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DISCUSSIONS

The Undergraduate Research Journal of CWRU

VOLUME XV, ISSUE II

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DISCUSSIONS
Undergraduate Research Journal of CWRU

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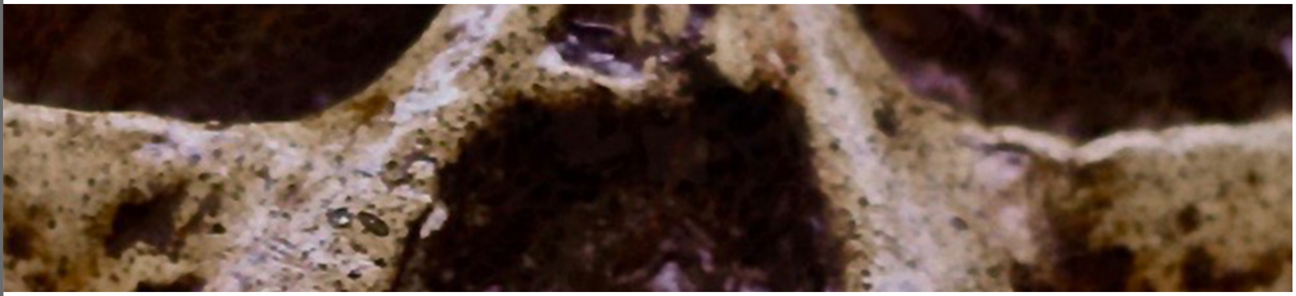

Letter from the Editor

Dear Reader,

First, I want to thank you for picking up this issue of ***Discussions: The Undergraduate Research Journal of CWRU***. This cycle we received a record number of submissions and are proud to present you with some of the best undergraduate research from across the nation.

In this issue, we have an interview with Dr. Patricia Princehouse, Outreach Director for the Institue for the Science of Origins, about her road to research. Our first undergraduate research article is an innovative study developing a comprehensive quality of life survey for patients with cerebral palsy and our second article is a literary analysis of the *Origins of Species* by Charles Darwin and its influence on future social movements.

As an organization, ***Discussions*** has made some strides in the past year. We attended our first conference in April, the National Conference for Undergraduate Research, where we met hundreds of undergraduate students doing incredible work, and we held our first annual awards ceremony to celebrate the authors we have published over the year. Our journal was also recognized as Organization of the Year by the University Media Board at Case Western Reserve University. We have continued building our name and our new website which you can visit at **www.discussionsjournal.com**. If you are involved in undergraduate research and want to submit to our journal, please visit our website for additional details. And if you have any further questions, please feel free to reach out to us at **discussionsjournal@gmail.com**.

Finally, I want to thank everyone who has been a part of this journal. Thank you to those who have submitted to our journal, thank you to our published authors, and a special thank you to our editorial board and staff, all of whom have worked tirelessly to make our journal the best it can be. I also want to thank Dr. Sheila Pedigo, our advisor, for her ongoing guidance as well as the University Media Board for their unwavering support through our publication.

Thank you again for celebrating undergraduate research with us, and I look forward to another year of growth for our journal!

Sincerely,

Saloni Lad
Editor-In-Chief

university media board

SOURCE
SUPPORT OF UNDERGRADUATE RESEARCH AND CREATIVE ENDEAVORS

Faculty Spotlight

An interview with

Dr. Princehouse

by Christopher Carr

Dr. Patricia Princehouse is a Senior Research Associate at Case Western Reserve University. She is currently the Director of the Evolutionary Biology Program, as well as a co-founder and current Outreach Director of the Institute for the Science of Origins, which runs and manages the Origins Science major at CWRU. Dr. Princehouse received her PhD from Harvard University under famed evolutionary biologist Dr. Stephen Jay Gould, and has been an important voice in the evolutionary biology field as well as in the world of science outreach and science education. In this interview, she details the story of how she entered her field of interest, and the work she has done advancing scientific inquiry in both the academic and public sphere.

Q: When did you decide you wanted to go into evolutionary biology?

A: It's hard to say exactly when I decided to go into evolutionary biology, but from the time I could even talk, even before that, I was so curious about animals. Dogs, horses, anything I could come across. By the time I was four, I was taking classes at the natural history museum, because they had some for kids. Between the time I was four and, like, fourteen, I took virtually every course that the natural history museum offered. And of course you end up being exposed to some theory - I mean, I even did taxidermy. And this is in Dayton, Ohio, where I grew up. They had an important Native American excavation affordation site they were doing, which we called the Incinerator site. Now, I believe it's called something like Sun Valley, but it was on the site of an old incinerator, so we called it the Incinerator site. I was doing fieldwork when I was nine years old, and I actually didn't associate it with universities, because my experience had been in the museum. Even Richard Leakey came through and gave a talk when I was in high school, and I was very impressed because a friend of mine asked him a question, you know, a great man, right, but it was at the museum, so I didn't associate it. When I went to college, I thought that I would be a veterinarian, because of the interest in animals, but in the meantime, I'm collecting fossils and doing school projects on evolution-related stuff; I just didn't associate it with that. After some of the in and out of a couple of different colleges, I finally found that anthropology is something that is offered at universities, and I took a course on finite behavior, and I took a course on, human evolution, a course on human diversity and variation, ancient Near East archaeology, stuff like that, and that was kind of my way in. It was like, on the one hand, I had invertebrate fossils because it's the Ordivician down there, right, and on the other hand, anthropology, paleoanthropology, physical anthropology. And so at some point, it just kind of converged on evolutionary biology as a major field.


Photograph by Chandana Pandurangi

Q: During your time at Harvard, you had the opportunity to work alongside Dr. Stephen Jay Gould, who was a real titan in the field of evolution. What was it like working alongside him?

A: So he was my doctoral advisor, and it's funny because when people would go to his talks, he was a bit brusque and he gave this feeling to a lot of people that he was unapproachable, which is the exact opposite of what he was actually like, and it, it's a funny thing. Um, he was one of the few Harvard professors - at Harvard, when you have some of these major professors and they offer a Monday, Wednesday, Friday course, they don't teach the Friday course, because you also have a recitation section, right, that you have with a graduate student or somebody. So the number of contact hours, as it's called, is met if you don't teach the Friday course. He taught the Friday class. He also held two-hour office hours every week when he was in town. He would often be out giving lectures, but if he was in town, there was a two-hour office hours. And he taught all three lectures, for the course, and then he had a second course as well that he taught about half of the lectures on that was co-taught with Richard Lewington, who's a famous geneticist, and I was a teaching assistant for both of those courses with him. So, I got to know him very well. He was terrific - smart, interested in everything. He was one of the best people I've ever met at articulating ethics - why he does things in particular ways, why he does or doesn't put in grants, why he is doing a particular thing. It was very important to him to think through moral questions, as well as scientific questions. And of course, his work famously addresses not just science, but also, ethics and society, and the sorts of interactions that there have been between science and other areas of human interest.

Q: After your time at Harvard, how did you find your way to Case?

A: So, before I was at Harvard, I was at Yale - I have a Master's from Yale. And my lab partners for gross anatomy, one of my best friends who was also at Yale, her husband was a Shakespeare expert, was a graduate student in English, and he got hired here at Case. And as I'm from Ohio, and my parents had actually relocated to just outside Cleveland, I would see them when I was back. And then after I finished, I was out of school for a while, I didn't go immediately for my PhD, and so I would see them fairly often and got to know more people at Case. Eventually, I met my husband, who is a professor here. The chair of Philosophy offered me a job - said, "you should just come here." So even before I had my dissertation, I was teaching here, and it just kind of happened. But Case is a great place, for just the sorts of things that I'm interested in, right - it couldn't have been just anywhere. I mean, the legacy here of science in evolutionary biology and particularly human evolution - Davidson Black from a hundred years ago, the Peking fossils. And of course, the Hamann- Todd collection, which are at the Cleveland Museum of Natural History, the largest collection of human bones, of human skeletons, for research collection, and also the largest collection of chimpanzee skeletons and some other non-human primates. So great resources here and a lot of really cool people. And so when I was started here, I got to know Cynthia Beall and we started the Evolutionary Biology major here - it's an interdisciplinary major, right? And then that led on eventually to me becoming involved in this newer enterprise - Origins, with Glenn Starkman. We developed the Origins major and a bunch of outreach stuff, and it just kind of came together. So that's how I ended up here.

Q: What particular parts of evolutionary biology have your most interest today?

A: Evolutionary biology encompasses a great many things. I have an interest in modern species of animals, domestication of our domesticated animals, particularly dogs. I breed dogs as a hobby. I also had horses for years too. There's that whole part, and there's also the fossil part. I've always loved fossils and paleontology. Since the time I was old enough to pick up a rock, I was looking for trilobites. Where those two things come together, and along with human evolution, is fossil apes. When I went to Yale for grad school, I was particularly interested in fossil apes. Everyone's drawn to the bipedal ones, the humans, the protohumans, or whatever. To me, well that's fine. Once you're upright, you get some brain expansion, and it's pretty much us. How did you get there? There's this huge proliferation of ape species in the Miocene between 25 and 5 million years ago that until very recently, virtually no one cared about. Except for when I was in grad school, my friend Isaiah Nengo and I both cared about apes. He came from a very different background, he's Kenyan, he grew up in Kenya, he was a protege of Richard Leakey. He decided that this guy needs to go study in the states. I met Isaiah at a conference, and I said that you need to go talk to Gould. You've read Gould's stuff. He's like, this is great. he also ended up, different timing, being a TA for Gould's courses. Anyway I digress, this is an issue of what's often called an evolutionary radiation. You had a radiation of apes in the Miocene. You had an evolutionary radiation of bipedal hominins in the Pliocene. You'll see this in Darwin's finches, famously as a radiation of different forms on different islands. To me, this issue of what causes new traits to arise, then kind of find a whole new radiation of things, or evolutionary novelties, are part of what's often called macro-evolution. To me, macroevolution is extremely interesting. How do you get trends in the fossil record? You'll have this radiation of giraffes or elephants, this sort of thing. Those kinds of trends. It's not enough to say that variation arose, and selection acted on it. This led me also to my more humanities interest, which is history of the philosophy of science, the history of evolutionary thought and my dissertation was on controversies in the past 150 years in macro-evolutionary theory. I got to be pretty familiar with Darwin.

> *"To me, macroevolution is extremely interesting. How do you get trends in the fossil record? You'll have this radiation of giraffes or elephants, this sort of thing. Those kinds of trends. It's not enough to say that variation arose, and selection acted on it."*

You hear a whole lot of people saying a lot of things about Darwin and what he thought, and unless you've really read his books, letters, and all kinds of things, It's very hard to interpret what's he's saying if you're just exposed to it here or there. If you don't understand the whole continuity of his thought, because he was a prolific writer. Darwin had a whole range of different mechanisms. People say it was all natural selection, but it was not all natural selection. Darwin himself said, in his own lifetime, you're getting me wrong and this is not everything. He says that great is the power of steady misrepresentation. There's one thing you can internalize, it's absolutely true. Not just for Darwin.

Darwin was very interested in how different parts of different animals grew at different rates, so if you have an evolutionary radiation, the larger ones might have longer necks than to smaller ones that get larger disproportionately or legs that get longer disproportionately. This is called allometric correlations. He called them correlation of growth, or allometry. Another thing that I fine very interesting in Darwin's thought and in certain things I've been looking at are called polyspecific associations, or associations involving more than one species. If you think about the savannah, you've got those big herds out there, you have wildebeests and zebras, and some giraffes, and sometimes some rhinos. You have different species living together and cooperating. You'll often hear Darwin represented as being a 'nature red in tooth and claw.' Darwin did talk about a struggle for existence, but he says that in a two canine animals, and in a time of drought, some will struggle who will need struggle and survive, but equally much, the plants at the end of desert struggle just as much. When you are talking about struggle for survival, it's on so many different levels. Polyspecific associations form when it's advantageous for individuals to cooperate. It's one thing to cooperate among members of your own species, but you can get other benefits from polyspecific associations because you will be using different aspects of the ecology at the same time, so you're not going to strip away their resources. If you have a bunch of monkeys and they all eat the same kind of fruit, you can't have that many monkeys in the trees, but if some eat from another kind of tree, if some eat leaves, and some are looking at bark, sap, bugs, and things like that, then you have a certain division of labor and everyone benefits from the larger group size because somebody's going to see predators. There're all kinds of advantages. Humans and dogs are a polyspecific association. If you look over time, it's coming out more and more in the past few thousands of years as humans started to leave Africa, or at least a small subset of humans left Africa, and gave rise to the rest of

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the people around the world. If you look at Europe and Asia, this was an ice age climate they were traveling in to. If you ask, people say that dogs came domesticated because they followed our camps and ate our garbage. We were the ones who came into their areas. They were well-adapted to the environment, so we probably came in and ate their garbage. We learned to cooperatively hunt with them, and cooperate in other ways. They can eat stuff we can't, vice-versa. We can get to some things they can't get to really well. That's probably how that came about. It's a very interesting thing. This leads to a whole host of issues that I'm interested in. Another area we haven't talked about is digital organisms, or artificial life, but I'll leave that for another time.

Q: You've devoted a lot of your time to scientific outreach. Why is it so important for scientists to go beyond just their research and actually try to speak up?

