists would exaggerate by explaining to us that scientists “need to be optimistic to keep pursuing their endeavors and pushing the science forward.” Similarly, Shannon said that “certain claims are made that are irrelevant to reality that are only there to make sure that the project goes on... they have to do that. Without that there is no funding, no grants... They are exaggerated to convince people that have to pay for it.”

In sum, in line with previous work, our interviews show a biomedical narrative of hope: patient hope in SCs due to a general belief in the efficacy of the scientific process and the consistent work that biomedical researchers and clinicians are doing with the SC therapies. While this hope may be tempered by their awareness that scientists may be hyping SC technologies, the majority of respondents still felt there was potential for SCs. Hence, our respondents expressed a distinct and active hope in biomedicine, one that might not be as blind or as naive as bioethicists concerned about therapeutic misconception may fear, but one that is nonetheless not contingent on the presence of current cures.

The Hybrid Nature Narrative of Hope

In this section, we describe a second narrative of hope which we call the hybrid nature narrative—patient hope in SCTs that is attributed to their beliefs in the power of science to enable the “natural” power of the body. We found that the respondents had hope in SCTs because they viewed SCs as “natural” and believed in the power of natural treatments. When asked to explain their stated optimism in and/or preference for SC therapies as a treatment for PD, respondents repeatedly described SCs as natural, articulating a worldview that elevated the benefits of more “natural” biomedical interventions over more “artificial” mechanical biomedical interventions, like deep brain stimulation (DBS). What they meant by natural was that the SCs naturally exist in their bodies; ideally the patient’s own autologous SCs can be used. This construction of the natural was often articulated in juxtaposition to what was unnatural, as the respondents often described the SCs as not “foreign” like medicine or devices created by humans. Most critically, respondents linked up the naturalness to efficacy; articulating a belief that since the SCs are natural in these ways they are then more likely to be efficacious.

At first glance, it was surprising that respondents would attribute the word “natural” to describe SC treatments for Parkinson’s Disease because they were presented with information that laid out a very interventionist process. The Mayo Clinic (2018) text we gave respondents described how cells are grown and manipulated with “genetic re-programming” in the lab and then implanted in the body, which for PD patients would require SCs to be injected inside of the skull (for scientific descriptions of the highly technological process required, see Henschliffe and Parmar 2018). This described process seems inconsistent with the meaning of the word “natural,” in at least American culture and the literature on complementary and alternative medicine (Coulter and Willis 2007). Among our respondents, however, about half described

SCTs as natural. Instead of focusing on the technological human intervention required in the *process* of a SCTs, they focused on the resulting SCs and their natural power to heal the body.

Bracketing the process of SCTs, respondents' hope in SC treatments as a natural option manifested in a dual-pronged belief that SCs are safer for the body and that SCs work to heal the body without outside biomedical intervention. As an example of beliefs that SCs are safe and do not require anything external to the individual, when Daniel said they would prefer SCs over medicine and we asked why, Daniel stated that: "Well to me, stem cells are more natural – using the natural cells in your body or whoever's being treated. Whereas the others are like an add-on third party drug." For Joshua, the invocation of a third-party drug denotes an introduction of a foreign, potentially unsafe, intervention into the individual body, a sentiment that Joshua similarly stated when he said that SCs are better "by far" because "any time you can do anything that's more natural, more healing that is produced naturally rather than medication will be far less complications." We asked Joshua what "natural" meant to him, and he stated that "it means simply that it's non-medicinal. It's something taken from your own body." When Joshua positively evaluated SCs, he was drawing an explicit comparison to his current PD medications, these "third-party drugs," which have side effects.

Similarly, Martha refers to the Mayo Clinic handout we gave her when saying that "it sounds like the use of stem cells would probably be more successful" than other PD drugs. That could be expected given the contents of the article, but what is more interesting is why she reached that conclusion from the article. She explained that "well if you're starting with the cell, it's not a totally foreign object in the human body and drugs have a lot of negative effects on the human body... Drug research is also complicated but we are starting from scratch, whereas with stem cells it sounds like you're starting with something that's at least human, and then

reprogramming it.” Conceiving SCs as natural to the human body appears to render them safer for respondents and allows respondents to seemingly ignore or pay less attention any risks from the “reprogramming.”

