

#### **Discussions**

Volume 14 | Issue 4 Article 5

#### [Discussions] Vol. 14 lss. 4

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() "[Discussions] Vol. 14 Iss. 4," Discussions: Vol. 14: Iss. 4, Article 5.

DOI: https://doi.org/10.28953/2997-2582.1165

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# DISCUSSIONS Undergraduate Research Journal of CWRU

# **Table of Contents**

# Interview

Faculty Spotlight: Dr. Lee Hoffer

Viral Mistry

## Research

Exploring the Differences Between Bilinguals and Monolinguals in Non-Communicative Spatial Perspective-Taking Tasks

8

Shira Yellin

# Review

An Analysis of Vaccine Hesitancy in the United States: Contributing Factors and Healthcare Response

71

Hannah Kent

Euthanasia: A Cross-Cultural Analysis of Right-to-Die Organizations and Euthanasia Legislature in the Netherlands and United States

33

Anjana Renganathan

# Letter from the Editor

Dear Reader,

Welcome to our newest edition of **Discussions!** 

With this issue of **Discussions: The Undergraduate Research Journal of CWRU**, I am pleased to present three CWRU authors who wrote articles about a range of topics. The authors explore the factors that contribute to the hesitancy to recieve vaccines in the United States, physician assisted suicide in the Netherlands and the United States, and the effect of languages learned on non-communicative spatial perspective taking tasks. These are issues with divisive sides, which is why our cover designer chose to emblazon the cover with a switch, representative of the potential opinions.

We hope you enjoy the breadth of knowledge in this issue and come away having learned something new or viewing the world from a different angle.

The deadline for the next issue will be January 19th, 2018. If you share **Discussions**' passion for celebrating excellent undergraduate research, consider submitting to the journal. Although **Discussions** is based at Case Western, we accept articles from any undergraduate institution. I encourage you to visit our website at **www.case.edu/discussions** for detailed instructions to submit your work. If you have questions, please feel free to reach out to us at DiscussionsJournal@gmail.com. I look forward to hearing from you.

I would like to thank the authors who dedicated themselves to their topics and chose to share their work with us, as well as the entirety of the Editorial Board for the time and effort they give to the journal every semester. I would also like to thank the reviewers, copy editors, and designers. This journal would be nothing without you. The entire Editorial Board is ever grateful for the assitance and guidance from our advisers, Bethany Pope and Sheila Pope, Director of the SOURCE Office. Without their support and encouragement from the SOURCE office, Discussions would never have been able to achieve the successes we have made.

Sincerely,

Monica Windholtz Editor-in-Chief





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# Faculty Spotlight

AN INTERVIEW WITH

# Lee Hoffer

by Viral Mistry

Dr.Hofferis an Associate Professor in the Department of Anthropology and a Professor in the CWRU School of Medicine Department of Psychiatry. In this interview, he discusses his research background, his take on the opiate epidemic, and the ways we discuss illicit and illegal drugs.

This interview has been edited for length and clarity with Dr. Hoffer's consent.

# Could you start by telling us about the research you've been doing, and what your focus is on campus?

Since I started work in 1993, I've been interested in substance use disorder, and how people who are not in treatment use drugs. I work primarily on "hard" drugs, like heroin or cocaine, but I've also done studies on club drugs, study drugs, and inhalants. I'm a medical anthropologist, so my primary methodology is ethnography. In ethnographic research, we go out into the field, talk to people in their natural environment, understand their lifestyle, and let them be the experts. We also observe what is happening around them. In the nine years I've been working at CWRU, I've primarily focused on the opiate epidemic, specifically on heroin use, and how things are changing with that, but also generally on how people understand their use and what their daily life is like.

#### What got you into this field of study?

I wish there was this grandiose story behind it, but the truth is, when I was in graduate school, one of my professors told me about research project that was looking for a survey interviewer. They were working on HIV prevention research, interviewing active users about their risk behaviors. I did that, and I found it really interesting, and I found talking to the users to be the most interesting. It felt



really genuine, the conversations were really free-flowing, and it cemented my desire to do anthropology research. The thing that still keeps me going is the people I meet. There's a lot of media that demonizes drug users; that they're all dangerous and violent. But most of

"There's a lot of media that demonizes drug users; that they're all dangerous and violent. But most of the people I meet are nothing like that, and it's working with them that keeps me wanting to keep doing this work and inform the public and the scientific community."

the people I meet are nothing like that, and it's working with them that keeps me wanting to keep doing this work and inform the public and the scientific community.

#### What are you currently working on?

In the last 15 years or so, I've focused on collecting qualitative data on drug use, usually from fairly personal interviews that I get only after spending time building a rapport with

people. In the last few years, I've focused on presenting that data in different ways. I use a complex-systems theory approach, trying to understand the interactions as they move from a micro to a macro level. To do this, I create agent-based models, where the agents represent users or dealers or all different roles, who interact with other agents, and we look at all of them interacting together. I'm currently working on a grant on trying to use this modeling approach to get a better sense for the demand for opiates. I ask questions like how is the market changing around the distribution of the drug, or the use of the drug? So basically, I create computer models of drug markets.

# So when you are trying to understand this network, you do so by talking to people, and understanding them?

Basically, yes. When you think and learn about an economy or a market, the appropriate literature is rarely focused on the activity of individuals. They are applying models on a set of assumptions. Here, we are talking to people about their interactions, and use that as a way to reproduce the model in a computer. For example, an important question in drug markets is access. If I were to tell you to try and go buy heroin, it's gonna be much harder for you than if I told you to go buy groceries. And for heroin, it's similar to how people buy marijuana; people access it from people they know who use the drug. We often see that users buy drugs from other users, who are buying from other users or from dealers. So we look at these relationships, and we build a network to understand consumption.

So you focus on the illegal heroin market, but the key problem in the current opiate epidemic has been the intersection of that illegal market with the legal, prescription opioid market. Can you talk about that?

So two years ago, I sat on a National Academies panel discussing that very topic, and from that

came a report, titled Pain Management and the Opioid Epidemic: Balancing Societal and Individual Benefits and Risks of Prescription Opioid Use. We were trying to go from understanding pain diagnostically to the opiate epidemic. It's a very complex topic, but essentially, as a response to medical trends, there has been an overprescription of opioids, something that was reinforced by both consumer groups and consumers. After all, if you're in pain, and I've got a pill that can make it go away, you are going to want the pill, right? This got out of control, for various reasons that are outlined in the report, and we ended up with an enormous number of people who were using an enormous number of opiate medications. Many of these people have serious, chronic pain issues, but the problem is these medications are not efficacious long-

"If I were to tell you to try and go buy heroin, it's gonna be much harder for you than if I told you to go buy groceries."

term, because people develop a tolerance to them. So a lot of the people I've been meeting here, since I moved here in 2008, have already moved from prescription opiates to heroin. Heroin is cheaper and it kills their pain more effectively. Since then, there have been changes that further promote heroin. For example, when you clamp down on opioid prescriptions, some of those people will switch to heroin. The data shows only about 3% of opioid users will switch to heroin use, but since the number of people with prescriptions was so large, that 3% grew exponentially. Since the population has grown so much, we see that even heroin isn't enough, and we see the use of much more potent derivatives of heroin, like fentanyl and carfentanil. Unfortunately, these drugs are being mixed with heroin without the user realizing it, which is rapidly increasing the mortality rate for overdose. The wide variation in the large market is causing that.

This is clearly a complex issue, but have you been involved with any attempts to change policy, or are you more focused on understanding the issue at hand?