A: I think that science has a lot to offer humanity. It has been responsible for most if not all the breakthroughs that have greatly improved things like survivability, lack of seriously damaging hard work, the sorts of things that basically produce the kind of freedom we have today. We use it for all sorts of silly things, but also, these kinds of breakthroughs that come from science have benefited all of humanity at a level that no other human enterprise has produced. It's all been done even as scientists have been fairly distant in many ways from the public. Science outreach is sometimes seen as scientists sharing a little bit of what they do, and that it's nice for them to do that. I think people who are outside science should be demanding that scientists explain this to them because it's self-defense. They need to know how to be making decisions about scientific issues and because scientists are often wrong about things. That's the art of science. It's the art of being wrong in useful and fruitful ways, and then correcting it. When you think about what makes science different from other ways of knowing, people say the scientific method. There's no scientific method. There's not one scientific method. It's a whole concatenation of different processes. As you're working through them, it's the democratic element of science, having a lot of people involved so that they correct each other's mistakes, that is important. You may have seen recently the big study that came out in Nature about the oceans absorbing heat faster than expected. Somebody on a blog caught an error in that, brought it up, and they issued a correction to the article, saying that it's still bad, but the error bars are larger than expected. That's democracy. Science is one of the best demonstrations of democracy because if you have enough people working, they do correct those things. It's still bad, but there's a little bit more respite.

Just as an example, what you really need is a whole lot of different people. The more people that understand science, the better science is going to be and the better society is going to be. The sorts of things that we've done, like outreach to alums of the university that come and enjoy our programs. We enjoy talking to them, and I like challenging our scientists to be able to talk to people not in their field. We do a lot of things that get folks of different fields to interact in the university, mainly with faculty, but also in the outreach. Beyond that, we have talks in bars. We have talks at libraries. We'd send a speaker just about anywhere.

Outside of my work at Case, I've also been involved with some science things. For example, I was Chair for the March For Science for the past 2 years in Cleveland. This is where you get some people who are really demanding science. I encourage that, and I'd like to see more of that. Folks need to press us on that. I've also been involved with the National Center for Science Education, and the Ohio Citizens for Science, which tried to counter some of the attacks on the integrity of science from folks that are particularly anti-evolutionist, which are often the strongest, but they don't stop at evolution. The Big Bang comes under scrutiny, climate change, stem cell usage. There are people who are either confused about science or object to some of the things about it, especially for religious reasons, but also you get people who want to attack science, or particularly evolution, as a sort of hook to convert people to their religious views. If you say, well science says it's like this and not like that, you should believe in my view of the world, which is not illegal except for when you're doing it to other people's children in public schools where they are required to attend by the government. It's illegal to try to use the science classroom to convert other people's children to your religion. That's the issue a lot of things have centered.

When I first got involved, I just wanted to do the science. I don't want to have anything to do with these other parts, but then, when they were introducing the anti-evolutionism in the science standards of the state of Ohio, I ended up going to Columbus. I have no background in government stuff, and I said that I'm just here to talk about the science. This is wrong, this is a misrepresentation, this is simply factually wrong, whatever, and the politicians on the boards said they don't care, it's what our constituents want. I was unprepared for this. Blatant lying was okay if that is what the constituents want, which most are wrong about by the way. People, when push comes to shove, when it does become an issue in any political campaign, people want real science. They want their kids to become doctors. If this stuff is fake, they don't want it. This is part of why, even on the constitutional grounds, the pro-science side always wins when it goes to court. Before it gets to court, the politicians usually get voted out of office. So I'm like, it's wrong and it's also unconstitutional, and we got some legal experts to explain this to them. They say they don't care because they're going to be out of office before this goes to court, and whatever locality loses a lot of money. This is wanted happened in the Dover Pennsylvania trial, which is often called a "Dover Trap" now. You get some of these big organizations like the Discovery Institute and come and seed this stuff like intelligent design, or just general anti-evolutionism stuff. Somebody latches on to it, and that community ends up paying the $2 million in legal fees and not the Discovery Institute. That's why it is called a Dover Trap.

Finally, it came to the ream of politics. This is so far away from me, having anything to do with academics or my involvement with Ohio Citizens for Science or National Center for Science Education. Some friends of mine and I thought that we got to run candidates. Then I ended up running political campaigns for people, and we won every single one. We raised more money than what has ever been raised for a candidate for state board because people do care about these issues. They do want real science, and we won on every single one. People said to me, you're going to run for office now right, and I said no. I'm a one-issue person. Every now and then, something will come up, and there will be a little delegation saying, "why are you here." It's hard, and I ended up going to a lot of churches. I'm Catholic, so my background is quite different than the Protestant megachurches you run into this stuff in. Getting to know people in those setting is very interesting, and we got some rapport. Several ministers apologize on behalf of their flocks for their behavior.

One other thing I'll tell you about for science outreach is a fairly new project. Bringing it back to my friend Isaiah, he works in the Turkana Basin, part of the Turkana Basin Institute. A year and a half ago, Kenya has started new universities. They have seven, and recently decided to have one in every county, which there are 36. There's a new one is Turkana county, which is completely desert. 80 percent of them are pastoralists, still living with the camels, goats, in these gorgeous huts. There's a new university there that has 12 faculty and 300 students, and no funding. They need to expand in the next 20 years to have 20,000 students. They asked Isaiah if he had any friends that could help them with new projects, and we're looking for starting a center for evoluFthat's tionary medicine and global nursing. The nursing school and public health people would much rather have things here, and so they ditched him into doing fieldwork, where we're going to be doing some public health stuff and some straight up science outreach. I have written a one-day curriculum that we have printed on the back of a t-shirt, and hand out to the nomads. There's more to it than that, but I'm hoping this will go viral. Oil has just been discovered south of the lake, and they're about to be entrenched with outsiders in the next

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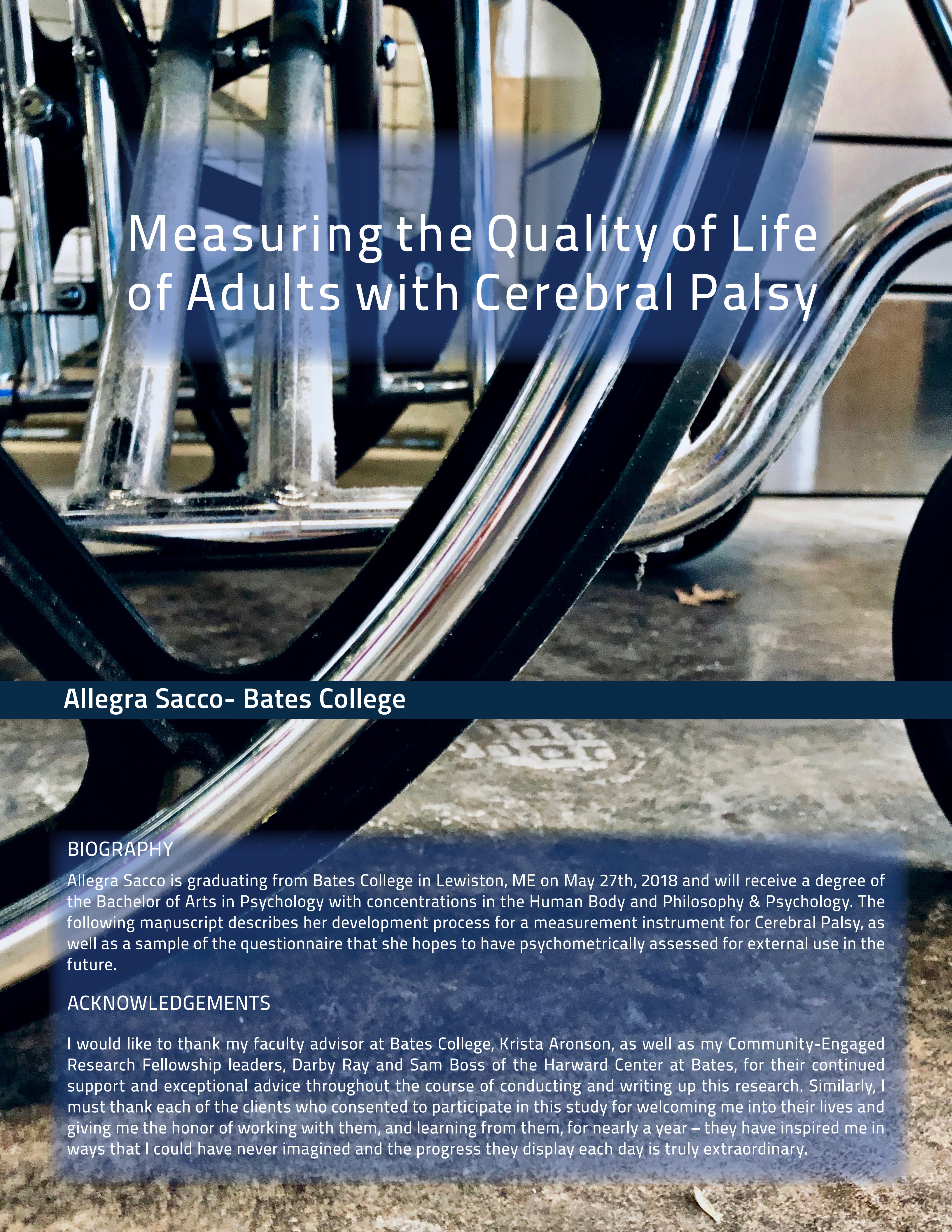
two years, so we'd love for all the young girls in Turkana to become nurses. We're going to work on that, but in two years, we aren't going to achieve that, but hopefully, we can give them some insight into scientific thinking. I have some specific ways I won't go into, but we have this curriculum which we hope will become viral. I'm taking students there on spring break, and we're going to look for fossils on Isaiah's sites. We're going to implement a one-day model curriculum as a pilot study.

A Selection of Dr. Princehouse's Work

Princehouse, P. (2009). Punctuated equilibria and speciation: What does it mean to be a Darwinian. *The Paleobiological Revolution*, 149-75.

Princehouse, P. M. (2003). 'Mutant Phoenix: Macroevolution in Twentieth-Century Debates over Synthesis and Punctuated Evolution. *Harvard University Doctoral Dissertation.*



Measuring the Quality of Life of Adults with Cerebral Palsy

Allegra Sacco- Bates College

BIOGRAPHY

Allegra Sacco is graduating from Bates College in Lewiston, ME on May 27th, 2018 and will receive a degree of the Bachelor of Arts in Psychology with concentrations in the Human Body and Philosophy & Psychology. The following manuscript describes her development process for a measurement instrument for Cerebral Palsy, as well as a sample of the questionnaire that she hopes to have psychometrically assessed for external use in the future.

ACKNOWLEDGEMENTS

I would like to thank my faculty advisor at Bates College, Krista Aronson, as well as my Community-Engaged Research Fellowship leaders, Darby Ray and Sam Boss of the Harward Center at Bates, for their continued support and exceptional advice throughout the course of conducting and writing up this research. Similarly, I must thank each of the clients who consented to participate in this study for welcoming me into their lives and giving me the honor of working with them, and learning from them, for nearly a year – they have inspired me in ways that I could have never imagined and the progress they display each day is truly extraordinary.

Abstract

While quality-of-life (QOL) questionnaires currently exist for children and adolescents with cerebral palsy (CP), a QOL tool for adults with similar impairments does not exist. QOL surveys for adults with CP will ensure that high QOL can be maintained, or low QOL can be improved, through different modes of intervention approved by certified caregivers. The current study explores, qualitatively and quantitatively, the most relevant aspects of life for an adult with CP in order to construct a QOL questionnaire for this population. Adults with CP (N = 11) from a New England cerebral palsy agency were interviewed using a draft of questions related to QOL based on the CP QOL-Child and -Teen. Both numerical and short-answer responses were obtained and analyzed using qualitative methodologies. Unique themes appeared in the responses given, most importantly, "relationships with adults," "specifically romantic relationships," "the CP program as a job," "wheelchair satisfaction," etc. Questions that prompted the answers to establish these themes were found to be different than the questions currently seen in the CP QOL-Child and -Teen. Similarities between the assessments were also found, as consistent themes included "online communication," "life achievements," "community access," etc. Findings revealed that adults with CP must be administered an individualized QOL questionnaire that is specific to the most relevant aspects of their life, their age, and the progression of their disease to calculate an accurate QOL measurement.

Measuring the Quality of Life of Adults with Cerebral Palsy

According to the Cerebral Palsy Alliance, cerebral palsy (CP) encompasses an array of conditions that result from an injury to the developing brain before, during, or shortly after birth (n.d.). There are numerous impairments that individuals with CP, specifically children, endure for the entirety of their lives, most commonly disturbances to movement and posture, including spasticity, muscle weakness, and reduced coordination (Carlon, Shields, Yong, Gilmore, Sakzewski, & Boyd, 2010). However, impairments also include disturbances of sensation, perception, cognition, communication, and behavior, as well as epilepsy and secondary musculoskeletal problems (Carlon et al., 2010). Although these issues may improve with age through different modes of therapy, they typically worsen as the individual matures as impairments compound and often cannot be cured. Such deficiencies include difficulty swallowing, excessive salivation, respiratory disorders, eating problems, gastrointestinal disorders, speech and language disorders, communication disorders, sleep disorders, behavioral problems, and learning disabilities (Park & Kim, 2017, p. 266). Unfortunately, with more than 17 million people globally living with CP, these ailments and their resulting impairments are not uncommon.

> *"...there is little research that explains whether adults with CP are happy with how they feel about themselves with such impairments, and in turn, how they experience certain aspects of life."*

Although there are numerous impairments associated with this disorder, only a few aspects of life have been studied in adults experiencing CP. In other words, the quality of life (QOL) of adults with CP is severely understudied; there is little research that explains whether adults with CP are happy with how they feel about themselves having such impairments, and, in turn, how they experience certain aspects of life. In this way, QOL is more broadly defined as "a broad range of human experiences related to one's functioning in comparison with personal expectations and is defined by subjective experiences" (Burckhardt & Anderson, 2003, p. 1). The World Health Organization (WHO) considers four main categories when evaluating QOL regardless of an individual's ability status: physical health and independence, social relationships, environmental factors, and psychological well-being, spirituality and personal beliefs (CerebralPalsy.org, 2018). These aspects of QOL change slightly when applying them to individuals with CP, as deficiencies associated with this condition affect mental and physical functioning. For instance, they may feel more pain or discomfort than adults without CP, as many adults with CP are restricted to a wheelchair. Additionally, they may have fewer opportunities to obtain a traditional education or engage in leisurely activities, as they do not have proper means of travel due to their lack of mobility and do have underdeveloped communication skills. Regardless of such differences, the criteria of the domains of QOL remain the same for people with and without disabilities.