In the same way, John says that SCs are more likely to be effective than other treatments because “the drugs simulate. The stem cells are using a real part, not a counterfeit... It’s more realistic; it’s more real.” In a follow up question we asked him to “imagine that doctors had a clinical trial for a Parkinson’s treatment that used drugs, and another that used stem cells. If the treatments were equally difficult, which one, if any, would you choose?” He said “stem cell” because “stem cell is more real. It’s actually made with your own body part. Just an intuitive guess, but the stem cells would have a lot less potentially adverse effects.” Melinda, too, thinks that “stem cells are working with the biological system instead of innovating it or pushing it or— to me drugs and surgery are very blunt instruments.” As a final example, Kerry also says SCs would be better than existing medicine. While Kerry misunderstands the science a bit, what they think happens— and why they value it — is instructive. Kerry says SCs would be better because

it’s a cell that’s in your body anyway, it’s part of the immune system. And what you are doing is you’re taking stem cells out of your body concentrating them in your injection and injecting them into the part of your body that needs it most to simulate whatever needs to be simulated, new heart cells, new blood supply, new cartilage, new neurons, new nerves so it’s a body healing itself. And we just stimulate it in the body to heal itself.

With these data we are unable to discern the source(s) of these beliefs, but respondents articulated clear and consistent beliefs that stem cell technologies somehow enable the body to heal itself with its own materials, naturally, and with less adverse effects than drugs.

Respondents held this perception while comparing SCTs to deep brain stimulation (DBS) as well, a biomedical intervention often utilized with PD patients. For example, when we asked Robert “imagine that scientists are working on a cure that uses drugs to regenerate the neurons lost in the brain in Parkinson’s, and scientists are working on a cure using stem cells. Which do you think might succeed?”, Robert responded, “stem cells” because “it’s going to be from your body... The stem cells come from your body and it seems like it’s more of a natural fix, I guess.” Note that for Robert it is not simply that cells from your own body would work better, it is that this is “more natural.” When Robert elaborated that SCs are also more natural than DBS, and we pointed out that both DBS and SC treatments would require the interventionist act of cutting through the skull, he said that he still prefers SCs “because they’re, like I said, it’s part of the body, and, and the DBS is, you know, I don’t know how to explain it, it’s an outside, like a pacemaker. I don’t know, it’s pretty scary.” Returning to the concept of the natural, he concluded that with SCs, “you’ve taken part of your own body and regenerated it.”

In line with other respondents, Paula thinks that SCs are more likely to cure PD because “they’re more organic, I guess just makes a little bit better sense. You put a real cell in there or some kind of a pill that’s going to dissolve. It’s a big difference.” Paula also contrasted SCs to DBS which requires electrical wires implanted in the brain and a device implanted in the chest. She thinks that SCs are better because “that’s so much more organic than some foreign machine.”

Statements about SCs as safer for the body because they are natural to the body were often interwoven with claims about the self-healing ability of the human body. When we asked her why she would prefer SCs to other treatments, Sara said that despite stem cells being so complex, with SCs “you don't have to understand it. You just have to get it to the right place and let it be and do what it normally does...it's this rich harnessing of the body's own biological capacity to affect change.” Similarly, Dave says that he has “a certain amount of hope I suppose” because “regenerative medicine seems very much aimed at using individuals' own biology to fight disease. This is touchy feely but you need to marshal your own resources to fight whatever it is.” Dave points to the way in which he conceptualizes the stem cell in accordance with the individual narrative, but it is the passive self that is responsible for the healing, not the active self, which is the dominant way of describing the individual narrative in the literature.

Hence, respondents described a hope in nature based in beliefs about the naturalness of SCs and the power of the human body. Respondents connected their preference for the natural to a form of trust that, once the process is started by scientific intervention, the body is able to self-heal. They therefore described a hybrid narrative of hope in SCTs, one in which patients actively trust in biomedical innovation to enable the stem cells in their individual bodies to do what they naturally know how to do.

DISCUSSION AND CONCLUSIONS

In this paper we discussed two narratives of hope in stem cell technologies (SCTs). The first is the biomedical narrative of hope in institutional science. As the literature would predict, we find that many respondents hold out hope that SC technologies will eventually cure PD, stemming mostly from their faith in the work scientists are doing and their belief in the eventual efficacy of

the scientific process (Moreira and Palladino 2005; Petersen et al. 2017). As other scholars have shown, we found that their articulation of the biomedical narrative was not an uncritical or untempered hope in science (Prasad 2015; Brown et al. 2015). Nevertheless, respondents did express hope in SCTs based on a general trust in science to eventually produce results.

The second narrative we find is a hybrid of the biomedical and the individual narratives found in the literature. We call this hybrid the nature narrative of hope, where respondents were hopeful because they perceive SCs to be a more natural treatment method. This hybrid simultaneously draws on both biomedical and individual narratives of hope because it describes patient trust that scientists will eventually be able to harness the power of the natural body to heal itself. That is, the nature narrative combines a hope in science with a hope in the self.

This narrative does not rely upon the active agency of the patient, as we see in the standard accounts of the individual narrative in the literature, but upon a more passive patient in that the individual body is trusted to heal itself. These findings build upon existing scholarship that highlights interdependencies between the biomedical and individual narratives. The nature narrative represents patient hope that is not just a combination of some hope in science and some hope in the agentic self, but an interdependent relationship between biomedicine and the individual. Like the findings in Metzler and Just (2017) and others (Brown 2015), the hybrid nature narrative helps upset the dichotomy between biomedical and individual narratives by demonstrating how they are connected.