So the report I co-authored has about a dozen policy recommendations in it, as it was commissioned by the Food and Drug Administration. It is a good example of how my research on the street can influence policy. But it is hard to make policy changes, because there are a lot of stakeholders involved. If you make one change in one part, it can have many effects all over the place. For example, you can try to cut down on prescriptions of opiates, in the long term that will be helpful, but in the short term that can create problems. There have been pushes for more medication-assisted treatment, and I'll all for that, but there are a lot of users who are not

"My perspective is that harm reduction is the most important feature of solving this problem. Needle exchanges, safe injection rooms, we really have to push the envelope to make a connection with people who aren't going to just walk into a clinic."

interested in treatment, so what do you do for them? My perspective is that harm reduction is the most important feature of solving this problem. Needle exchanges, safe injection rooms, we really have to push the envelope to make a connection with people who aren't going to just walk into a clinic.

# What would you say to a student interested in anthropology research, who wants to learn more?

Take my anthropology methods class! I also teach an illegal drugs in society class, where we cover all major illegal drugs. I think it's important for students to be educated on these topics; college age students have been taught a lot of misinformation about drugs, from the D.A.R.E. program to the media they consume, to the nightly news. Having that basic knowledge is really important, even if you aren't going to go into it any further, and if you are, that's where you start. I've had students contact me, telling me they are interested in this topic because it has affected their friends and family. First, you need to get educated, and then figure out what part of the problem you want to tackle. There are a lot of different topics to tackle, and students can and do help.

#### A Selection of Lee Hoffer's Work

(2017) McKay V, Dolcini M.M., Hoffer L. The Dynamics of De-adoption: a case study of policy change, de-adoption, and replacement of an evidence-based HIV intervention. *Behav. Med. Pract. Policy Res.* doi:10.1007/s13142-017-0493-1

(2016) Hoffer, LD. The Space Between Community and Self-Interest: Conflict and the Experience of Exchange in Heroin Markets. The Economics of Ecology, Exchange, and Adaptation: Anthropological Explorations Research in Economic Anthropology. (36):167-196. ISSN: 0190-1281/doi:10.1108/S0190-128120160000036007.

(2012) Hoffer LD, Bobashev G, and Morris RJ. Simulating Patterns of Heroin Addiction within the Social Context of a Local Heroin Market. (In) Computational Neuroscience of Drug Addiction. Gutkin & Ahmed (Eds.) New York: Springer.

Exploring the Differences Between Bilinguals and Monolinguals in Non-Communicative Spatial Perspective-Taking Tasks

#### Shira Yellin - Case Western Reserve University

#### **BIOGRAPHY**

Shira Yellin is a fourth year student at Case Western Reserve University. She is in a dual degree program, and will earn both a Bachelor of Arts degree in Cognitive Science and a Master of Arts degree in Bioethics. She is involved in CWRU Emergency Medical Services, and hopes to have a career as an emergency medicine physician.

#### **ACKNOWLEDGEMENTS**

I would like to thank Dr. Fey Parrill for advising me throughout the research and writing process.

#### Introduction

While there is much evidence to demonstrate that bilinguals have an advantage in certain types of cognitive tasks, social scientists have long been debating how far this advantage extends. This study seeks to determine if a bilingual advantage is present in spatial perspective-taking tasks that do not involve communication. Perspective-taking is part of a broader category of cognition known as theory of mind (ToM) (Baron-Cohen, Tager, Flusberg, & Cohen, 2000). ToM includes the mental tasks of keeping someone else's beliefs in mind, and the spatial tasks of taking someone's perspective based on their physical location. Bilinguals have been shown to outperform monolinguals in both mental and spatial ToM tasks. Tversky and Hard (2009) showed that individuals will sometimes take another person's perspective, even if they are not directly communicating with another person. Their original study did not take into account the participants' language status (i.e. monolingual or bilingual). This study seeks to extend the work of Tversky and Hard to determine if bilinguals are more likely than monolinguals to forgo their own perspective.

#### Literature Review

#### Theory of Mind

ToM refers to the ability to understand that different people have different mental states. Mental states include thoughts, beliefs, ideas, and knowledge (Pylyshyn, 1978). One hallmark of ToM is the ability to distinguish one's own mental state from another's (Keysar, Lin, & Barr, 2003). Wimmer and Perner (1983) tested the development of this ability in children using the story of Maxi and his chocolate. Researchers used a paper cut-out of a child to represent Maxi. In this story, Maxi placed a bar of chocolate into a cupboard labeled X. When Maxi left the room, represented by the cut-out being removed from view, the children were told that his mother had moved the

chocolate from cupboard X to a different cupboard, Y. This was shown with the researcher moving the chocolate from one box to another on a wall that had been set up for the experiment. Participants were then asked where Maxi would look for the chocolate when he returned. Individuals who possess ToM will understand that even though they know the chocolate is in cupboard Y, Maxi still believes that it is in cupboard X so he will look there for the chocolate. In other words, individuals with ToM are able to consider Maxi's false beliefs and understand that he has different knowledge than they do. Participants without a developed ToM will say that Maxi will look in cupboard Y, since they know that this is where the chocolate is, and cannot understand that Maxi has a different set of knowledge than what they know to be reality. A meta-analysis of studies conducted on ToM acquisition confirms that it develops around the age of four (Wellman, Cross, & Watson,

"...even though adults have ToM, they do not automatically use it."

2001). Once children develop ToM, they are able to use this ability throughout their lives. However, even though adults have ToM, they do not automatically use it. This means that they still make mistakes when attempting to adopt another person's perspective (Keysar et al., 2003). In a 2003 study, Keysar et al. used a box array setup in which some squares in the array were occluded from the director, the individual running the experiment, and other squares were visible to both the director and the participant. In this case, the participant believed the director was also participating in the study. An example of such a setup can be seen in Figure 1. One of the occluded slots contained a roll of tape in a paper bag. The participant knew the contents of the bag and that the director did not know the contents of the bag. During the experiment, the director gave a critical instruction to "move the tape," referring to a cassette tape that both the director and participant could see. However, 71% of participants attempted to move the paper bag by grabbing or reaching for it in at least one of the four critical trials.

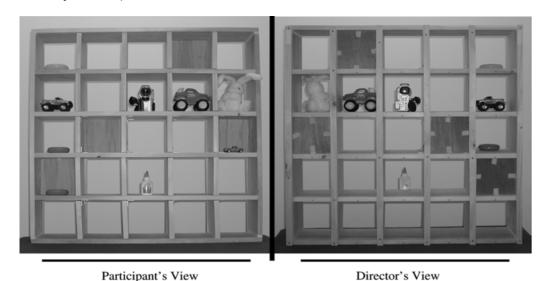
Epley, Morewedge, and Keysar (2004) furthered this line of research by using a similar procedure to directly compare adults and children. They found that both adults and children had the same initial egocentric tendency to look at objects that only they could see. This is because, even as adults, individuals still use their own knowledge as a guide to understanding the knowledge of others (Keysar, 1994). However, the adults were able to more quickly correct their initial egocentric observation and look toward the mutually observable object. These results further bolster the idea of egocentric primacy, and support the claim that adults overcome egocentrism each time they take another person's perspective, rather than becoming less egocentric overall (Shelton & McNamara, 1997; Nickerson, 1999).

ToM is an important ability for adults to have as it allows them to understand another person's behavior. Additionally, having ToM allows individuals to act cooperatively and altruistically because they understand the needs of others (Moore & Frye, 1991). Failure to em-

ploy ToM causes different interpretations of situations, leading to miscommunication and conflict (Pronin, Puccio, & Ross, 2002). Due to the importance of ToM in social interactions, it is necessary to gain a better understanding of what causes someone to use their ToM. Schober (1995) found that when someone is asked where an object is, their answer often favors the perspective of the person who asked. These scenarios involve direct communication between two people.

"...both adults and children had the same initial egocentric tendency to look at objects that only they could see."

Tversky and Hard (2009), on the other hand, wanted to study the likelihood that an individual would take another's perspective, even if they were not communicating with that person. They showed participants one of three photos of a table with a bottle and a book (Figure 2). In one photo, there was a person reaching for a book. In the second photo, there was a person looking at the book. In the third photo, there was no person. Participants saw the photo as part of a set of unrelated questionnaires. All participants, re-



**Figure 1.** An example of a box array setup where some objects seen by the participant cannot be seen by the director (Epley, Morewedge, & Keysar, 2004).