Domains of Quality of Life

Physical health and independence refers to the "energy and fatigue, pain and discomfort, sleep and rest, mobility, dependence, and productivity, as well as one's ability to self-care, earn an income, and perform activities of daily living" ("Quality of Life", 2018). Moreover, psychological well-being, spirituality, and personal beliefs take into account one's "self-perception, self-image, and self-esteem, as well as his or her cognitive ability to think, learn, remember and concentrate. This domain also looks at the influence of religious beliefs, spirituality and personal beliefs" ("Quality of Life", 2018). Lastly, while social relationships refer to "relationships with others, socialization, and sexual activity," environmental factors include "safety, security, housing, mobility, freedoms and independence, as well as access, inclusion, participation, and the opportunities to learn, develop skills, participate in recreation, leisure interests and employment" ("Quality of Life", 2018). MyChild, a website dedicated to informing the public about CP, explains that "those reporting a level of dissatisfaction with their quality of life, often have health problems and live short and less fulfilling lives" ("Quality of Life", 2018). Thus, if the criteria within these domains of QOL are not consistent with what is perceived to be significant aspects of life, his or her QOL could dramatically decrease or remain dangerously low; the true QOL of the individual has not been accurately measured. In the case of adults with CP, these individuals already live with health problems that can lead to a shortened life, so maintaining a high QOL is essential to living a long, desirable life. However, as previously stated, while there are some studies that attempt to discuss the QOL of adults with CP, research revealing how such individuals feel about the aspects of their lives within each of the domains of QOL presented by the WHO ("Quality of Life", 2018) is scarce.

Physical Health and Independence

Physical health and independence encompass a number of aspects of life, such as overall health and nutrition, as they relate to the ability to self-care, as well as to one's energy, fatigue, etc. Limited research has been published that show how these aspects of life make an adult with CP feel about their life in general, but Turk (2009) and Becker & Schaller (1995) have introduced compelling preliminary discussions.

First, Turk (2009) investigated the overall health of adults with CP. Although Park and Kim (2017) discussed the many impairments associated with an aging individual with CP, Turk (2009) explained that "the general health of adults with CP is self-reported as good or satisfactory to excellent" (p. 25). Turk (2009) found that 76% of her participants reported musculoskeletal issues, such as contractures, deformities, or pain, and that approximately "half of persons who did not walk" (p. 25) also experienced urinary incontinence. Nonetheless, she found that a large number of adults with CP in upstate New York "were overwhelmingly healthy (based on clinical information and self-report) and reported no significant health problems" (Turk, 2009, p. 26). Turk (2009) also successfully reported the way in which these adults experienced their very few self-reported impairments, such as pain and musculoskeletal, bladder, bowel, and dental problems: "They were nonetheless worried and concerned about their health status and futures" (Turk, 2009, p. 26). Thus, although these adults with CP were not diagnosed with any additional severe health problems, they were still observed to be somewhat distressed about their current health issues. Yet, their concerns for the future did not seem to affect their perception of, or feelings about, their overall health, as seen in their self-report results. This health-specific research is intriguing and highlights the need for additional research on how various aspects of life, such as mobility and pain, are experienced by adults with CP.

In subsequent research, Turk (2009) found that although "chronic pain (present for >3mo) is common, and reports of pain can be daily and characterized as moderate to severe intensity" (p. 26), adults with CP often attempt to manage their pain on their own, rather than ask for help. Turk (2009) explains that "pain reports may be difficult to elicit because of communication difficulties or severe intellectual disability," forcing individuals with CP to experience their pain in a more difficult way, as they must do so independently (Turk, 2009, p. 27). However, this conclusion may be merely an assumption as there are limited studies that directly address adults with CP and inquire about their personal experiences with pain.

Social relationships

The social relationships that exist for adults with CP, specifically romantic or sexual relationships, is a domain that has been studied much more deeply than the domain of physical health and independence. A recent study by Maestro-Gonzalez et al. (2018) was seemingly the first to measure the QOL of adults with CP to determine which aspects of an adult's life are most relevant in determining their QOL. The researchers utilized the GENCAT Quality of Life Scale, which is an "unprecedented approach to the evaluation of the quality of life of the users of social services" (Gomez, Arias, Verdugo, & Navas, 2011, p. 91). Gomez et al. (2011) noted its validity, particularly in Catalonia, Spain, and explain that it is the "only instrument so far available that is sensitive to those intervention programmes designed to improve personal results (and therefore the quality of life of users) and so can be of considerable use when applied in the services and in the development and assessment of programmes" (Gomez et al., 2011, p. 91). Although this scale is not directed towards adults with CP, it is currently the only scale that includes questions for adults with "physical disability and mental health problems" (Maestro-Gonzalez et al., 2018, p. 4). The researchers ultimately found that adults with CP reported an overall mean QOL score of 103.29, "which corresponds to the 56.6th percentile on the GENCAT scale", meaning "adults with CP tend to perceive their QOL the same way the general population does" (Maestro-Gonzalez et al., 2018, p. 7-8). They also found that "'interpersonal relationships', 'personal development', and 'social inclusion' were the most important factors for QOL" of adults with CP, whereas "'material wellbeing' and 'physical wellbeing' were the least" (Maestro-Gonzalez et al., 2018, p. 10).

Maestro-Gonzalez et al. (2018) also found that higher QOL in adults was associated with having a current sexual relationship. People with CP were found to have low mean scores for certain items such as "has a satisfactory sexual life" and "presents with depression symptoms" (Maestro-Gonzalez et al., 2018, p. 5). Meanwhile items such as "has good personal hygiene" and "reports feeling love by most people to him or her" were found to have the highest mean score for reported QOL (Maestro-Gonzalez et al., 2018, p. 5).

These findings demonstrate that there should be a distinguished QOL measurement for adults, and that it should include questions regarding sexual and romantic relationships. Young adults with CP often experience a delay in sexual development, meaning that this may become troublesome for older adults with CP (Wiegerik et al., 2007).

Psychological well-being, spirituality, and religion

Although there is very little research presented on this domain of QOL, King, Cathers, Polgar, MacKinnon, & Haven (2000), as well as Maestro-Gonzalez et al. (2018) touched on the aspects of self-perception and self-esteem. King et al. (2000) found that ten adults with CP, between the ages of 18 and 20 years of age, believe that being successful is equivalent to being happy in life. They associated success with "being believed in, believing in yourself, and being accepting by others (belonging)" (King et al., 2000, p. 743). Therefore, King et al. (2000) and Maestro-Gonzalez et al. (2018) revealed that adults may maintain less focus on optimal physical functioning, and instead, they focus on how much they can do with the physical abilities they maintain and how successfully they can accomplish their goals. If successful, a higher QOL may be achieved, as their idea of "success" is fulfilled.

Environmental factors

Employment is just one aspect of the environmental factors within one's life that has been briefly studied in relation to adults with CP and other diseases. Mitchell, Adkins, & Kemp (2006) reported that people with disabilities, such as polio, CP, spinal cord injury, rheumatoid arthritis, and stroke, among others, undergo a "sharper decline in employment in their later years than those without disabilities" (Mitchell, Adkins, & Kemp, 2006, p. 162). Participants in this study were 20 to 64 years of age, and were required to report their demographic information and their employment status at the time of the interview: "A person was counted as employed if he or she worked either full or part time for a salary or earned a major part of his or her income through self-employment" (Mitchell et al., 2006, p. 159). Mitchell et al. (2006) provided significant information with regards to the importance of a college education on the ability to maintain employment for those with disabilities, as well as the negative effect of a decrease in physical function and an increase in pain, fatigue, and medical needs. However, the researchers do not describe how a lack of employment caused the individual to feel about their life. As stated previously, research is limited to whether unemployment and several other aspects of life, such as religion and communication, impact the quality of life of an adult with a disease such as CP.

Current QOL Measurement Assessments

The research describing aspects of the four QOL domains presented above, demonstrated that adults with CP may experience certain aspects of their lives differently from those without disabilities, as well as from other people with CP who are younger. In this way, although QOL domains may be universal across all people, even for those with disabilities, the QOL of adults with CP is unique to their age and their disease. Thus, it is essential to consider the similarities and differences that may exist between the pre-established QOL questionnaires for determining the QOL of children and adolescents with CP, such as the CP QOL-Child and -Teen, and a QOL questionnaire for adults with CP that has yet to be created (Waters et al., 2013).

The CP QOL-Child, which is intended to be used with children ages 9 to 12 years old, and CP QOL-Teen, which is intended to be used with adolescents aged 13 to 18 years old, are condition-specific QOL assessments (Waters et al., 2013). These tools are used to evaluate interventions designed to improve the lives of children and adolescents (University of Melbourne Australia, 2016). Similarly, the CPCHILD™ Questionnaire "measures caregivers" perspectives on the health status, comfort, well-being, and ease of caregiving of children with severe developmental disabilities … including non-ambulant children with severe cerebral palsy, and traumatic or other acquired brain injuries" who are being given such interventions (Sick Kids, 2004). Interventions essentially signify programs established to care for individuals with CP, and in turn, they provide support for families and children with CP across America. The Cerebral Palsy Program at the Children's Hospital of Philadelphia utilizes the CPCHILD™ widely across their clinics for all of their pediatric CP patients. They have been using this questionnaire for over a decade and have just begun a prospective study enrolling CP children with orthopedic conditions in their hip(s) and spine; the CPCHILD™ is being used as the mode of patient reported outcome. Although the results of this study have not yet been reported, it is clear that quality of life is essential in determining whether the needs of these children have been satisfied, as a high quality of life is being used to represent a successful physical recovery and return into the world without these impairments.

For the purpose of this study, the CP QOL-Child and the CP QOL-Teen will be used as springboards for creating an adult CP QOL measure (Waters et al., 2013). These measurement instruments ask questions about aspects of the individual's life, such as his/her family, friends, health, participation, communication, school, special equipment, and pain and bother (Waters et al., 2013). Each question begins with "How do you feel about…" (Waters et al., 2013, p. 3); the individual must then choose the number that best reflects how he/she feels on a numerical scale, numbered 1 ("very unhappy") to 9 ("very happy"). When asking about pain and bother, the numbers within the scale remain the same, but 1 indicates "no pain at all" and 9 indicates "a lot of pain". For example, a question may ask, "How do you feel about… the level of pain you experience?" (Waters et al., 2013, p. 14) and the individual must select a number between 1 and 9. Several researchers have revealed the validity of these questionnaires, as well as the strength of their psychometric properties, which is why they serve as such exemplary templates for an adult CP QOL questionnaire (Carlon et al., 2010 & Davis et al., 2013).

QOL of Children and Teens with CP versus Adults with CP

The concerns brought to light by adolescents with CP may also be considered by adults with CP when asked about their QOL, but the WHOQOL – Old Project reveals that adults are primarily concerned with "energy, freedom from pain, ability to do activities of daily living and to move around" (Molzahn, Skevington, Kalfoss, & Makaroff, 2010, p. 296). This perspective on what is important in life to adults is consistent with the findings of the research presented, and specifically that of Davis et al. (2013), which explains that the caregivers of children or teens with CP "remain focused on physical function associated with CP" (Davis et al., 2013, p. 351). In this way, it is difficult to determine whether adults with CP will take the perspective of children and teens with CP, in regard to what is more important to them in life, or if they will take the perspective of the adult caregivers of children and teens with CP, as they seem to share both concerns. However, it may be more beneficial to disregard the opinion of the caregiver of adults with CP, as the individuals with disabilities have most likely come to terms with their disorder and now maintain their own views regarding what does or does not make them happy.

In contrast, Murphy, Molnar, and Lankasky (2000) found that 84% of their 101 volunteer participants, who were all adults with CP, felt as though "their parents overprotected them and that children should be allowed more liberties and risk-taking" (p. 809). Similarly, "the majority stated that physicians should talk not only to the parents but also directly to the child and attend equally to their personal and physical needs" (Murphy et al., 2000, p. 809). In fact, Hemsley, Balandin, & Togher (2009) found that, while adults with CP depend on family carers for supporting them with their communication, they simply wanted to be treated as adults who have the capacity to be included in healthcare-related decisions. In other words, even though they appreciate the emotional and communicative support from their family caregivers when needed, adults with CP prefer to be included in the conversations with the hospital staff, as they want to learn about their disease and necessary treatment (Hemsley et al., 2009). As individuals over the age of 18, adults with CP should have the right to make their own decisions and learn about their healthcare, if they are physically, mentally and emotionally capable. This logic should remain the same when adults with CP are asked to discuss their quality of life.

Based on this research, it seems logical for there to be differences in a CP QOL assessment for adults from that of the self-report versions of the CP QOL-Child and -Teen, as well as from that of the Caregiver versions of these assessments (Waters et al., 2013). However, these findings also indicate that some categories of the CP QOL-Child and CP QOL-Teen (Waters et al., 2013) should overlap with that of an adult CP QOL; those with CP must physically maintain themselves properly and obtain assistance from friends, family, and/or caregivers. Seeing as it is unclear if the CP QOL-Child (Waters et al., 2013) or the CP QOL-Teen (Waters et al., 2013) are appropriate assessments to be used alone or in conjunction to assess the QOL of adults with CP, it is necessary for an alternate version of these psychometrically sound assessments to be established as an adult CP QOL instrument. Such adults likely have difficulty improving aspects of their condition any further, and instead work to control their impairments, while also maintaining as high a QOL as possible. In an attempt to do so, many begin to enroll in programs that help them maintain a happy and healthy lifestyle.