Our data prohibit us from making claims about why respondents perceive SCTs as more natural or why respondents prefer a more natural remedy, but this emphasis on the natural raises a range of questions that we hope additional research will address. The first set of questions raised centers on the public's perception of the power of the natural. Other research has found

something similar regarding the valorization of natural treatments for disease. For example, scholarship on complementary and alternative medicine (CAM) found that what all these techniques have in common is “the acceptance of all living organisms as sustained by a vital force that is both different from, and greater than, physical and chemical forces” (Coulter and Willis 2007: 216). Consumers of CAM believe in “the healing power of nature,” which “implies that the natural order is for the body to heal itself” (Coulter and Willis 2007: 216). Another study found that clients of CAM “regard the body as a natural phenomenon involving bodily energies, which they regard as potential self-healing resources,” and the body’s “self-healing resources can create (or restore) the body’s balance and hence cure it of its ills” (Baarts and Pedersen 2009: 726-727). Similar to how consumers of CAM describe their hope, the hope in SCs that respondents described was rooted in a belief that SCs are a natural part of the body and can therefore heal the body.

What is interesting is that CAM consumers tend to eschew biomedical technologies precisely because they are unnatural, yet our respondents are interpreting biomedical technologies as natural or bracketing the certain aspects of the technology to retain a natural core. Perhaps this is because the relationship between nature and technology is muddled under conditions of late modernity (Giddens 1991; Beck 1992), where “nature as a single entity independent of human civilization has been replaced by multiple natures” (Murphy 2002: 314). Other scholars outside of the hope literature have observed examples of cognitively bracketing all the “non-natural” aspects of what comes to be considered a “natural” act. For example, there are proposals to restore “natural ecosystems” through “existing and emerging genomics tools” such as “genome editing that can generate novel genotypes for restoring challenging environments” (Breed et al. 2019 615). Similarly, Murray (2004: 971). finds that for limb

prostheses, the user perceives the body as allowing the instrument or object to “melt” into it, as a “sentient extension of the body.” Moreover, in an example of biosociality in action (Dimond et al. 2015), our respondents clearly have at least part of an identity as a Parkinson’s patient. Theoretical discussions in the biosociality and related literatures often invoke claims of a change in the concept of nature over time (Rabinow 1996), and we leave it to future researchers to consider what these patients’ appeal to nature means for these theories.

A second set of questions revolve around the discursive use of “nature” in relationship to social inequalities. Our research not only shows an example of the social construction of “nature,” and that nature and society are co-constituted (Soper 1995: 7), it also relates to the idea that actors can mobilize “nature” to achieve sociopolitical ends by claiming a goal is “natural” (Douglas 1986). Moreover, because our respondents are hoping for a treatment that comes from scientists in industrialized Western nations, they are operating within a particular sociopolitical notion of the natural. Indeed, we need to keep in mind that gendered, racialized, and colonized “others” are negatively portrayed as being associated with “nature” (Neimanis 2014). Therefore, our findings about nature may only be relevant to white people in wealthy Western societies, and research in other settings is important.

Finally, in addition to broadening the empirical literature on the complexities of hope, our findings contribute to our understanding of the public cultural discourse about stem cell science and innovation. This deepened understanding of the nuances among narratives of hope may be of particular use for SC researchers and practitioners concerned with ameliorating what they see as the pernicious consequences of hyped, yet unproven medical technologies. Just as practitioners have had to take into account that patient hope is fueled by individual narratives, as well as shaped by things such as spatiality (Brown 2003), temporality (Borup et al. 2006), and patient

“mode” (Metzler and Just 2017)—in addition to scientific claims of efficacy and the direct promotion of faith in science—concerned practitioners may benefit from paying more attention to hope generated by claims to naturalness.

In conclusion, in this paper we described two narratives that Parkinson Disease patients used to describe their hope in SC technologies: a biomedical narrative and a hybrid nature narrative constituted by an interdependent relationship between individual and biomedical narratives. Both narratives bolster hope in biomedical technologies and have the potential to fuel the political economy of hope, however it remains unclear how patients have come to interpret SC technologies as a more natural intervention. Though cultural sociologists have long demonstrated a preference for natural remedies which helps explain respondents’ preference for an intervention they perceive as more natural (most recently in complementary and alternative medicine (CAM)), this preference is usually premised on an opposition to the biomedical (Nolan and Schneider 2011), not a reliance on the biomedical. This finding opens up future research opportunities to empirically understand where this natural narrative comes from, how it is promoted, who leverages it within the political economy of hope, whether it holds in other cultural contexts and how this version of the “natural” impacts our theoretical understandings of biotechnology and society.

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