10

#### EXPLORING THE DIFFERENCES BETWEEN BILINGUALS AND MONOLINGUALS

gardless of condition, were asked the same question: "In relation to the bottle, where is the book"? The researchers found that when shown one of the first two photographs, participants were significantly more likely to take the person's perspective, compared to the photo that had no person. However, there was no significant difference in perspective-taking between the two scenes with a person in them. Our study builds upon Tversky and Hard's findings, adding a condition for bilingual individuals, as there is much research to support that bilinguals have an advantage when faced with ToM tasks.

#### Bilingual advantage

Much research has been done to show that bilinguals have advantages on a number of different ToM tasks. Bilinguals are believed to have an advantage in both spatial and mental tasks. One type of task in which bilinguals outperform their monolingual counterparts is appearance-reality tasks, wherein an object is purposely made to look like something else as with the sponge-rock task. In this task, children saw a sponge painted to look like a rock. Most children believed it to be a rock until they felt it and noticed that it was a sponge. The experimenter then asked them what another observer who had not touched the object would think it is (Bialystok & Senman, 2004). In a similar experiment, bilinguals were more likely than monolinguals to correctly answer the experimenter's question (Goetz, 2003). Additionally, bilinguals have been found to

perform better in unexpected transfer tasks as in the aforementioned story of Maxi and his chocolate (Kovacs, 2009). Bilinguals also have an advantage in global reaction times on conflict resolution tasks (Donnelly, Brooks, & Homer, 2015). Most relevant to our study, researchers have shown a bilingual advantage in perspective-taking tasks (Greenberg, Bellana, & Bialystok, 2013). In this study, children were shown an array of four blocks of different colors. An owl, acting as an observer, then appeared at one of three positions, 90°, 180°, or 270° from the child's view of the blocks. Children were asked to choose, from four points of view provided by the researchers, how the owl saw the blocks (Figure 3). The results showed that bilinguals outperformed monolinguals in determining the correct answer for all three positions.

In addition to research on the evidence of a bilingual advantage, there are also studies which seek to determine the cognitive basis for the advantage. The three most robust lines of research focus on metalinguistic awareness, inhibitory control (i.e., the ability to ignore distracting information), and sociolinguistic competence. Metalinguistic awareness, or the awareness of properties of language, is increased in children who are bilingual (Cummins, 1978). This confers many advantages to bilinguals such as the ability to make syntactic judgments and a greater sensitivity to feedback in communication tasks (Galambos & Goldin-Meadow, 1990; Ben-Zeev, 1997). Additionally, bilinguals are more aware





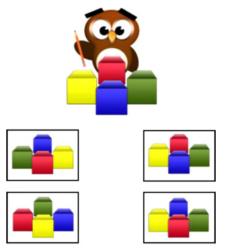


**Figure 2.** The three photos that Tversky and Hard used in their experiment for the three different conditions: reaching (a), looking (b), and no person (c) (Tversky & Hard, 2009).

of the arbitrary nature of the connection between words and referents (Ianco-Worrall, 1972). The utility of this line of research lies in investigating the connection between the bilingual advantage, metalinguistics and metarepresentation.

ToM tasks are related to metarepresentation, which is the idea that the same object can be represented in different ways by the same person or different people (Doherty 2000; Flavell, Green, & Flavell, 1986). Bilinguals are accustomed to the idea of metarepresentation through their metalinguistic awareness. Being able to express the same thought in different ways shows children that there are different ways of representing language(Vygotsky, 1962). Because bilingual children are aware of the idea of dual representation in language, they are theoretically more suited to outperforming monolinguals in ToM tasks, which require the knowledge that one thing can be perceived in different ways (Goetz, 2003).

By virtue of speaking more than one language, bilinguals develop greater inhibitory control, which aids in their performance on ToM tasks. Inhibitory control involves focusing on relevant information and ignoring competing or distracting information (Bialystok, 2006).



**Figure 3.** Children have to choose which picture correctly shows what the blocks would look like from the owl's point of view (Greenberg et al., 2013).

"Being able to express the same thought in different ways shows children that there are different ways of representing language."

There are two levels of inhibitory control in which bilinguals engage: the higher level involves involves selecting one language and inhibiting the other, and the lower level involves activating lexical forms for the selected language and inhibiting the competing forms in the non-selected language (Green, 1998). Bilinguals have many opportunities to practice these skills, and if this practice helps bilinguals with their general ability to focus on necessary information, then it would stand to reason that bilinguals would have an advatage in inhibitory control over monolinguals (Paap & Greenberg, 2013). In fact, bilinguals have been shown to have greater control over their selective attention (Bialystok, 1999). Inhibitory control is related to performance on false-belief tasks in which bilinguals have an advantage (Carlson & Moses, 2001). Bialystok and Codd (1997) further explain that inhibitory control is most useful in situations where there are salient distractions, conflicting rep resentations, or ambiguity. These factors are generally present in ToM tasks, suggesting that bilinguals with greater inhibitory control would outperform monolinguals, who have not developed these skills to the same extent.

One final line of research suggests that the bilingual advantage arises from an individual's sociolinguistic competence because bilingual children need to be aware that their partner may not speak all of the languages that they do (Genesee, Boivin, & Nicoladis, 1996). Even children as young as one and two years old make language choices depending on the language their interlocutor speaks, and bilingual children rarely make mistakes in selecting what language to use in a particular situation (Lanza, 1992; De Houwer, 1990). Further, bi-

#### EXPLORING THE DIFFERENCES BETWEEN BILINGUALS AND MONOLINGUALS

lingual children have been found to use their mother's native language when speaking to their mother and their father's native language when speaking to their father. This occurs even if both parents are in the room and conversing with the child (Genesee, Nicoladis, & Paradis, 1995). These situations show that bilingual children understand that different people have different perceptions. This benefits bilinguals in ToM tasks because they are more aware than monolinguals that people can have different mental states (Goetz, 2003).

In addition to the different theories on the origin of bilingual advantage, there is also debate as to whether or not a person's spoken language and cultural origin affects their ToM development. Some researchers believe that ToM development is universal and that it develops similarly across cultures (Leslie, Friedman, & German, 2004; Sabbagh, Xu, Carlson, Moses, & Lee, 2006; Tardif & Wellman, 2000; Vinden, 1999; Callaghan et al., 2005; Liu, Wellman, & Tardif, 2008). With these two different theories come many studies to support each side. One study showed that Chinese subjects performed better than American subjects in perspective-taking tasks as they were less likely to fixate on privileged objects (Wu & Keysar, 2007). Researchers hypothesized this result was due to Chinese collectivist culture, in which individuals put the needs of their in-group, such as their family or community, above that of their own (Wu & Keysar 2007; Hofstede, 1983). It has also been shown that Chinese and Western participants have equivalent egocentric interference, but Chinese participants were able to quickly and ef-

"Even children as young as one and two years old make language choices depending on the lanquage their interlocutor speaks..." fectively suppress this interference (Wu, Barr, Gann, & Keysar, 2013). One study took a group of English-Mandarin bilinguals and primed them with either Chinese, Western, or neutral photographs of nature (e.g., a photo of Superman for Western priming). They found that within the primed group of individuals, those who experienced Western priming made more errors in following a director's instructions to move objects in a boxed array in which some boxes were only visible to the participant (Luk, Xiao, & Cheung, 2012).

"...even if being a monolingual from a collectivist culture conferred an advantage ... the idea of a bilingual advantage would still hold."