Many widespread cerebral palsy programs have not implemented a QOL measure for adults with CP, as one does not currently exist that would be accurate for individuals over eighteen years of age. However, many adults with CP opt to attend, or are sent by their guardians, to CP programs. Many of these agencies are non-profit organizations that may even provide residential accommodations for clients who opt to live with caretakers and other adults with CP. In this way, such programs support their clients and help them become satisfied with many of the aspects in their life mentioned in the CP QOL-Child and CP QOL-Teen (Waters et al., 2013). However, many of the CP programs for adults do not currently utilize the QOL measurement instruments in their annual evaluations of their clients, as the CP QOL-Child and CP QOL-Teen are not directed towards the adult age group with which they work (Waters et al., 2013).

The Current Study

The current study aims to create a reliable and valid measurement instrument that can be used to determine the QOL of adults with CP and other developmental disabilities in adult CP programs, specifically at a New England agency serving adults with CP. Seeing as many of the clients attended the program daily and have been a part of the program for decades, they have begun to view it as their occupation, since "employment and independent community living are indicators of successful rehabilitation in CP" (Murphy et al., 2000, p. 807). With that, their attendance at the program has become a stable and frequent aspect of their lives that cannot be ignored, it will continue to affect them physically, emotionally, and mentally as they continue to age. In other words, they may not be able to maintain a high QOL if their experience at this program is not fulfilling their wants and needs. However, as previously stated, there is currently a lack of standardized QOL assessments or tools for adults with CP and similar developmental disorders to ensure this program is abiding by its mission. Although the GENCAT QOL Scale was created for individuals who utilize social services, those with CP have distinct wants and needs, related to their impairments mentioned previously, that must be satisfied in order to maintain a high QOL.

> *"...A QOL measurement that produces data showing that this agency, and similar programs, can truly increase the quality of life of an adult with CP will also reveal its importance in the adult CP community."*

Using the CP QOL-Child and CP QOL-Teen self-report questionnaires (Waters et al., 2013), as well as the results of the studies previously discussed, as guidelines, the first goal of the study was to determine which questions and aspects of life are most significant to adults with CP. This was done by examining qualitative and quantitative data from the participants who consented to participate from the New England CP agency. In this way, additional aspects of life were considered, aside from those mentioned in the CP QOL-Child and CP QOL-Teen (Waters et al., 2013), when deciding which questions should exist in the assessment for adults with CP. Some questions coincided with those included in the CP QOL-Child and CP QOL-Teen (Waters et al., 2013), as inquiries related to interactions with family and other caregivers seemed to be relevant in the life of children, teens, and adults with CP (Hemsley et al., 2009).

In addition, the determination of the questions on the adult CP QOL survey was accomplished using the annual evaluation used by employees at the New England CP agency serving adults with CP. Their annual evaluation involved obtaining information regarding their clinical status, communication skills, skills and interests, neuromuscular status, self-care skills, and community skills. However, this "objectively evaluated health, or functional, status is just one of many factors that influence subjectively perceived quality of life" (Dammann & O'Shea, 2007, p. 2137). It is important not to "confound [QOL] with functional status, symptoms, disease processes, or treatment side-effects" as the meaning of QOL, which "transcends health" (Burckhardt & Anderson, 2003, p. 1). With that, it is essential to implement a QOL scale that asks clients how they feel about their memory and problem-solving skills in order to determine if the client believes it is a significant aspect of their life that needs improvement. This will allow the client and the caregiver to approach the client's goals in a collaborative manner to ensure that his or her wants and needs are effectively and efficiently satisfied.

Finally, the second goal of this study is to propose recommendations to the staff at the New England CP agency, related to the quantitative and qualitative data provided by participants, that will aid in the increase of QOL of the clients at the New England CP agency over time. In other words, recommendations will be given pertaining to how one may approach administering the QOL survey to a participant, as interactions and communications with adults with CP may be unique due to the nature of the disease.

Seeing as the New England CP agency is a non-profit organization that will continue to thrive if the community is willing to fund their programs, a QOL measurement that produces data showing that this agency, and similar programs, can truly increase the QOL of an adult with CP will also reveal its importance in the adult CP community. The current, limited research on this topic demonstrates the lack of knowledge that researchers, doctors, therapists, caregivers, and more, have about the QOL of adults with CP. This is a population of individuals who have been severely overlooked and deserve attention to ensure that they are living with the highest possible QOL with their disease.

Methods

Participants

Participants were 12 clients, 10 females and 2 males, from a New England agency serving adults with cerebral palsy. The participants in this study were all over the age of 18-years-old. One male participant from this sample was excluded from data analysis as his responses were inconsistent with his personal history upon further review. Eleven of the twelve participants have been given a primary diagnosis of Cerebral Palsy. One participant has a primary diagnosis of acquired encephalomyelopathy, but was not excluded from the study, due to the similarities of the diagnoses. Nine of the participants are verbal and three are non-verbal, thus requiring the use of a communication device, such as a manual alphabet tray, a communication binder consisting of letters, numbers, terms, phrases, etc., or an electronic device, like an iPad, similar to the communication binder. Ten of the twelve participants are their own legal guardian and consented to participate in the study and two participants received consent from their legal guardians after expressing their interest in the study.

Measures

For this study, the Self-Report Questionnaire version of the CP QOL-Child (Waters et al., 2013) and the CP QOL-Teen (Waters et al., 2013), as well as the results reported specifically by Maestro-Gonzalez et al. (2018), were used as guidelines to develop a new quality of life measurement tool for adults with Cerebral Palsy and other disorders. This adult QOL questionnaire will be used at CP programs to be completed in future annual evaluations of the clients in attendance, similar to the CP QOL-Child and CP QOL-Teen (Waters et al., 2013).

These questionnaires cover family and friends, school, communication, health, special equipment, and pain and bother. Examples of questions include, "how do you feel about… how you get along with people in general" and "how do you feel about… your ability to participate in your community", etc. (Waters et al., 2013). These questions are to be answered on a scale of 1-9, 1 indicating "very unhappy" and 9 indicating "very happy". (Waters et al., 2013). However, these questions were taken and modified from the CP QOL-Child and –Teen (Waters et al., 2013) to be applicable to adults. A draft of potential adult CP QOL questions was constructed and used during the client interview sessions. These new or modified questions required quantitative and/or qualitative responses. The draft used during the interviews included the following sections consisting of such questions: Friends and Family, Employment, Unemployment, Participation at your CP Program, Participation Outside of your CP Program, Communication, Health, Special Equipment, and Pain and Bother. Questions from the Friends and Family, Employment, Unemployment, Participation at your CP Program, Participation Outside of your CP Program, Health, Communication, and Special Equipment sections required a quantitative response on the same 1 to 9 scale. The "Unemployment" section, for example, was added and it is not present in the CP QOL-Child or –Teen (Waters et al., 2013), but still asked how the participant feels on the 1 to 9 scale about his/her employment status. It then asks a several open-ended questions, such as, "do you consider your CP program to be your job"? Depending on the communication skills of the participant, he/she could provide quantitative responses to the questions and qualitative responses to the questions, but some participants were only capable of one type of response. The qualitative responses entail an elaboration of the quantitative response or a short-answer response to the question, explaining why they feel the way they do. The second half of the "Health" section asked for a quantitative answer on a scale of 1 to 9, which indicated "not concerned at all" to "very concerned". Similarly, the "Pain and Bother" asked for quantitative responses on the 1-9 scale but with answers about pain ranging from "not at upset at all" to "very upset", and with answers about bother ranging from "not bothered at all" to "very bothered". In the same way, a participant was asked "are you bothered by doctor's visits", and the participant was to respond quantitatively to indicate that he/she was "not bothered at all", "very bothered", or somewhere in between. See Appendix A for the draft of questions used during participant interviews.

Furthermore, the results of Maestro-Gonzalez et al. (2018) reveal that the QOL of adults with CP is highly affected by their involvement in sexual or romantic relationships. Based on these findings, questions regarding intimate partnerships was also included in the draft of questions in the "Friends and Family" section. The answers provided by participants from the draft of questions were used as indicators for which questions deserve to be on the final adult CP QOL assessment.

Procedure

The occupational therapist from the New England CP agency explained the reason for the visitations; she explained the attempt to create a quality of life survey that will measure the clients' happiness. The clients at the program were told that they did not have to participate in this study if they did not want to.

An initial list of 28 potential participants, created by the occupational therapist from the New England agency serving adults with Cerebral Palsy, was sent for review. After gaining IRB approval to proceed with the study, the primary diagnoses of each potential participant were determined. The clients with a primary diagnosis of cerebral palsy or acquired encephalomyelopathy were asked to have a short 5 to 10-minute conversation regarding the study and, if they were interested, to obtain their consent to participate. Of the 21 clients with a primary diagnosis with CP, one had left the program and was unable to participate, four did not give their consent or their guardians did not give consent, three were overcome by health emergencies and were unable to participate, and one could only use sign language to communicate, which I am unable to interpret. The remaining 12 participants provided consent to participate in the study. Participants were interviewed individually for 30 minutes to 1 hour throughout the course of three days. The goals of the study were reiterated to each participant and their consent to participate in the conversation was re-confirmed if they had initially consented to the terms of the study. If the participant was verbal, the conversation was recorded on my cell phone, if they initially consented to this. During each interview, the draft of questions created from the measures previously stated was used to guide the conversation. Participants were asked to give a quantitative answer on a scale of 1-9 and/or explain their feelings about the question in detail, or both if possible. These answers were to be given verbally by the participant, if capable, or using his/her communication device after the questions were read aloud. The participant had to finish answering the question before moving on to the next question or section. If the participant began to stray from the topic, the question was repeated. Some questions were skipped if the participant became upset or did not understand the question, which was noted. The answers provided by the participants were recorded on the computer in their own personal files of the draft of questions. After each interview was complete, their responded were saved. Once most or all of the questions on the draft were discussed, the participant was debriefed by explaining that he/she had just helped determine which questions were most relevant to his/her life, by describing if it made them, for example, "very unhappy" or "very happy", or somewhere in between. After the participants were debriefed about the adult QOL questionnaire that is being developed to be implemented into their annual evaluations, the participants were thanked for their patience and time taken to engage in the conversation. All procedures were reviewed and approved by the IRB at the appropriate institution.

Analysis

After the answers to each question asked were recorded in the participants' personal documents on the computer, as well as recorded using a voice recorder iPhone application (if the participant was verbal and consented), each interview was listened to again to confirm the written information in the documents. Questionable information that could not be confirmed with the audio recording from the participants who are non-verbal was double-checked with the participants who provided such information non-verbally. To analyze this data, three previously established methodologies were used, consistent with the data analysis procedure utilized by Niobe Way (1995): narrative summaries, conceptually clustered matrices, and a variation of the Listening Guide. As Way (1995) explains, the combined use of these three methodologies "allowed for a detailed examination of the interview data" (p. 111). A fourth methodology was also utilized prior to the Listening Guide procedure, which analyzed the themes within each matrix, as well as the portions of the narrative summaries associated with each theme, to determine how such themes fit within the overall category. Finally, each question was categorized into one of the four domains adopted from The World Health Organization (WHO), that being "physical health and independence", "psychological well-being, spirituality and personal beliefs", "social relationships", or "environmental factors" ("Quality of Life", 2018). These domains will be used to score the individual's QOL.

> *"Participants were asked to give a quantitative answer on a scale of 1-9 and or explain their feelings about the question in detail, or both if possible."*

First, narrative summaries were written for each participant within each section of the draft of questions. In other words, each individual participant was given a narrative summary including the information he/she provided in the "Friends and Family" section, and each section thereafter. Such narratives are meant to give a snapshot of the participant's view on the specific aspects of his/her life. The participants were quoted in these summaries if the personal details that they provided also contributed to their feelings about the topic.

After narrative summaries were written for each participant within each, conceptually clustered matrices were created, which organized the qualitative data and allowed detection of themes present within the narrative summaries. There were eight matrices, titled as "[Part] Themes" ("Employment" and "Unemployment" information was combined). Each matrix consisted of varying numbers of themes found to be relevant in the answers provided by participants. For example, the "Friends and Family Themes" consisted of "Attitude", "Self-Perception", "Ability to do things", "Relationships with adults", "Relationships with children/animals", and "Outlook on future". The "Relationships with adults" theme consisted of sub-themes including "Relationships in general", "Relationships with friends, family, and caregivers", "Relationships with strangers", and "Relationships with a romantic partner(s)". The relevant aspects of the narrative summaries previously developed for each participant were added to the themes' columns, to the right of the participant's name.

Analysis of the themes within each matrix was then required, as it was apparent that many themes did not appropriately fit within its current section. If a significant theme appeared in a section that was more appropriate for a different section, that aspect of the narrative summary was included in the different section or placed into an entirely new section that was to be created. For example, themes presented within the "Friends and Family" section, such as "attitude" and "self-perception" were found to include aspects of narratives relating to the self, rather than to the friends and family of the participants'. For example, within the "self-perception" theme, one participant explained that although she is happy with herself, she is "not happy about her eyes", as her eyesight is deteriorating. This perception of herself does not consider the way that friends, family, or other people in general, view her. Thus, this theme is more appropriately included in a "Self-Identity" section, in which a participant may be asked "how do you feel about... yourself"? Similar considerations were made for each of the themes within each section's matrix.

Way's (1995) final approach was then utilized for each theme in the original documentation of the interviews. This allowed determination of where, when, and how each of the common themes appear. To do this, the portions of the interview consistent with each theme were highlighted in different colored pens, to create a "trail of evidence"; this reveals when and where the specific theme appeared in the interview. This methodology of "keeping an audit", allowed determination of which questions and topics were most significant in the lives of adults with CP, and allowed assessment of how the participant expressed his/her response, as well as what he/she said (Way, 1995). Simultaneously, it allowed reflection on the interviewers ability to remain engaged in the participants' responses, and in turn, reflect on the process of interpreting their answers (Way, 1995).

Following this procedure, the highlighting was reviewed a second time, but this time, the four QOL domains previously established by The WHO were kept in mind ("Quality of Life", 2018). The questions that were deemed significant after completing the Listening Guide were rewritten, which questions triggered emotion were noted, as well as which answers to questions were explained thoroughly, actively avoided, or consistently repeated. Next to each question, the first letter of the domain that it was best associated with was written down. Placing questions in one of the four domains allows for more efficient scoring, as each domain maintains a highest potential score, depending on the amount of questions it contains, for the individual's QOL score to be compared to.

These five modes of analysis ultimately led to the determination of the sections and questions that are most relevant to the life of an adult with CP. By noting the most frequent and significantly expressed themes within each section, a quality of life measure for adults with CP was established. After this was completed, the titles of each section were also examined and changed, if necessary, to be more descriptive of the questions being asked in that section. For example, the sections that were originally named "Participation Outside of your CP Program" and "Participation at your CP Program" were later combined, and the title of the "part" was changed to "Participation". In this way, questions are easier for participants to understand and respond to, as they can more efficiently comprehend what the questions are referring to.

Results

The data provided by 11 participants was analyzed, as one participant was excluded from data analysis; the participant's responses were inconsistent with his personal history upon further review. This exclusion was established during the first methodology, Narrative Summaries (Way, 1995).

Each of the five methodologies led to evident differences in the important aspects of life for adults with CP in comparison to that of children and teens with CP. This, in turn, allowed for there to be numerous different questions presented on a new version of a QOL questionnaire for adults with CP, known as the Quality of Life Questionnaire for Adults with Cerebral Palsy (QOLQ-ACP). In the same way, many questions from the child and adolescent versions of the questionnaire were removed or rephrased to make them more relevant to the lives of adults with CP. Questions that prompted thorough explanations or were avoided due to their triggering of emotions, for example, were considered to be important as they were emphasized and mentioned frequently. With that, numerous themes within each "part" of the questionnaire were recognized as being significant as the narrative summaries were analyzed. Each "part", along with its relevant themes and samples of the narrative summaries associated with each theme are elaborated on below. Only themes that are associated with new questions that are not currently on the CP QOL-Child and –Teen (Waters et al., 2013) are described. Refer to Appendix B for a sample page of the QOLQ-ACP.

QOLQ-ACP "Parts" and Important Themes

Friends and family

Participants spoke in depth about their friends and family within several different aspects of their life, which translated into the themes that appeared in this category. First, "relationships with adults" was a consistent theme as participants discussed how other adults, whether that was their caregivers, friends at or outside of their CP program, family members, significant others, or strangers, treat and accept them. One participant explained that she does not want a significant other because she feels like she is "too old and can't have kids anymore, but would have liked to. [Her] previous significant other passed away." Another participant shared her feelings towards her guardian, as she doesn't "feel completely comfortable making [her] own decisions," and prefers having someone who supports her. In addition, "relationships with children" appeared as a theme. A participant explained that he "like[s] interacting with children because they accept [him] and are more aware of [his] disability." Lastly, "going out" proved to be a necessary theme, specifically related to the "company" the participant is in when going out, as several participants shared that they felt more comfortable venturing out on daily activities or doing errands with someone else. One participant "feel[s] better when someone is with [her], like a 'big brother' or a 'big sister'." Another participant revealed that she would like to go out to do an activity with someone, but her "PCAs aren't always around to go out with [her], so [she] can't go out when they can't. [Her] dream is to take [her] entire paycheck and pay [her] PCA $100 to go to Michael's and buy everything in the art store." The questions asked to receive such responses were placed in either the "Social Relationships" domain or the "Physical Health and Independence" domain.

Participation

The Participation category referred to involvement both at the CP program and outside of the CP program. First, regarding participation at the CP program, common themes included "groups," "social events," and "the CP program as a job." One participant shared that she enjoys physical therapy groups, but wants more attention during session; she "want[s] to walk outside more but there is not enough people to help [her]." Another participant explained that "some [social] events are on Sundays and [he] can't go because that's when [he goes] to see [his] mom. [He loves] seeing [his] mom, but [he wants] to go to [social] events too." Lastly, several participants considered their CP program to be their occupation. One participant gave a response that explained that she "wouldn't want any other job"; she feels like she is "helping people and wants to help people like [herself], which [she] is able to do at [her CP program]." She also "likes that it doesn't cost a lot of money". Moreover, questions about participation outside of the CP prompted themes such as "life at home" and "camp participation." "Life at home" was found to be a relevant theme as participants commented on their living situation. One participant explains that she does not like where she lives and has a goal to "get a nicer place." Finally, participants either touched on their strong desire to attend camp, or their intense need to avoid it: One participant doesn't attend camp anymore and didn't like it; she "almost died from drowning" because they did not pay enough attention to her. The questions asked to receive such responses were placed in the "Environmental Factors" domain.

Communication

Only one new theme related to communication was found to be relevant to the lives of adults with CP, that being "devices". Participants either spoke about their use of their current device and their satisfaction or dissatisfaction with it, or about their want or need for a device. One participant shared that he wants a communication device "for his learning disability and wants to learn more about them." The questions asked to receive such a response were placed in the "Environmental Factors" domain.

Health

This "part" of the questionnaire contains questions relating to physical, mental, and emotional health, thus, it included themes such as "overall health – mental and emotional," "overall health – physical," "dependence," and "progress." Regarding "overall health – mental and emotional," one participant bravely shared that she "suffers from depression and anxiety, but [has] a counselor and takes medication to help [her]." The theme "overall health – physical" includes similarly personal responses in that one participant commented that he "wishe[s] [he] could shower more." In addition, a participant responded to questions related to "dependence" by saying that she finds it very hard to get dressed every day and would like to have a PCA to help her. At the same time, another participant explained that he also depends on special equipment, just as he does people, to go to the bathroom. This participant uses a catheter to go to the bathroom and is learning to accept that he needs to use it now. Lastly, "progress" was a significant theme as it related to all aspects of health and how the participants were improving specifically at the CP program. One participant explained that she does not feel like her CP program is helping her progress improve, but that it is just a "nice place to go". She feels like she is "helping the staff because they get paid for [her] to come." The questions asked to receive such responses were placed in the "Psychological Well-being, Spirituality, and Personal Beliefs" domain, as well as the "Physical Health and Independence" domain and the "Social Relationships" domain.

Special equipment

Like the Communication "part", only one new theme was introduced in the "Special Equipment" category, labeled "wheelchair satisfaction." Many participants solely use a wheelchair for their main mode of movement, except for one participant who primarily uses a walker. With that, participants frequently elaborated on their feelings towards their wheelchairs, or lack thereof, with one participant explaining that, although she usually uses her walker, she "feel[s] like a wheelchair would be better for long distances". The questions asked to receive such responses were placed in the "Environmental Factors" domain.

Pain and bother

Pain and Bother not only refers to the pain and discomfort that an adult with CP experiences, but also the interferences in his or her day to day life that occur because of having CP. Themes that appeared within this category include "physical health – discomfort," "tolerance," "dependence," and "interferences - physical." Although some of these themes overlap with other themes presented in different "parts" of the survey, the responses are still unique to each "part." First, several participants commented on not only the pain they experience, but also specifically their discomfort. One participant shared that she feels very upset about the discomfort in her feet, as she constantly uses them to propel her wheelchair. In addition, "tolerance" was a relevant theme as participants discussed how they cope with and control their pain or discomfort on their own. A participant explained that he can "cope with spasms if they are slow, but can't if they are fast" (an hour or more). Moreover, although "dependence" was a theme also noted in Health, this theme, within the category of Pain and Bother, is associated with how participants rely on others to help them cope with or control their pain or discomfort: "Someone brings me warm water or takes me to the ER." Lastly, responses describing the appearances of "interferences" in a participant's life were emphasized, specifically related to being physically handled by someone who is familiar, as well as by someone who is unfamiliar to the participant. One participant explained that she is not bothered by being physically handled by someone she is familiar with "if they know what they are doing." However, another participant shared that she feels uncomfortable with new people and would like to get to know them first if they are going to be physically handling her at some point. The questions were placed in either the "Physical Health and Independence" domain or the "Social Relationships" domain.

Response Scoring

Although most the responses to each question was in the format of short-answer, numerical responses were also given as answers to the questions associated with the themes presented. However, many numerical responses to questions were observed to either be 1, indicating "very unhappy," or 9, indicating "very happy," and not the numbers in between, signifying the different levels of happiness. It was uncommon for a participant to respond with numbers such as 3, 4, or 5, as their meanings were unclear to the participant. Thus, a modified, and shortened version of the numerical scale, such as a scale of 1-5, may provide adults with CP with the ability to fully understand their own numerical responses to these questions.

> *"Participants either spoke about their use of their current device and their satisfaction or dissatisfaction with it, or about their want or need for a device."*

QOL Assessment Similarities and Differences

Although there are clear differences between the CP QOL-Child and CP QOL-Teen (Waters et al., 2013) and the newly establish QOLQ-ACP, the questionnaires maintain vast similarities. Questions regarding the individual's thoughts on having CP and the impact of the disability, as well as questions within the themes of "online communication," "life achievements," and "community access," are maintained throughout all surveys. With that, the "part" titles within the QOLQ-ACP are very like those presented in the CP QOL-Child and –Teen (Waters et al., 2013), except for the "part" titled, "School," which was removed, the newly modified "Friends and Family," from "Family and Friends," and the newly added "Self-Identity." The "parts" within the QOLQ-ACP are as follows: "Self-Identity," "Friends and Family," "Participation," "Communication," "Health," "Special Equipment," and "Pain and Bother." Similarly, the phrasing of the questions is identical, as each question in the QOLQ-ACP begins with "how do you feel about...," except for several questions that begin with "are you..." or "how much...," which is also seen the CP QOL-Child and CP QOL-Teen (Waters et al., 2013).

The differences presented within the themes, and in turn, the questions in the QOLQ-ACP were implemented to establish a more accessible and relevant QOL survey to adults with CP. Specifically, these questions are targeted towards an adult audience that is attending a CP program, as the interviews were conducted with clients at this facility. However, due to the reliability and validity of the CP QOL-Child and CP QOL-Teen (Waters et al., 2013), numerous similarities in the questionnaires remained to maintain a sense of credibility, regardless of the target population.

Discussion

The life of an adult with CP is complex and unpredictable, yet simultaneously simple and routine. The severity of the impairments they must endure, such as reduced coordination, disturbances in cognition and communication, learning disabilities, and more (Carlon et al., 2010) may interfere with their ability to maintain a high quality of life. Yet, to be truly certain that such physical and mental issues limit their QOL in any way, it is essential that researchers ask the adults with CP directly. Assuming or inquiring through another source about their perspective of their QOL may result in an inaccurate measurement, as these individuals opt to be involved in conversation having to do with themselves (Hemsley et al., 2009). Researchers, such as Davis et al. (2013), have created a way to communicate directly with children and teenagers with CP by administering QOL assessments that determine whether they maintain a low or high quality of life, and in turn, that determine what is most important in the life of a child or adolescent with CP. Although conclusions have been made that adolescents with CP tend to be more concerned with their future and independence (Davis et al., 2013), similar, definitive conclusions have yet to be made for adults with CP as a QOL assessment does not exist for this population. Through the administration of the newly established QOL tool, The Quality of Life Questionnaire for Adults with Cerebral Palsy (QOLQ-ACP), individuals working with adults with CP can finally measure their QOL.

Domains of Quality of Life

The WHO ("Quality of Life", 2018) introduced four QOL domains that are thought to be universal to all people, regardless of whether a person lives with a disability. The aspects of three of the four domains, Physical Health and Independence, Social Relationships, and Environmental Factors, have been more-so researched in relation to how significant they are to the QOL of an adult with CP, while that of Psychological Well-being, Spirituality, and Religion has seemingly been overlooked by researchers. The current study confirmed or rejected many of the assumptions of what is important within the life of an adult with CP made by Strauss et al., Carlon et al. (2010), Turk (2009), and Mitchell et al (2006). In addition, the preliminary discussions of the importance of sexual and romantic relationships, hygiene, (Maestro-Gonzalez et al., 2018) and overall health (Turk, 2009) in the life of an adult with CP were further investigated. In this way, these aspects of the domains of QOL introduced by The WHO ("Quality of Life", 2018) that had not been entirely explained by previous research, or that had not been introduced by previous research at all, were validated in the process of creating an adult QOL questionnaire.

Physical health and independence

The research presented by Turk (2009) was confirmed as participants did not find their overall health to be of major concern, yet they were still worried about their future and what was to come of their physical health. Many participants opted not to speak about their future as it was extremely upsetting to them; instead, the majority explained they like to "take one day at a time". In this way, their perception of the progression of their overall health as they age did not seem to impact their feelings about their current health status. Yet, questions about how one feels about his/her overall health and future should be asked to an adult with CP, as it was clear that their responses were indicative of the satisfaction with his/her life. In addition, Becker and Schaller's (1995) discussion of why it is so difficult for adults with CP to promote their health was confirmed;

> *"Participants in the current study felt passionate about discussing such a topic, as the majority described themselves as happy regarding their self- perception, as well as having positive attitude."*

participants in the current study elaborated on the claim that it is challenging to find doctors who “specialize in treating adults with severe cerebral palsy” (39) by explaining that such caregivers are too busy and force the adult with CP to wait a long period of time before being helped. Although this research was already telling of how adults with CP felt about their overall health and their promotion of health, the research merely introduced by Strauss et al. (2004), Carlon et al. (2010), and Turk (2009) was built upon.