Supporting the opposing theory, Mainwaring, Tversky, Ohgishi, and Schiano (2003) found that Japanese and American participants were similar in their perspective-taking. used the addressee's perspective if the addressee had the higher cognitive burden and tried to use landmarks or cardinal directions if available. Goetz (2003) compared English monolinguals, Mandarin monolinguals, and English-Mandarin bilinguals on ToM tasks to ensure that neither monolingual group had the same advantage as bilinguals. She found that both monolingual groups had the same performance on the tasks and that both were outperformed by the bilingual group. Currently, both theories have robust empirical support, and no consensus has been reached on whether ToM development is constant across cultures.

Based on the current literature, there are still unanswered questions regarding the scope of the bilingual advantage. Research on culture as a confounding variable shows one area in which there is still ambiguity. More explicit-





**Figure 4.** (a) Scene used in the "person" surveys. (b) Scene used in the "no person" surveys. (Tversky & Hard, 2009)

ly, all of these studies focus on bilinguals who speak English and an East-Asian language. This means that researchers have only been focusing on bilinguals with strong connections to a collectivist culture; even if being a monolingual from a collectivist culture conferred an advantage over monolinguals from

individualistic cultures, the idea of a bilingual advantage would still hold from these results. There are many bilinguals who speak languages that are not tied to a specific culture, such as Spanish, or languages that are tied to individualistic cultures. For this reason, studies on the bilingual advantage can still be conducted despite the unanswered question of the role of culture. Other areas that require further study include the effects of bilingualism on mental versus spatial tasks and on communicative versus non-communicative tasks. While this experiment will not be able to fully explore all of these areas, it will explore an area that has not yet been studied in depth, the effect of bilingualism on non-communicative spatial perspective-taking tasks in bilinguals from a non-collectivist culture. This study seeks to discover if bilinguals from a non-collectivist culture are more likely than monolinguals to adopt the other's perspective even when not communicating with the other person, and not explicitly asked to take their perspective into account.

#### Methods

#### Surveys

Participants completed one of four surveys. For all surveys, participants were shown an image (Figure 4) and asked the question, "In relation to the book, where is the bottle"? Two

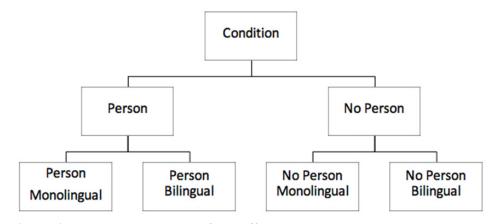


Figure 5. Diagram showing the four different surveys utilized in the study.

#### EXPLORING THE DIFFERENCES BETWEEN BILINGUALS AND MONOLINGUALS

of the surveys had photographs that showed an individual sitting at the table with the book and bottle, facing the participant (Figure 4(a)). The other two surveys showed the same table and room but without another person (Figure 4(b)). Within each set of two surveys, one other survey created with questions specific to monolinguals and the other with questions specific to bilinguals. Therefore, the four surveys were classified as follows: person monolingual, person bilingual, no person monolingual, and no person bilingual (Figure 5).

In the surveys for monolingual individuals, participants were asked questions about other languages they may speak to confirm their monolingualism. In the surveys for bilingual participants, bilingualism was confirmed by having the participants translate from Spanish to English and respond to a question asking if they have been speaking both English and Spanish since early childhood.

#### **Participants**

A total of 691 responses to the four surveys were recorded via Amazon's Mechanical Turk (MTurk). MTurk was used to collect data as internet surveys in general have been shown to be consistent with data collected from traditional methods (Gosling, Vazire, Srivastava, & John, 2004). Additionally, MTurk specifically is useful for obtaining high-quality data both quickly and inexpensively (Buhrmester, Kwang, & Gosling, 2011).

The bilingual-specific survey was conducted on individuals who are bilingual in English and Spanish. Spanish was chosen because it is one of the most convenient languages to target for translation in MTurk as there are many Spanish-speaking workers who provide quick and accurate translations (Pavlick, Post, Irvine, Kachaev, & Callison-Burch, 2014). Another reason Spanish was chosen is due to its lack of association to one specific culture. Spanish is spoken in many countries with various cultures, which mitigates any potential

cultural bias. Had the study been conducted with bilinguals whose language is spoken mainly in one country, such as China, it would have been unclear whether the bilingual advantage was influenced by collectivist Chinese culture as some studies have suggested (Wu & Keysar, 2007).

#### **Exclusion criteria**

Responses were excluded if survey responses satisfied any of the enumerated criteria.

- Monolingual exclusion criteria were met when
  - a)subject spoke another language "moderately" or "very fluently";
  - b)subject learned a second language in childhood;
  - c)subject stated they lacked fluency in a second language but responded from a nation where that language is used.
- Bilingual exclusion criteria were met when
   a)subject failed to provide correct, complete English-to-Spanish translations
   of assigned sentences. Clear, English explicative translations were accepted;
   b)subject has not been speaking fluently English and Spanish since the age of four;
  - c)subject became fluent in either language outside of upbringing (e.g., classes, YouTube);
  - d. subject has used language other than English or Spanish since childhood.
- General exclusion criteria were only met when
  - a)subject provided blank or incomplete answers;
  - b)subject provided nonsense responses.

After excluding data, there were a total of 59 respondents to the no person monolingual survey, 53 respondents to the person monolingual survey, 17 respondents to the no person bilingual survey, and 17 respondents to

the person bilingual survey.

#### Results

Participant responses were scored as either self, other, or neutral depending on whether they gave their answer from their own point of view, the other person's point of view, or did not use left/right terminology. In situations where participants gave two points of view, their answer was scored based on the first point of view with which they responded. Examples of answers scored as self included, "The book is to the right of the bottle" and "about two book lengths to the right of the book." Examples scored as other included, "The book is on the table to the left of the bottle" and "To the person's left." Examples of answers scored as neutral include, "The book is nearby to the water bottle on the desk" and "On the table, about eighteen inches away from the bottle." Five participants were excluded for giving answers that could not be coded into any of the three categories such as, "On the guy's right hand side." This participant seems to be taking the other perspective, but the book would actually be on the left hand side of the man in the photograph.

The responses were then translated into three binary variables. The first variable was coded as a one if the response was the self perspective and a zero if it was not. The second variable was coded as a one if the response took the other perspective and zero if it did not. The third variable was coded as one if it was neutral and zero if it was not. The coding

system used for this study is identical to the one used by Tversky & Hard (2009). However, our study also coded the neutral responses as a binary variable to be analyzed, which the 2009 study did not do.

Three separate two-factor analyses of variance (ANOVAs) were conducted to compare the main effect of the independent variables, language status and condition, and the interaction between them on the dependent variable of perspective taken by the participant. Language status was either bilingual or monolingual and condition was either a survey with a person or a survey with no person. One ANOVA was run for each of the three perspectives: self, other, and neutral. The numbers of each group, means, and standard deviations can be found in Table 1.

For the self perspective, a main effect for language status was found, with monolinguals taking the self perspective significantly more than bilinguals F(1, 142) = 5.31, p < 0.05. No main effect for condition, F(1, 142) = 2.13, p = 0.15 was found. There was also no significant interaction between the two variables Language Status\*Condition F(1, 142) = 2.13, p = 0.15. For the other perspective, there were no significant main effects for Language Status, F(1, 142) = 0.48, p = 0.49, or Condition, F(1, 142) = 2.51, p = 0.12. Additionally, there was no interaction effect for Language Status\*Condition, F(1, 142) = 0.003, p = 0.95. For the neutral perspective, there was a main effect of Language status, F(1, 142) = 4.00, p < 0.05. However, there was no main effect of

**Table 1.** Number of participants in each group, means, and standard deviations.

Language Status	Condition	Sample Size	Self Mean (SD)	Other Mean (SD)	Neutral Mean (SD)
Bilingual	No Person	17	0.41 (0.51)	0.18 (0.39)	0.41 (0.51)
	Person	17	0.41 (0.51)	0.29 (0.47)	0.29 (0.47)
Monolingual	No Person	59	0.76 (0.43)	0.12 (0.33)	0.12 (0.33)
	Person	53	0.49 (0.51)	0.25 (0.43)	0.26 (0.45)

#### EXPLORING THE DIFFERENCES BETWEEN BILINGUALS AND MONOLINGUALS

Condition, F(1, 142) = 0.03, p = 0.86, and no an interaction effect for Language Status\*Condition, F(1, 142) = 2.66, p = 0.11. In addition to the three ANOVAs, an analysis that considers only Condition, and not Language Status, was run. These results are trending toward significant, F(1, 144) = 3.75, p = 0.055.

#### Discussion

The results of this study indicate that regardless of condition (person or no person), bilinguals are significantly less likely than monolinguals to use the self perspective, and significantly more likely to use the neutral perspective. Interestingly, the same results as Tversky and Hard (2009) were not observed in these ANOVAs. Tversky and Hard (2009) found that when shown a picture with a person, participants were more likely to take the other perspective as compared to when shown the picture without a person. Our results showed no statistical significance for condition in any of the three perspectives. However, by looking only at the effect of condition, a near significant effect was observed, even with a low observed power (0.49).

While this study did produce statistically significant results for Language Status for two perspectives, there are improvements that can be made to increase the statistical power. Due to both the unequal sample sizes between monolinguals and bilinguals and the small sample sizes of the bilingual groups, the observed power for the analyses was very low. For example, in the main effect that was found for language status in the self condition, the observed power was 0.63. For the non-significant effect of language status in the other condition, the observed power was 0.11. Future studies could mitigate this problem by restricting IP addresses to places that do not speak a language other than English or Spanish as their national language. For example, many responses were recorded from individuals in India, who would be expected to speak a language other than English and Spanish,

even if they also spoke both these languages. Restricting participants in the survey may result in more usable answers and therefore a higher number of participants. Additionally, future researchers could include more questions to verify a participant's language status. This could vary from having more translation questions to asking where they were born or what languages their parents speak.

The significant results that were found in this study add to the already robust repertoire of tasks to which bilinguals respond differently than monolinguals. The study was designed to see if the bilingual advantage found in spatial perspective-taking tasks extends to non-communicative tasks. We tested this hypothesis by seeing if bilinguals were more likely than monolinguals to take an observer's perspective, even when not asked or member of a non-collective culture. The original advantage was that bilinguals could more accurately convey an observer's perspective (Greenberg et al., 2013). The results provided evidence that the bilingual advantage in perspective-taking extends to tasks that do not involve direct communication. This is important because it upholds previous research done on bilinguals, thus helping to solidify the idea of the bilingual advantage. None of the previous studies focused on bilinguals' performance in non-communicative spatial tasks; this study opens up the possibility for further research into this area.

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18

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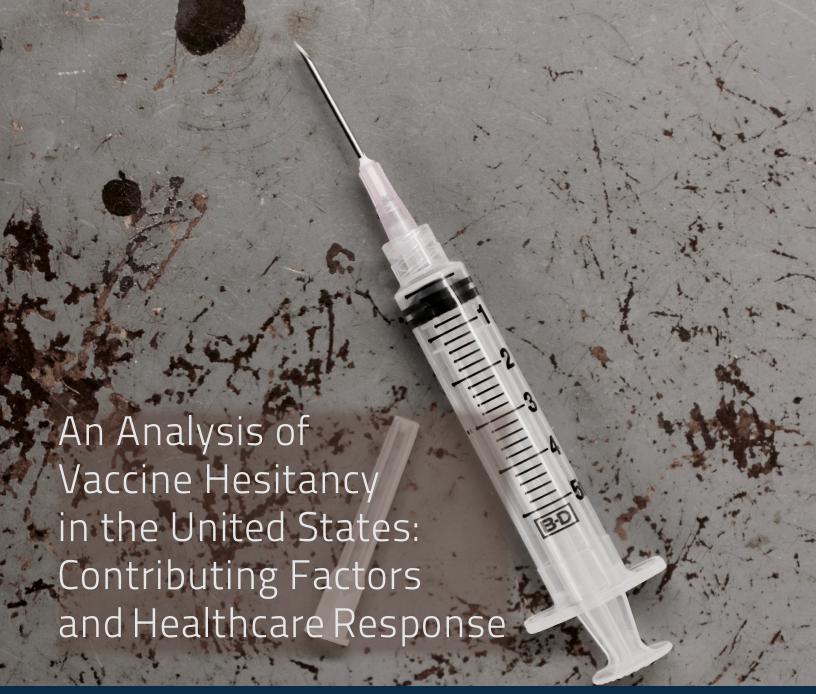
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# Hannah Kent - Case Western Reserve University

#### **BIOGRAPHY**

Hannah Kent is a fourth year undergraduate in cognitive science at Case Western Reserve University and will be pursuing a Master of Arts in Bioethics. Hannah hopes to go on to complete a doctorate in Ethics and work with institutions and organizations on real-world dilemmas concerning health and public policy.

#### **ACKNOWLEDGEMENTS**

I would like to thank Dr. Janet McGrath for her exceptional class on medical anthropology. I would also like to thank Dr. Vera Tobin for her support in my studies.

#### Introduction

Before the advent of vaccines, diseases such as diphtheria, pertussis, measles, mumps, rubella, and chickenpox were extremely prevalent worldwide and impacted the health of many, including the vulnerable populations of children and the elderly. Now, vaccines provide a safe and effective method of protecting the population from a number of highly infectious diseases, making them uncommon in developed nations such as the United States (Chen et al., 1994). However, recent levels of vaccination have dropped, due to vaccine hesitancy, which is described as real or perceived concerns of vaccine-adverse events among parents in the developed world, making them unwilling to vaccinate their children (Sadaf, Richards, Glanz, Salmon, & Omer, 2013). Ironically, due to their widespread success, vaccines may lead parents and caregivers to underestimate the severity of the diseases vaccines prevent. Additionally, modern pathways of information dissemination can portray a skewed picture of rare cases where vaccines show adverse effects, as well as inaccurate information about the contents and effects of vaccines in general (Connolly & Reb, 2011; Sadaf et al., 2013; Brown et al., 2010; Edwards, Hackell, Committee on Infectious Diseases, & Committee on Practice and Ambulatory Medicine, 2016). These, and other aspects, influence public and individual understanding and attitudes toward vaccines, leading some parents to refuse vaccinating their children (Hendrix, Strum, Zimet, & Melsin, 2015). While a majority of caregivers do choose to vaccinate, the small subset of those who do not can majorly affect the health of the general population by reducing protective factors of herd immunity (Connolly & Reb, 2011). This work explores the history of vaccine refusal, important factors that contribute to vaccine hesitancy and refusal, reasons why parents are hesitant, the factors that influence their behavior, the response of physicians and healthcare professionals, the role of public

health and ethics, and the ways in which anthropological contributions can affect the discussion by making recommendations for future research and tangible solutions.

"...real or perceived concerns of vaccine-adverse events among parents in the developed world..."

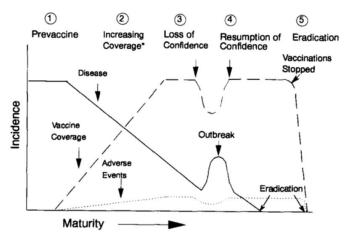
# Analysis of disease incidence and vaccine uptake in the lifetime of a vaccine

Chen et al. (1994) analyzes a timeline of events that outline disease incidence, vaccine uptake, adverse events, and the way the population perceives a vaccine throughout the stages of its introduction (Figure 1).

- **Stage 1:** No vaccine exist and disease incidence is high.
- Stage 2: Vaccine is introduced and its implementation increases. As a result, incidence and prevalence of the disease decreases.
- Stage 3: Marked by a reduction of confidence in vaccines. The probability that an adverse event is associated with vaccines in a causal rather than a temporal relation increases, even if the association lacks scientific evidence (Chen et al., 1994).
- Stage 4: Salience of the importance of vaccines and confidence in vaccines increases.
- **Stage 5:** Eradication of the disease since there are no available hosts and there is no more risk of contracting the disease.