The assumption that a decline in function forces adults with CP to lead a life consisting of low activity and participation restrictions, which will in turn, reduce their over QOL (Carlon et al., 2010) was rejected by the participants spoken to in the current study. Functioning was found to be extremely important to adults with CP, as most participants answered that they were happy with their ability to move their arms, hands, and legs. Thus, their participation restrictions were seemingly not a consequence of their decline in function, but rather, their access to activities and companionship to participate in these activities with. In addition, Turk (2009) found that adults with CP attempt to manage their pain independently, which is an action that is assumed to decrease QOL, as it can be daunting and challenging when pain becomes severe. However, many participants in the current study revealed that, although they may attempt to cope with or control their pain or discomfort when possible, with stretching or physical exercise, they are fully aware and take advantage of the resources they have for help when they need more assistance. In this way, depending on the individual being asked, pain and discomfort may not reduce one’s QOL in such a dramatic manner; it has become a major aspect of the lives of adults with CP because of their increasing impairments. Thus, they must quickly learn how to effectively cope with and control such pain and discomfort in any way they can so that they remain satisfied and comfortable.

Social relationships

Romantic and sexual relationships is one of the only aspects of social relationships that has been studied in relation to adults with CP. However, brief findings related to other aspects of social relationships were presented by Maestro-Gonzalez et al. (2018). Researchers found that “‘interpersonal relationships,’ ‘personal development,’ and ‘social inclusion’ were the most important factors for QOL” (Maestro-Gonzalez et al., 2018, p. 10) of adults with CP, whereas “‘material wellbeing’ and ‘physical wellbeing’ were the least” (Maestro-Gonzalez et al., 2018, p. 10). These results were reiterated in the present study, as participants were found to give more in-depth, elaborated responses to questions relating social relationships, rather than physical and material health. This is not to say that the latter is insignificant in determining the QOL of an adult with CP, but patterns were found in relation to participants being more-so concerned with the individuals they do or do not interact with when needing physical care, for example, rather than the need for the physical care itself. In addition, Maestro-Gonzalez et al. (2018) found that higher QOL in adults were associated with having a current sexual relationship. Unfortunately, in the current study, none of the participants were involved in sexual relationships, and only one participant was involved in a romantic relationship that did not involve sexual interactions. In fact, any conversation of sex made this participant extremely uncomfortable. Because of this, it is difficult to conclude whether a current sexual relationship is indicative of a higher QOL for adults with CP from this sample of participants. However, Maestro-Gonzalez et al. (2018) findings that participants’ “reports feeling love by most people to him or her” is correlated with having the highest mean QOL scores is consistent with the findings of the current study. Many of current participants explained that, although they were content with not having a significant other, they feel they would be much happier in life if they had one, or even had the chance of meeting someone worthy of an intimate relationship.

Psychological well-being, spirituality, and religion

The QOL domain of Psychological Well-Being, Spirituality, and Religion in relation to adults with CP has been understudied, and yet the current study revealed that it is extremely significant in the lives of these individuals. King et al. (2000) have provided some of the only research presented on these aspects of life, as they reported that adults with CP associated success with "being believed in, believing in yourself, and being accepting by others (belonging)" (King et al. 2000, p. 743). Although being believed in and accepted by others more appropriately falls into the domain of "Social Relationships", believing in oneself leads to a more positive attitude and self-perception, which were two themes found during data analysis. However, these themes warranted the creation of a new "part" in the questionnaire called "Self-Identity", as they relate to the person, rather than that person's friends and family. Participants in the current study felt passionate about discussing such a topic, as the majority described themselves as happy regarding their self-perception, as well as having a positive attitude. In addition, participants were positive regarding what they have achieved in life; they were happy with their accomplishments and either felt as though they discuss them an adequate amount or would even like to discuss them more frequently. However, more specific questions about their psychological well-being were deemed necessary, as believing in themselves can also imply accepting themselves for who they are. Thus, questions like, "how do you feel about having CP", for example, seemed to be essential in determining whether they believed in themselves and were satisfied with their lives, as these individuals often identify themselves with the characteristics or the name of this disease, and understand they must accept their circumstances to move forward in life.

Environmental factors

There is limited research on the aspects of Environmental Factors in the lives of adults with primarily CP, but Mitchell et al. (2006) reported several findings regarding the effect employment or unemployment on adults with CP and similar diseases. However, Mitchell et al. (2006) solely reported that employment is more easily attainable for those with disabilities who have completed a college education. Although this may be true, the findings give no insight as to whether being employed or unemployed impacts the QOL of an adult with CP. The current study reveals that many adults with CP consider their CP program to be their occupation, as it provides them a facility to attend each day where they can participate in routine activities. This was described as very beneficial for most participants. However, some participants also expressed their frustration with their inability to maintain a real, "paying" job, due to the interference of government benefits. With that being said, it is important to inquire about how the employment status of an adult with CP makes him or her feel, regardless of whether having a college education gives the individual more of an ability to maintain a job.

Similarities between Children and Teens with CP & Adults with CP

The significant aspects of the domains explained above are not all solely specific to adults with CP, as they have been translated into questions asked to children and teens with CP in the CP QOL-Child and –Teen (Waters et al., 2013) to determine their QOL. Some of the most important aspects of life that children, teens, and adults with CP share are their thoughts on having CP, as well as their satisfaction with their social interactions, successes in life, physical functioning, and the impact of their disability. Although previous research may show that adults with CP are more focused on the frequency of their participation in activities, rather than whether they are physically capable of participating in such activities (King et al., 2000 & Maestro-Gonzalez et al., 2018), all populations nonetheless desire to function at their highest ability to be successful in what they do, and ultimately participate in the activities they enjoy. In the same way, the CP QOL-Child and –Teen (Waters et al., 2013) ask questions related to the acceptance of others, as well as the verbal reactions of others, which were found to be major talking points of the participants in the current study. Many participants felt happy about the way they were generally accepted by other adults but were simultaneously frustrated and upset with the way other people communicate with them, as it was more-so reactionary to their disease. This, in turn, shows the relevance of the impact of CP on all populations, as it not only affects their social relationships, but also the physical aspects of their bodies as they share some of the same pain and discomfort that come because of this disease. Lastly, because children, teens, and adults with CP all share the same diagnose, inquiring about their thoughts on CP may be of utmost importance when attempting to determine their QOL. This question is present in both versions of the CP QOL (Waters, et al., 2013) and has been proven significant from the research presented by King et al., (2000) and from the personal responses of the participants in the current study; they shared that living with this disease has simply become their way of life.

Moving Forward

The administration of the QOLQ-ACP must be done by an individual who has ample prior experience working with adults with CP, as well as by one who thoroughly understands the data collection and scoring process. Through the process of creating this questionnaire, there were several notes made to ensure future success during interviews and administration of the survey, as adults with CP maintain specific needs that must be tended to when halting their daily routines for a period of 30 minutes to an hour. With that being said, it is important for the individual being interviewed to stay on topic, which can be achieved in several ways. For example, taking short breaks for walks or simply leaving the room in which the interview is taking place was found to refresh the mind of the adult participant with CP, as it allowed them to have a brief mental hiatus. Similarly, soothing music with scenic visuals, specifically found on YouTube, was found to be beneficial when participants became frustrated or upset when asked a certain question, or while they were answering a specific question. Moreover, it is important for the person administering the survey to remain patient and repeat the question if necessary. It was often observed that participants would become lost in their responses, forgetting why they began answering the way they did. Repeating the question will allow the participant to attempt to solely answer the question being asked, rather than go off on a tangent. In addition, adults with CP may be non-verbal, so it is essential that the administrator understands sign language and/or how to interpret communication books, trays, or electronic communication devices, such as iPads, to accurately report responses. Lastly, the administrator must understand and accept that not all the questions will be answered in every interview, but that he/she must encourage the participant to answer any question they can or want. Many participants in the current study opted not to answer certain questions because it was triggering, or was too difficult for them to understand. In the same way, their desired answer may have been too difficult to put into words. With that being said, scores of the QOLQ-ACP will vary across individuals, but it is important to understand how to compare an individual score to the highest potential score of each domain before administration.

As previously presented in the "Results" section, each question is now to be asked on a scale of 1-5, 1 indicating "very sad" and 5 indicating "very happy". The scoring of the questions changed to this 1-5 scale from the 1-9 scale that is currently in the CP QOL-Child and –Teen (Waters et al., 2013), as it was seemingly difficult for participants in the current study to understand the meaning of multiple numbers between 1 and 9. The shorter, more concise scale allows for participants to be aware and understand how they are responding, which, in turn, provides administrators with a more accurate measurement of their QOL. Moreover, to score the QOLQ-ACP, the administrator must calculate the participant's score within each domain and compare it to the total score that the domain can ideally receive. Several questions are reversed scored, which is noted in the completed

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version of the QOLQ-ACP. Once the scores of the participant has been calculated and confirmed, the QOL of the individual can be maintained or worked on to improve each year. In this way, adults with CP can continue to receive a high QOL score, which would be assessed in conjunction with their already established annual evaluation. Thus, the QOLQ-ACP is most appropriately fit for administration within CP programs that evaluate their clients annually, as this study was conducted at a New England Cerebral Palsy agency, with all participants being enrolled in this daily program. It is suggested that after the QOLQ-ACP is administered to clients at the CP program, administrators, ideally program therapists or psychologists, continue their conversations about the numerical responses provided by the participant. This way, in the future, staff and clients can work together to achieve the highest QOL score possible for each adult with CP. This not only aids in the improvement of the CP program to enhance their curriculum in a way that optimally benefits the clients QOL, but it also greatly helps the client medically.

The life expectancy of an adult with CP can range anywhere from 30 to 70 years old, depending on the severity of the condition (Birth Injury Guide, 2018). The numerous impairments associated with CP are often unavoidable and are difficult to improve, and in turn may lead to a life expectancy closer to 30 years of age when considering this range. However, maintaining a high quality of life, or having satisfaction with one's quality of life, often leads to a healthier adult with CP who can achieve a longer lifespan ("Quality of Life", 2018). Unfortunately, "the reverse is also true. Those reporting a level of dissatisfaction in their quality of life, often have health problems and live shorter and less-fulfilling lives" ("Quality of Life", 2018). By administering a QOL questionnaire specific to adults with CP, or in other words, specific to the current and most important aspects of their life, as well as to their age and progression of their disease, longer lifespans and more fulfilled lives can be achieved.

Limitations

Limitations of this study should be considered, as most participants were female, aside from one male. In addition, there was a relatively small sample size and the participants interviewed were only enrolled in a New England agency serving adults with cerebral palsy that consented to participating in this study. Thus, the findings and conclusions presented are solely based on the information provided by the participants interviewed in the study. In the future, it may be beneficial to converse with a larger number of males with CP to inquire about what they believe to be important aspects of life, which could affect their QOL, as well as to other adults with CP, both males and females, at other CP programs. This could allow for the questions presented in the QOLQ-ACP to be confirmed as significant aspects of life to much of the population of adults with CP. With that, the QOLQ-ACP has yet to be psychometrically evaluated. Although this is the ultimate goal, the QOLQ-ACP is not psychometrically sound in its current form, but is accurate to the procedure and participants from this study.

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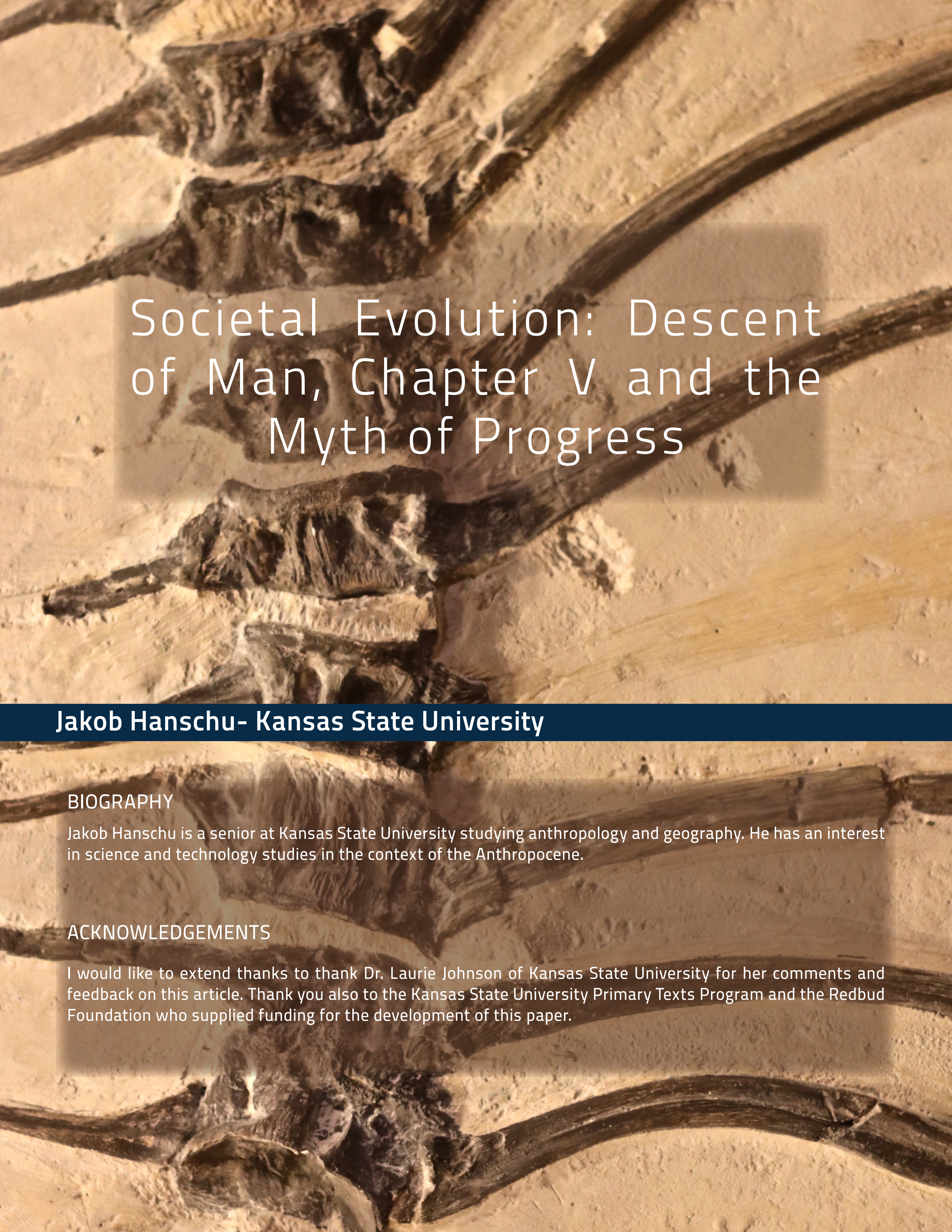

Societal Evolution: Descent of Man, Chapter V and the Myth of Progress

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BIOGRAPHY

Jakob Hanschu is a senior at Kansas State University studying anthropology and geography. He has an interest in science and technology studies in the context of the Anthropocene.