Reaching the fifth and final stage indicates that the population no longer needs to be vaccinated as the disease is no longer a threat. However, in most cases, the disease will not be eradicated from the world, and vaccination will need to continue indefinitely. As the authors note, public acceptance of immunization is at risk when adverse events

are linked to vaccines, either by coincidence or as a legitimate negative consequence of immunization (Chen et al., 1994). This framework and understanding of the public opinion and its interaction with the public health intervention of vaccines is crucial in analyzing the anti-vaccine movement (Chen et al., 1994).



**Figure 1.** Stages 1-5 outline the relative incidence of disease associated with the maturity or life of the vaccine. Peaks and valleys of disease incidence are driven by factors such as public opinion and favor of the vaccine as well as recent outbreaks (Chen et al 1996).

One important caveat to note is that there is a difference between attitudes and behaviors regarding vaccinations (Hendrix et al., 2015). One may vaccinate and still be hesitant about the effects and efficacy of the vaccine, and one may have positive attitudes about vaccines and yet not vaccinate due to lack of access to care; neither situation is driven by the caretaker's beliefs. This is important when considering that there is a spectrum of beliefs on vaccination. In fact, many parents are not entirely polarized to one end or the other; the decision to vaccinate is an involving process and has many factors that may interact with one another, so solely analyzing the resulting action is only a partial picture of the vaccine controversy (Brown et al., 2010). Even those who do choose to vaccinate and have generally positive attitudes on vaccination may still have reservations.

"...the decision to vaccinate is an involving process and has many factors that may interact with one another..."

#### The decision-making process

As with many complex medical decisions, vaccination can be a difficult and involving process. Brunson (2013) studied the behavioral patterns of parents in the process of making vaccination decisions and found that there are different stages of decision-making, as well as different tactics for addressing each state. Firstly, in the awareness state, the actual decision-making begins, and parents start to think about vaccination. The second state is assessing, when parents analyze vaccine-related issues. This state contains the most variation in decision-making tactics; parents break out into three 'general assessment groups' including acceptors, who generally accept social norms but tend to be uninformed due to lack of exploration; reliers, who depend on their social networks for information and direction but tend to be uncritical of the received advice; and searchers, who are aware of social norms but do their own research and continually assess different perspectives while being critical of the sources (Brunson, 2013). Assessment may occur on a continuum as the decision-making process can lead to accepting vaccinations or rejecting them as well as delaying the vaccine schedule. Each decision process results in one of these three options for every available vaccine. At the conclusion of the decisionmaking process, there are still options for future action: the parent can either lapse into stasis where the parent's decision remains the same: reassess their decision, where the parent's decision can transition from not vaccinating to vaccinating or vice versa; or continually assessing the situation (Brunson, 2013). Now that the decision-making process has been outlined, it is important to explore

what factors affect these decisions and understandings in the first place.

#### Why parents hesitate or refuse

Parents act on the basis of their perceived best interests for their children. However, when acting on false or skewed information, their perception of best interest may be unrealistic. Some parents are concerned about the pain of immunization, which can easily be addressed with certain techniques and distraction tools, while others are unsure of the effects vaccines are speculated to be associated with, a pervasive idea that cannot necessarily be eradicated (Edwards et al., 2016). Specific concerns also differ by vaccine as the HPV vaccine was thought to trigger early sexual activity, while the MMR vaccine was feared to be linked with autism and developmental disorders (Edwards et al., 2016). While there are some obvious contributions to the antivaccine movement, such as the Wakefield et al. (1998) study, other underlying factors are important to consider and serve to portray a more informed account of the reasons for vaccine hesitancy. Of these include structural and political factors, the role of popular culture, and the crucial interaction of webbased resources on vaccine decision-making.

#### Recent outbreaks due to low vaccine uptake

Recent outbreaks include measles, mumps, whooping cough, and chickenpox, to name a few. In the case of measles, which has been vaccinated against since 1963, there were 668 cases across 27 states in 2014; this is an extreme amount considering that measles were classified as eradicated from the United States since 2000 (Medscape, 2015a). In January of 2015, there was an outbreak of measles in California, a state with both religious and ideological exemptions for vaccination, wherein about 3.1% of kindergarteners had a non-medical exemption. The vaccine for whooping cough has been available since the 1940s, and yet annual incidence has actually

increased since the 1980s with outbreaks every three to five years (Medscape, 2015a; 2015b). Traditionally, vaccines were mandated requirements for school and childcare centers (Edwards et al., 2016). However, with the rise of the anti-vaccination movement, there have been more policies that allow non-medical exemptions, including religious and ideological objections.

"...with the rise of the anti-vaccination movement, there have been more policies that allow non-medical exemptions..."

Reasons for low vaccine uptake include but are not limited to: general side effect and safety concerns, poor perception of vaccine effectiveness and importance, false belief that vaccines cause autism, personal and others' experiences of vaccines and vaccine adverse events, preference for and belief in safety of single vaccines, false belief in the danger of immune overload, thinking about vaccine in advance of it being due, and a general belief that children receive too many shots (Brown et al., 2010). In many cases, these factors result in nonmedical exemptions which are highly utilized. Rates for nonmedical exemption in states that allowed philosophical exemptions were 2.5 times higher than states that only allowed religious exemptions (Omer, Richards, Ward, & Bednarczyk, 2012). The main themes of the specific philosophical exemptions include vaccine safety, lack of necessity of vaccines, and freedom of choice (Edwards et al., 2016).

# Structural and political factors in vaccine hesitancy: advocates of bad science

Some structural factors include the policies surrounding vaccination and action taken by public health organizations in response to the rise in vaccine hesitancy. Non-medical exemptions reinforce the belief that personal

choice and autonomy in medical decisionmaking is more important than regulated public health policy, especially when those exemptions are due to ideological stances that are based in false or skewed information. As one would expect, increasing the options obtaining nonmedical exemptions increases the likelihood of parents obtaining exemptions for their children (Sadaf et al., 2013). Additionally, some actions can imply the legitimacy of certain claims; after Brian Deer reported that thimerosal in vaccines contributed to autism spectrum disorder, a claim since proven false, there was a significant increase in vaccine hesitancy and refusal (Rao & Andrade, 2011). The uproar concluded in the removal of thimerosal from all but the influenza vaccine (CDC, 2015). This action only validated the disproven science and detracted from the public's views of the safety of vaccines.

Political factors include the involvement of many prominent political figures. In March of 2014, then-businessman Donald Trump posted on Twitter, "Healthy young child goes to doctor, gets pumped with massive shot of many vaccines, doesn't feel good and changes - AUTISM. Many such cases" (Trump, 2014). Dr. Ben Carson, a pediatric neurosurgeon that ran for the Republican nomination for president in 2016, made his stance on the issue unclear when asked to refute Mr. Trump, vaguely referring to science and evading a solid stance in either direction (Miller, 2015). This public discussion contributed only conflicting information, often politicizing the issue and eliciting emotional responses without addressing real concerns with valid science.

The most prominent study indicating that vaccines could have extremely adverse effects was the 1998 Wakefield study. Lancet published the study that suggested that the MMR vaccine had a causal role in behavioral regression and a pervasive developmental disorder, ultimately suggesting that the

vaccine predisposed children to autism spectrum disorder (Wakefield et al., 1998; Rao & Andrade, 2011). The paper had an unusually small sample size, and was eventually found to have been unethically performed; the General Medical Council noted that Wakefield acted "dishonestly and irresponsibly" and that the methods of the study were done with "callous disregard for the distress and pain" the children suffered from procedures that were "against their best clinical interest" (Triggle, 2010). The study was initially retracted by 10 of the 12 original authors, and in February of 2010 the journal retracted the paper due to inaccurate science (Rao & Andrade, 2011). Eventually, Wakefield was found guilty of ethical violations, scientific misrepresentation, and deliberate fraud for money, as it was discovered that Andrew Wakefield had been funded by lawyers engaged in lawsuits against companies that produce vaccines (Rao & Andrade 2011). This was an incredibly influential study and vaccination rates dropped even after its retraction. Many studies since have disproven the proposed causal link, but the Wakefield study is still cited as a main argument against vaccines.