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Summary

In the fifth chapter of *The Descent of Man*, Charles Darwin explicitly argues that humans have undergone moral and intellectual evolution through the centuries. By applying his ideas from *On the Origin of Species* to the non-biological aspects of humans, Darwin added to the conversation about societal evolution that was taking place during his time. These ideas would eventually form into a train of thought termed "Social Darwinism" and influence the mind of Adolf Hitler. Today, ideas about societal evolution manifest themselves in the racist doctrines of the alt-right and the "myth of progress." This review aims to critique the thoughts that Darwin expresses in *The Descent of Man*, Chapter V. However, to do so it must first trace and unravel Darwin's thought.

Introduction

Charles Darwin solidified his place as one of the most influential scientists of all time through his theory of evolution by natural selection (Darwin, 1859). In *On the Origin of Species*, he alluded to future work that would discuss the evolutionary history of humans, "Light will be thrown on the origin of man and his history" (Darwin, 1859, p. 295). *The Descent of Man* was published twelve years later, in 1871. Darwin laid out many ideas in this book, including the extension of his evolutionary theory to the moral and intellectual faculties of humans (Darwin, 1871, p. 152-177). As remarked by Robert Pennock (1995, p. 288), it seems as though Darwin's objective in The Descent was "not to show how we descended, but to show that we descended from lower forms" (emphasis original). Chapter V of The Descent, entitled "On the Development of the Intellectual and Moral Faculties During Primeval and Civilized Times," is an interesting illustration of this (Darwin, 1871, p. 152). Darwin's main thought in this chapter is that individuals and societies with greater moral and intellectual characteristics succeed over those that are less-endowed. Thus, these qualities play a unique role in the evolution of the human species, especially at the societal level, and Darwin argues that levels of morality and intelligence increase through time.

"Darwin's scientific work on evolution greatly affected his thinking about humans and societies, a prime example of the intermingling of science with social conceptions and structures."

Throughout history, scientific discoveries have had considerable impacts on social and political thought; for instance, the findings of Copernicus (Copernicus, 2002 [1543]). As Johann Wolfgang von Goethe stated, "Of all discoveries and opinions, none may have exerted a greater effect on the human spirit than the doctrine of Copernicus" (Hawking, 2002, p. 6). Darwin's Origin of Species illustrated how evolution took place in nature, but over time began to influence social thought as scientists and scholars attempted to extrapolate Darwin's theory to account for social change (e.g., Childe, 1951; Morgan, 1877; Tylor, 1871; Sahlins and Service, 1973):

> The triumph of the theory of evolution and its Darwinian explanation in the late nineteenth century had repercussions in almost every field of thought. Not the least of these followed the application of the Darwinian ideas of competition and struggle for existence to the social life of man. (Etkin, 1964, p. 1)

In Chapter V of The Descent, Darwin too attempts to stretch his theory. Thus, it could be speculated that Darwin's scientific work on evolution greatly affected his thinking about humans and societies, a prime example of the intermingling of science with social conceptions and structures. In a letter to Alfred Russel Wallace, Darwin remarks that "sexual selection has been the most powerful means of changing the races of man" (Darwin, 1888, p. 90-91). Furthermore, in a letter to H. Thiel, Darwin writes that he is highly interested in "observing that you [Thiel] apply to moral and social questions analogous views to those which I have used in regard to the modification of species" (Darwin, 1888, p. 112-113). In the same letter, Darwin discusses that the application of his theory of natural selection to moral and social issues is of high interest to him, though he had not yet considered it.

Intellectual Evolution

Darwin begins Chapter V with a discussion of the development of humankind's collective intellectual abilities, stating that these mental faculties allow humans to "keep with an unchanged body in harmony with the changing universe" (Darwin, 1871, p. 152). He essentially argues that humans' intellectual capacities have allowed them to adapt, or evolve, to a varying array of environments without changes in biology. To illustrate this point, he uses the example of the changes that take place to humans and "lower animals" when they migrate to a colder climate. The human creates shelter, clothing, fire, using its mental capacity to adapt. On the other hand, the lower animal must "become clothed in thicker fur, or have their constitutions altered" (Darwin, 1871, p. 153). Just as animals modify their biological and bodily characteristics to survive, humans utilize their intellect to meet their needs through what Darwin terms "arts," or technologies (e.g., the making of fire, the wheel, computers, etc.). Stated another way, "change and progress" in human civilization "can take place through an invention without any such constitutional alteration of the human species" (Kroeber, 1917, p. 166). Thus, the complex thinking skills of humans allows them to adapt to their environment and efficiently reproduce.

However, Darwin takes his theory one step further, believing that the collective intellectual faculty of humankind has increased through the process of natural selection. He rationalizes, "it is highly probable that with mankind the intellectual faculties have been gradually perfected through natural selection" (Darwin, 1871, p. 154). The argument is that more intelligent "primitive" societies had a competitive advantage over others. These intellectually-endowed "tribes" (as Darwin refers to them) would have been more successful and displaced other "tribes" (Darwin, 1871, p. 154). As these intelligent tribes grew larger and became societies, the trend continued. Darwin uses the growth of civilized societies and the shrinkage of primitive societies as an example, stating that the civilized ones overtake and absorb the primitive ones mainly "through their arts [e.g., technologies.], which are products of their intellect" (Darwin, 1871, p. 154). The society with the smartest members would have an advantage over others, allowing them to out-strategize them in war or out-compete them for resources. This continual process would result in a highly intelligent society that dominates its contemporaries.

Moral Evolution

Darwin explains moral faculties consequently developed from societal self-interest. The idea that virtues derive from individuals seeking their own benefit seems to relate to the writing of James Madison in "Federalist No. 10", where he argues that we should promote public virtue through private vice. Madison believed that "ambitious self-interest" could be used "as the principal security for the public good" (Diamond, 1977, p. 39-72). He reasons that people living in a society will have to acquire certain traits and abilities if they are to meet their personal, selfish ends. For example, as Diamond explains, acquisitiveness, the emphasis on getting—rooted entirely in self-interest—actually

> teaches a form of moderation to the desiring passions from which it derives, because to acquire is not primarily to have and to hold but to get and to earn, and moreover, to earn justly. . . This requires the acquisitive man to cultivate certain excellences (Diamond, 1977, p. 64).

In this way, vice breeds virtue. Darwin's similar position is exemplified where he says that "selfish and contentious people will not cohere," illustrating that individuals have to sacrifice these feelings to be a part of the greater whole (Darwin, 1871, p. 156). He states that early humans "would have felt uneasy when separated from their comrades, for whom they would have felt some degree of love; they would have warned each other of danger, and have given mutual aid in attack or defense" (Darwin, 1871, p. 155-156). He then goes on to credit "the praise and blame of our fellow men" as the "stimulus to the development of social virtues" (Darwin, 1871, p. 157). Humans seek to receive praise and reward and avoid shame and blame. "To do good unto others—to do unto others as ye would they should do unto you—is the foundation of morality," says Darwin (1871, p. 159). He believes that "feeling and being impelled by the praise and blame" of "fellow-creatures" is an animalistic instinct that humans inherited from their earliest ancestors (Darwin, 1871, 158).

> *"Darwin's claim about the origin and development of our morals challenges the validity of what we currently define as moral and immoral, because it is necessarily changeable with times and needs."*

Social learning and experience then perpetuated and further developed moral behavior within societies. Darwin lists courage, loyalty, and sympathetic qualities as virtues in the prehistoric world (1871, p. 156-157). Individuals possessing these virtues would be praised by the other members of their society. Seeing the benefits of acting morally encouraged other members of prehistoric tribes to follow suit. Soon, through experiences, an individual would learn that "if he aided his fellow-men, he would commonly receive aid in return" (Darwin, 1871, p. 157). Thus the continued moral behavior of an individual would be transmitted to other members of the society. "Tribes" with strong moral characteristics would also have an advantage over tribes that lack those traits. For example, Darwin states that when two tribes would come into contact, the one that included more "courageous, sympathetic, and faithful members" would "succeed best and conquer the other" (Darwin, 1871, p. 156). This is because members of that tribe would warn each other of danger and defend each other. This is not to be interpreted to mean that tribes conquered others through compassion, but that tribes that had these moral characteristics functioned better as a social unit, allowing them an advantage over a less-endowed social unit. As tribes continued to interact, "social and moral qualities would tend slowly to advance and be diffused throughout the world" (Darwin, 1871, p. 156).

Many philosophers and biologists disagree with Darwin's "moral evolution" (Weikart, 2004, p. 1-3). Henry Sidgwick, a renowned English philosopher and economist contemporary with Darwin, stated that "the theory of evolution . . . has little or no bearing on ethics" (Sidgwick, 2000, p. 11). Frances Cobbe wrote that the hypothesis of moral evolution is "the most dangerous . . . [that has] ever been set forth" (Cobbe, 1872; quoted in Lillehammer, 2010, p. 362). Lillehammer (2010, p. 365) explains that the reason for such discourse about Darwin's theory is that it "questions the epistemic credentials of our ethical beliefs by pointing out that we would have had very different beliefs if certain things about us had been different, even supposing the relevant ethical facts to remain the same." In other words, Darwin's claim about the origin and development of our morals challenges the validity of what we currently define as moral and immoral, because it is necessarily changeable with times and needs. Several years after Darwin's Descent, Friedrich Nietzsche, in a similar but less subtle manner, would attempt to strip morals of their absolute status (Nietzsche, 1998 [1887]). Dirk Johnson explains that "Nietzsche shares many of Darwin's key insights and agrees with some of his cardinal assumptions—including . . . the natural origins of morality" (2013, p. 333-334). It is known that Nietzsche was aware of Darwin's writings, and it is often assumed that a reading or knowledge of Darwin's Descent of Man influenced Nietzsche's thought; though Darwin is never specifically cited in Nietzsche's works (Babich, 2014; Claeys, 2000, p. 226; Johnson, 2010, 2013). Johnson remarks that Darwin's ideas, more than those of any other scholar, allowed Nietzsche "to become who he was" (2010, p. 2). However, Johnson also notes that Nietzsche's later writings appear to be in opposition of Darwinian thought. Thus, the relationship between the thought of Darwin and Nietzsche remains complicated to this day.

Morality and Intellectual Ability through Time

In his discussion about the intellectual and moral evolution of civilized states, Darwin remarks:

> With savages, the weak in body or mind are soon eliminated; and those that survive commonly exhibit a vigorous state of health. We civilized men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws; and our medical men exert their utmost skill to save the life of every one to the last moment. (1871,p. 161-162)

Darwin here recognizes that civilized states have "checks" against evolution by natural selection: it is no longer the strongest, smartest, or most morally-upright that survive. "The weak members of civilized societies propagate their kind," he continues, clearly seeing the conflict between modernized nations and his evolutionary theory (Darwin, 1871, p. 162). He believes that this is dangerous for humankind, calling it a "degeneration" (Darwin, 1871, p. 162). However, he believes that there is "one check in steady action" preventing humankind from degenerating fully: the weaker or more inferior members of society will not be able to marry and reproduce as freely as the superior members (Darwin, 1871, p. 162).

"Once Darwin's theories became associated with racial prejudices and certain political or colonial agendas, they became the foundation for genocides, race wars, ethnic cleansing, and other similar atrocities"

Darwin realizes that natural selection becomes increasingly complicated once complex societies are formed. Democracy, without a doubt, would only exponentially increase this evolutionary complexity. For example, Darwin claims that moral characteristics that formerly ensured the survival of the "tribe" are undermined in a state-society. Additionally, those individuals possessing the "superior" characteristics may not reproduce more than those "inferior" members of society, quoting Mr. Greg:

> The careless, squalid, unaspiring Irishman multiplies like rabbits; the frugal, foreseeing, self-respecting, ambitious Scot, stern in his morality, spiritual in his faith, sagacious and disciplined in his intelligence, passes his best years in struggle and in celibacy, marries late, and leaves few behind him. (Darwin, 1871, p. 167)

In civilized nations, remarks Darwin, the "inferior, less favored race" would prevail in "the eternal struggle for existence," but that it would do so "by virtue not of its good qualities but of its faults" (Darwin, 1871, p. 168). However, he claims that though these groups would have more offspring, they would remain less successful than the less-numerous but better-endowed groups. His thoughts are exemplified in the following example, in which the Saxons represent the moral and intelligent "race" and the Celts the less-endowed group:

> Given a land originally peopled by a thousand Saxons and a thousand Celts—and in a dozen generations five-sixths of the population would be Celts, but five-sixths of the property, of the power, of the intellect, would belong to the one-sixth of Saxons that remains. (Darwin, 1871, p. 167-168)

From this example, it is evident that Darwin not only believes that the weaker members of society propagate their kind (1871, p. 162), but that the more intelligent, moral, and stronger members do so as well, albeit at a slower rate. The result of this, as evidenced by the Celts-Saxons example, is a small, but powerful, rich, and intelligent class, and a large poor and uneducated class.