# The role of popular culture in vaccine hesitancy

Popular culture is an inescapable aspect in the interplay between parental decision making and vaccination. Famous opponents often take to the media in spreading their viewpoints, while scientific and researchbased sources are often centralized in scholarly journals or federal websites. Jenny McCarthy is perhaps the biggest name in the anti-vaccination movement, although she prefers the term 'pro-safe vaccine.' She expressed in an interview that she suspected '[the] compilation of so many shots to a kid that obviously [has] some autoimmune disorders" contributed to the development of her son's autism diagnosis (Frontline, 2010). The New Yorker took offense to the ABC show, The View, for hiring McCarthy as a host,

accusing the network of giving her a "regular platform on which she can peddle denialism and fear to the parents of young children who may have legitimate questions about vaccine safety" (Specter, 2013). Alternatively, Mark Zuckerberg, founder of Facebook, posted to social media that he was vaccinating his daughter in a subtle attempt to promote vaccination (Alter, 2016). People with a platform can either affirm or denounce the anti-vaccination movement and the claims of its spokespeople, portraying a public debate as relatively two-sided, while the scientific argument is in favor of vaccination.

#### The role of web 2.0 in vaccine hesitancy

McCarthy also expressed the use of the internet in assessing her son's circumstance:

Google is one of the most incredible breakthroughs that we have today. Yes, it can scare a lot of patients, thinking we're all dying because we look up something on Google. But there's also a lot of anecdotal information from parents, firsthand accounts of what they did for their own child (Frontline, 2010).

In fact, access to first-hand accounts is an extremely important factor when making decisions, as personal anecdotes from other concerned parents are more powerful persuaders than statistics and symptoms of diseases prevented by vaccines. Online, antivaccination videos have a significantly higher prevalence of personal stories, including video montages of normal children apparently regressing into autism after vaccination, interviews of people who themselves claimed to have suffered following vaccination, and parents of affected children coming forward with their experiences (Venkatraman, Garg, & Kumar, 2015). In an effort to utilize the same emotional appeal, pro-vaccination

and anti-anti-vaccination websites such as JennyMcCarthyBodyCount.com, use scare tactics to portray how many preventable deaths have resulted from the anti-vaccination movement (Bartholomaus, 2015). Both viewpoints utilize modern technology and the ability to quickly share information via the internet.

The internet has played a major role in information dissemination and affects the vaccine discussion more than most other factors. Firstly, the internet enables the shifting emphasis of decision-making authority, as the physician's credentials and reliability are undermined by the widespread availability of fast information (Venkatraman, Garg, & Kumar, 2015). One study analyzed the interaction of the internet, specifically Web 2.0, in vaccine views. Web 2.0 refers to websites that feature a lot of user-generated content, even from non-credentialed sources such as YouTube and Wikipedia, and is highly connected with the idea of freedom of speech (Venkatraman, Garg, & Kumar, 2015). In an analysis of four web sources, YouTube, Google, Wikipedia, and PubMed, authors found that the more freedom of speech allotted in the source, defined by the likelihood that posts would be kept on the site and available to be seen, the more hits correlated with anti-vaccine views specifically with regard to the vaccine-autism controversy (Venkatraman, Garg, & Kumar, 2015). In some ways, the increased freedom is beneficial and makes health communication more accessible, but the authors also noted that the unchecked nature of web-based sources "diluted the voice of science in the public arena" (Venkatraman, Garg, & Kumar, This is increasingly important as refusing vaccination is often due to beliefs

"...the internet enables the shifting emphasis of decisionmaking authority..." formed from false information or lack of understanding of vaccines (Hendrix et al., 2015). Their findings suggested that editorial control could contain and restrict inaccurate and alarmist information, extending to a media that is required to pass editorial review (Venkatraman, Garg, & Kumar, 2015).

#### How Physicians Respond: Ethics

Clinical and professional ethics such as the ideals of distributive justice, autonomy, nonmaleficence, beneficence. and involved in responding to families that refuse to vaccinate (Hendrix et al., 2015). There is a constant conflict between the ability of the parents to deny care, and the responsibility of the physician to enforce actions that achieve the best health outcomes for their patient. Distributive justice weighs the benefits and burdensofthoseinvolvedinthesituation. While it is beneficial to respect the ideals and values of the parents, it is generally more beneficial to consider the health of the population in terms of herd immunity. Herd immunity is the reduction of disease carriers, which results in the overall protection of the community, including vulnerable populations who may not be able to protect themselves; when herd immunity is not compromised, benefits of protection extend to those who cannot be vaccinated, are immunocompromised, are undergoing chemotherapy, or have incomplete vaccination status. There is a very real danger for highly transmittable diseases like measles, which needs a 96-99% vaccination rate to achieve maximum herd immunity, undermining the argument that a small portion of unvaccinated children are harmless to public health (Hendrix et al., 2015).

Maintaining the effect for the common good requires that every eligible community member get vaccinated and mandates can be effective in this goal (Hendrix et al., 2015; Sadaf et al., 2013). Contrasting distributive justice is the individual's right to autonomy. Individuals

are capable of making their own decisions, and in the case of dependents, parents and guardians retain the ability to make decisions for those that they are responsible for. If the guardian so chooses, they are able to deny care for the dependent, just as they are able to accept treatments. Mandatory vaccine laws would infringe upon this right. Lastly, the medical principles of beneficence and nonmaleficence, two fundamental values of the health care profession, are also at play. Physicians must weigh the risks of allowing individual patients and families to go unvaccinated for that particular family and for the population.

Care providers should be available and open to discussing specific parental questions about vaccines, including the production, composition, and effects. However, addressing families' concerns can be an involving and time consuming process that many physicians may not be able to afford. Two ways to navigate this issue are for physicians to schedule longer appointments to individually address parents' concerns, or omit the discussion and concede to the parent's preference to defer, delay, or skip vaccines in the recommended schedule (Edwards et al., 2016). Consequences of these actions include suboptimal care from a delayed vaccine schedule, the need for multiple care visits which can be difficult for some families, and a compromised herd immunity. decision lies with the physician.

Some physicians address these dilemmas by dismissing ideologically based vaccine-refusing families from their practice. While dismissal is technically legal, regulations vary from state to state and often require official notification, information for finding a new physician, and obligatory continued care for a reasonable period. This decision is not one to be made lightly, and some practice settings may limit the possibility of dismissal including in areas where there is limited access to care or insurance restrictions (Edwards et al.,

2016). A compounding factor is the increased density of unvaccinated individuals into fewer waiting rooms, exacerbating their risk for contracting vaccine-preventable diseases (Costill, 2015).

Additionally, the physician is often the only medical professional that parents can consult in their decision-making process. Refusing to

"While it is beneficial to respect the ideals and values of the parents, it is generally more beneficial to consider the health of the population in terms of herd immunity."

see the family not only damages the physicianpatient relationship, but also restricts the availability of scientifically sound information (Edwards et al., 2016).

Physicians who do not dismiss vaccinehesitant families have a number of options to navigate the parents' understanding of vaccinations and subsequently their ultimate decisions. Physicians continually remind themselves that most vaccine-hesitant parents are not opposed to vaccinating their children, but do need reassurance and guidance about issues surrounding vaccination such as the complex schedule and the number of vaccines required. Physicians may take a presumptive strategy, where they assume compliance to vaccination and act as though the decision has already been made to vaccinate, rather than opening discussion; research has shown that presenting vaccination as a required treatment encourages the majority of parents to vaccinate their children (Edwards et al., 2016). The presumptive approach may lead to less resistance among parents as they no longer have to undergo the decision-making

process. The physician may also utilize the participatory or the guiding approach wherein, respectively, the physician either solicits the family's input on whether or not to vaccinate or addresses the parent's specific concerns by assuming an active role in the decision to vaccinate (Hendrix et al., 2015).