As shown in the above examples, modern societies have a more complex relationship to evolutionary processes than prehistoric ones and behave in more complicated ways. Despite this, Darwin continues to stress that morality and intellectual ability among humankind have increased through time. Complete degeneration of mankind is kept at bay because of the "checks to this downward tendency" (Darwin, 1871, p. 168). He pulls examples from "an enormous body of statistics" to show that mortality rates are higher among the uneducated and the immoral. "Men with a weak constitution, ill health, or any great infirmity in body or mind, will often not wish to marry, or will be rejected," Darwin says (1871, p. 169). He concludes: "Obscure as is the problem of the advance of civilization we can at least see that a nation which produced during a lengthened period the greatest number of highly intellectual, energetic, brave, patriotic, and benevolent men, would generally prevail over less favored nations (Halliday, p, 391)."

Social Evolution to Social Darwinism

The last point Darwin looks to make in Chapter V of The Descent is that "all civilized nations were once barbarous," discussing the concept of social evolution (Darwin, 1871, p. 174)—applying his processes of physical (i.e., biological) (Darwin, 1859), intellectual (Darwin, 1871, p. 152-155), and moral (Darwin, 1871, p. 155-161) evolution to societies. Referring to the evolution of nations from "barbarous" to "civilized," he writes, "As we have had to consider the steps by which some semi-human creature has been gradually raised to the rank of man in his most perfect state, the present subject cannot be quite passed over" (Darwin, 1871, p. 174). By first describing the way in which humans developed intellectually and morally, Darwin provides the evidence for how humankind has collectively "progressed." He reasons that if humans have generally progressed through time in their moral and intellectual faculties—descended from primitive ancestors—then civilized societies must also have descended from "primitive" or "less advanced" ones. This analysis mirrors that of cultural evolutionists Lewis Henry Morgan (1877) and Edward Tylor (1871), who both took cultural evolutionist stances to argue that states progressed towards civilization through time.

Darwin's reasoning seems sound, but ulterior motives may have been at play. Interestingly, Darwin resided in Great Britain at a time when it was a powerful empire with many colonies. It was thought that Great Britain was more "evolved" than its colonies—especially morally and intellectually. Thus, his theories may have been used to justify colonial repression of indigenous peoples. A similar strategy was used by Pedro Sarmiento de Gamboa in 1572 (nearly 300 years before the publication of The Descent), who was sent to prehistoric Peru by the Spanish king to illustrate how immoral and unrefined the Incas and other indigenous peoples were, so that the Spanish could justify their colonization. These justifications were common when a colonial power wished to conquer a land and its inhabitants. Darwin's theories of intellectual and moral evolution simply added scientific backing to further justify colonial conquests. More recently, they have been used to justify the structural and institutional violence of laissez faire capitalism (Hofstadter, 1944).

Furthermore, Darwin's nascent claims about moral and intellectual evolution, as well as his work on biological evolution, were combined with the work of others (e.g., Malthus, 1798; Spencer, 1852), and transformed into the movement of Social Darwinism (Claey, 2000; Halliday, 1971; Lillehammer, 2010; Pennock, 1995). Some of these theories were disastrous (e.g., Nazi Germany), while others simply stimulated intellectual debates and critiques. Once Darwin's theories became associated with racial prejudices and certain political or colonial agendas, they became the foundation for genocides, race wars, ethnic cleansing, and other similar atrocities (Halliday, 1971, 391; Weikart, 2004). Robby Kossman's statement provides an example of how Darwin's ideas were further applied to social and ethical spheres:

> The human state also, like every animal community of individuals, must reach an even higher level of perfection, if the possibility exists in it, through the destruction of the less well-endowed individual, for the more excellently endowed to win space for the expansion of its progeny . . . the state only has an interest in preserving the more excellent life at the expense of the less excellent. (1880; quoted in Weikart, 2004, p. 2)

The position taken by Kossman may seem highly provocative, but it was (and is) the common ideology embraced by supporters of Social Darwinism. Perhaps the most disastrous use of Darwin's theory is best exemplified by Adolf Hitler. As Weikart writes, Hitler took on "these social Darwinist ideas, blended in virulent anti-Semitism, and–there you have it: Holocaust" (2004, p. 3).

While working from Darwin to Hitler may seem quite a stretch, recall that Darwin's Chapter V in The Descent explicitly states that some societies are more intellectually, morally, and physically endowed than others, while implying that these societies will succeed and conquer. Hitler embraced Darwin's ideas, writing in *Mein Kampf* that "the stronger has to rule and he is not to amalgamate with the weaker one, that he may not sacrifice his own greatness" (Hitler, 1941 [1939], p. 390). In Hitler's view, the Aryans were the supreme race of the world, and not only could they dominate over other societies, but they should, given their superior nature (Hitler, 1941 [1939], p. 389-455).

"Hitler embraced Darwin's ideas, writing in Mein Kampf that "the stronger has to rule and he is not to amalgamate with the weaker one, that he may not sacrifice his own greatness."

Social Darwinism Today

Social Darwinist thought has made a reappearance in contemporary America through the rise of alt-right groups (Futrell and Simi, 2017). Organizations like American Renaissance state that racism is not detrimental and should be accepted because it has been accepted by Americans throughout most of the nation's history. These organizations claim that their racist attitudes are justified, believing, like Darwin, that intelligence is inherited. This is rooted in alt-right doctrine that "race is foundational to human identity," that you "cannot understand who you are without race" (McConnell, 2016, p. 13). Through this statement, the alt-right hopes to "spur whites into a kind of pan-white racial consciousness and galvanize them to become 'aware of who we are,' and to prepare themselves, one day, somehow, to form an ethnostate" (McConnell, 2016, p. 13). They promote such topics as "race realism" and "white advocacy" (Taylor, 2012, p. 1), while claiming that "multi-racialism has failed" (Taylor, 2006, p. 10). Furthermore, groups like American Renaissance call for closed borders and segregated neighborhoods, and state that there is a dire need to keep races from mixing (Biddle, 2017; Taylor, 2006, 2012). All these claims are rooted in Social Darwinist ideologies that incorrectly correlate intelligence, behavior, morality, and other characteristics with 'race' (Arciniega, 2017; Biddle, 2017; Futrell and Simi, 2017). The Social Darwinism of the alt-right is based on "supremacy and de-humanization of others, and is unacceptable" (Arciniega, 2017, 176).

"The Social Darwinism of the alt-right is based on "supremacy and de-humanization of others, and is unacceptable."

Theories of Cultural Evolution

The idea of a progression of humankind and societies through time could be termed "general cultural evolution" (as opposed to "specific cultural evolution"), the "successive emergence of new levels of all-around development" (Sahlins, 1973, p. 28). When this hypothesis is not linked to racism or other prejudices, it can be quite fruitful for academic analysis and theory (Childe, 1951; Dunbar et al., 1999; Sahlins and Service, 1973; White, 1949). The Australian archaeologist V. Gordon Childe (1951) harnessed Darwin's evolutionary ideas in an attempt to find universal trends in prehistory. Childe concludes that, indeed, there are some general evolutionary trends among cultures, though specifically, the adaptations of those cultures differ dramatically. He also makes a tweak to Darwin's (and Hitler's and Kossman's) theory of social evolution, stating that societies do not need to be "annihilated to make room for a better adapter culture . . . actually this seldom happens" (Childe, 1951, p. 178). Instead cultural assimilation takes place, which merges the innovations, technologies, behaviors, and moral and intellectual faculties of the two societies in contact. This allows for increased and expedited cultural or social evolution as these ideas are combined and the members of the societies adapt to those that are best (Childe, 1951, 178-180). In their book Evolution and Culture, Marshall Sahlins and Elman Service use the terms "specific evolution" and "general evolution" to differentiate between the ways in which societies adapt and evolve (Sahlins and Service, 1973). Their claim is that societies undergo both types of evolution, specifically evolving into their niche in the environment (Sahlins, 1973, p. 23-28), but also generally evolving by improving in "all-around adaptability" (Sahlins, 1973, p. 37). More recently, attempts to "model cultural evolutionary processes . . . have focused mainly on . . . [how] . . . cultural patterns can be expected to change over time" (Knight et al., 1999, p. 2). These analyses remove "the arrow of progress" and center around explaining cultural change as a process. Hypotheses such as those by Childe and Sahlins and Service have received much critique from their respective academic circles. To quote Berthold Laufer, "the theory of cultural evolution is to my mind the most inane, sterile, and pernicious theory in the whole theory of science" (quoted in White, 1973, v). A common criticism of social evolutionists is that they remove human agency from their analysis, eliminating choice and free will (Hodder, 1991; James, 1880). Another is that they simplify culture and do not account for its particular and historical uniqueness (see Boas, 1940).

Darwin's theories of intellectual and moral evolution set the stage for evolutionary-based social thought. The outcomes of such thought have had varied impacts on humankind. We often consider scientific theories to be strange devices employed only in laboratories and applicable only to the natural world. Chapter V of Darwin's Descent of Man shows the immense and far-reaching effects that science can have on humanity. Thoughts, attitudes, and behaviors can all be shifted through scientific discovery, and those theories can be twisted and manipulated to serve a variety of needs. Darwin made an attempt to universalize evolution to show the progress of humankind. The ideal of progress can be stated as "the assumption that a pattern of change exists in the history of mankind . . . that it consists of irreversible changes in one direction only, and that direction is towards improvement" (Pollard, 1968, p. 9). Over time, the notion of progress has served as a driving force in the development of modern societies.

The Myth of Progress

With the advent of postmodernism these conceptions of grand, progression-type narratives and universal "best ways" of doing things have been called into question (e.g., Foucault, 1977; Lyotard, 1984). Ronald Wright has challenged this idea of progress (Wright, 2005, p. 12), of a general evolution among human individuals and societies through time, through his concept of "progress traps, the headstones of civilizations which fell victim to their own success." He states that:

> As cultures grow more elaborate, and technologies more powerful, they themselves may become ponderous specializations—vulnerable and, in extreme cases, deadly. The atomic bomb, a logical progression from the arrow and the bullet, became the first technology to threaten our whole species with extinction. (Wright, 2005, p. 27)

In this way, the atomic bomb, the result of what could be called "progress," represents a horrific "progress trap" (Wright, p. 27). Wright further mentions the "human inability to foresee" as a primary cause for our species' continual falling into progress traps (2005, p. 85). If society could think with a more "future-oriented" perspective, perhaps many of our current problems could be minimized or resolved.

Naomi Klein similarly challenges the common narrative by claiming that capitalism, neoliberalism, and economic growth all need to be replaced if societies are to become sustainable (Klein, 2014). This is not to say that the solutions put forth by Wright or Klein or others are necessarily correct, but that they represent an important step in human history—a reassessment of the validity of the story we have been telling ourselves for centuries. Others ought to do so as well, as critiques of current models of progress and formulation of new and alternate models are much needed.

We ought to accept Darwin's ideas about biological evolution in *The Origin of Species* but reject his hypothesis about social evolution in The Descent. If humankind and its societies have continually advanced, where is the proof? Currently, humans are destroying ecosystems, eliminating biodiversity, acidifying the oceans, polluting the atmosphere, and changing the (previously stable) climate (Crutzen, 2002; Rockstrom et al., 2009; Steffen et al., 2007; Steffen et al., 2015; Thiele, 2016). These changes could "trigger abrupt, unpredictable and potentially irreversible changes that have massively disruptive and large-scale impacts" (Molina et al., 2014, p. 15-16), destabilizing the Holocene conditions that fostered the growth of modern societies (Rockstrom et al., 2009; Steffen et al.. 2015). Moreover, the changes will bring about negative effects on water resources, energy, transportation, agriculture, human health, and ecosystems (Karl, Melillo, and Peterson, 2009; Mitchell, 2011; Molina et al., 2014; Moore, 2015). In short, we have created a precarious present (Haraway, 2016, 55; Tsing, 2015), in which we have disrupted the "mosaic of relations" that have supported modern modes of social life for centuries (Mitchell, 2011; Moore, 2015). If our intelligence has continually made us more inclusively fit, how is it that we continue to destroy and destabilize our environment—our home—despite the known impacts of our actions?

One out of every nine people in the world is hungry, and one out of three is malnourished. More than sixty-five million persons have been forcibly displaced. Numerous minority groups are discriminated against on a regular basis, barred from education and employment opportunities, while other are targets of ethnic cleansing (Jahan, 2016, pp. 29-39, pp. 56-80). Human deprivation is rampant in the world, and while some aid has been given, resources continually end up elsewhere. For example, the United States porn industry has an estimated annual income of more than $13 billion (Szymanski and Stweart-Richardson, 2014, p. 1) and the annual revenue of United States alcoholic spirit suppliers is over $25 billion (Ozgo, 2017). If we as a society have advanced, why are people starving while porn and alcohol industries make billions of dollars each year?

Modern societies continue to fall into a variety of progress traps. Against which parameters do we gauge our "progress"? Though our economic capital continues to grow, other important forms of "capital" including morality and sustainability have been overlooked. We have become focused on economic growth as the single parameter by which to measure "the good life," when "often what is most important in life is precisely what money cannot buy" (Fischer, 2014, 16). Previous conceptions of progress have been critiqued and

> *"If humankind and its societies have continually advanced, where is the proof? Currently, humans are destroying ecosystems, eliminating biodiversity, acidifying the oceans, polluting the atmosphere, and changing the (previously stable) climate."*

dismantled (Foucault, 1977; Klein, 2014; Lyotard, 1984; Wright, 2005). It is high time we put some thought into the "evolution" of our societies, because it is time we change our ways.

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