# Input from the American Academy of Pediatrics

The American Academy of Pediatrics (AAP) has a stance on the treatment of anti-vaccine families. Initially, they discouraged refusing care, instead insisting on dialogue between physicians and families to reach a middle Every encounter with vaccinehesitant parents is an opportunity to express the importance of vaccination, potentially determining the result of their vaccine decisions (Hendrix et al., 2015). As Edwards and Hackell (2016) note, "the single most important factor in getting parents to accept vaccines remains the one-on-one contact with an informed, caring, and concerned pediatrician" (p. 7). Personal anecdotes of vaccine success are crucial, and physicians can share their own experiences with families regarding the safety, importance, and efficacy

"...the most vaccine-hesitant parents are not opposed to vaccinating their children, but do need reassurance and guidance..."

of vaccines. However, recently, the AAP has altered their stance to include an acceptance of the refusal of patients as last resort. They continue to recommend initiating dialogue but concede that individual physicians are the most appropriate actors to ultimately decide for their practice. Furthermore, the AAP strongly recommends against deviating from the current vaccine schedule, but situational deviation is acceptable if it is the only route

to immunization after all other reasonable attempts to convince hesitant parents (Edwards et al., 2016). Other contributions the AAP notes include refraining from vaccine deferral and eliminating all non-medical exemptions for vaccines—a position concurrent with the American Medical Association and the Infectious Diseases Society of America (Edwards et al., 2016).

# Anthropological approach to monitoring policies and effectiveness

Anthropology can play an important role in navigating the anti-vaccine movement in public health and public policy. Policymakers should analyze non-medical exemption policies and consider how they would affect families, practitioners, and communities if there were to be a mandate for vaccines. Considering that there are different requirements due to state-based regulations,

"...the AAP strongly recommends against deviating from the current vaccine schedule, but situational deviation is acceptable..."

research could be conducted on the influences that different policies have on the population. Given that 47 of the 50 states have personalbelief exemptions, there may be insights that anthropological viewpoints can supply in the effort to vaccinate (Hendrix et al., 2015; Haelle, 2016). California has removed the option of ideological exemptions, and the ramifications of this amendment should be carefully examined. Research must target how parents assess vaccination, their own knowledge, attitudes, beliefs, and levels of hesitancy (Brunson, 2013).

# Re-evaluate how to address hesitancy and analyze proposed solutions

Research is unanimous in the view that a onesize-fits-all approach to vaccine interventions is inappropriate (Brunson, 2013; Connolly & Reb, 2011; Edwards et al., 2016; Hendrix et al., 2015). Instead, public health officials and health care workers must identify and address specific, overarching factors in vaccine hesitancy. To do so, anthropological work can clarify the structural, political, and interpersonal factors contributing to vaccine hesitancy and apply the data to frameworks that focus on the role of the caretaker and the influence of decision-making practices in medicine. Demographics of vaccinehesitant families are also useful, but should be analyzed further to include social influences as prevalence seems to vary by geography. For instance, highly-educated white families are more likely to refuse, even though research has shown that lack of education about vaccines can contribute to hesitancy (Edwards et al., 2016). Anthropologists could reveal other concurrent factors that explain this seemingly incongruent phenomenon.

Training on communication and guidance healthcare professionals regarding vaccine-hesitant parents is another proposed intervention as physicians are effectively at the front lines of the controversy. Currently, only 55% of practitioners routinely explain the possible adverse effects and the rationale behind vaccines, but nearly half of the hesitant families accept vaccination after this discussion (Opel et al., 2013). While training physicians to communicate with their patients is vital, the importance of vaccines in the process of medical training itself should be reiterated. Recent graduates are less likely to believe in the safety and effectiveness of vaccines than senior practitioners (Edwards et al., 2016). Medical professionals in training must be educated on the value, safety, and efficacy of vaccines in order to express this to

patients. The anthropology of public health can address the medical training system to identify the reasons behind the sentiments of recent graduates, highlight areas in which the training system may be improved, and study the culture of the healthcare system itself.

The internet will also be an important tool in addressing vaccine hesitancy. Examining the ease of access, freedom of speech, and lack of reliable information that parents find on the web is crucial. The relative novelty of this access can be met with anthropological approaches to studying culture. The internet has a culture of its own, and emulating the types of information pools that vaccinehesitant parents interact with or identifying ways to portray the validity of internet-based information would be extremely useful. For example, while Edwards et al. (2016) found that web-based vaccine hesitancy interventions were largely ineffective and may actually increase misconceptions about vaccines, Venkatraman, Garg, & Kumar (2015) propose the use of user-generated sites that are similar to Wikipedia pages but which are moderated by experts in the field; this could be a possible compromise between freedom of speech, quality, and accurate information. Connolly and Reb (2011) propose a tri-level software decision aid that includes ways for users to explore a decision tree that they navigate to receive an action recommendation. In order

"Alterations to policy should be careful to ensure that the resulting changes do not harm the majority of the population that already vaccinates while also meeting the needs of the minority that does not."

for this to be effective, there must be two-way communication between users and developers to ensure accessibility and transparency.

Anthropological work can promote research on decision aids in analysis for effectiveness, cultural relevance, and social influence. The sheer amount of information available must be streamlined to make an informed decision. Even if parents have access to credible information, they can easily be overwhelmed when attempting to convert information into action (Connolly & Reb, 2011).

# The next stages of the movement and necessary future policy

Moving forward, there are many steps that would benefit health care and public policy as it relates to vaccinations. aforementioned training for health professionals should continue to focus on the safety and effectiveness of vaccines and then target improvements with communication and satisfaction with vaccine consultations (Brown et al., 2010). Future policy should also work to promote trusting relationships with patients. Alterations to policy should be careful to ensure that the resulting changes do not harm the majority of the population that already vaccinates while also meeting the needs of the minority that does not (Brown et al., 2010). Additionally, interventions should continue to remove barriers for those who have positive vaccine attitudes but cannot vaccinate due to other factors. Interventions must also be careful not to overlook this factor when focusing on the ideologically opposed population of vaccine-hesitant parents (Brown et al., 2010).

Another approach could be to omit the option of non-vaccination by eliminating non-medical exemptions, or making the process for a non-medical exemption more complex. Mandates would enforce herd immunity and there is support that increased difficulty in obtaining an exemption reduces the unvaccinated population (Sadaf et al., 2013). In addition to increasing procedural complexity of the exemption process, there is room to revise the informed consent process

"Therefore, public health must continually improve its approach in addressing vaccine hesitancy."

to be more inclusive. Policies could make informed consent applicable to those refusing or deferring vaccines so that they are fully aware of the implications of their choices (Hendrix et al., 2015). A revised informed consent process coupled with individualized

approaches from physicians is more powerful than generic material (Brown et al., 2010).

Research must focus on the fundamental reasons for vaccine hesitancy while also keeping in mind that the observed lifetime of a vaccine includes stages wherein confidence is expected to lessen. This research focus will help to develop cost-effective interventions that promote the health of the whole population while maintaining caregivers' control of their child's health. Interventions should be multi-component and address specific determinants that drive vaccine hesitancy, specific to the needs of the community in question (WHO 2014).

#### **Conclusions**

Vaccines continue to be a safe, effective, highly regulated, preventative measure in public health, and yet continue to be controversial in some contexts. The lifetime of a vaccine indicates that there will be stages in which public support may decrease, leading to outbreaks of vaccine-preventable diseases, but that the resulting change in outlook will restore confidence. However, it is likely that the risk of confidence loss will continue indefinitely for diseases that cannot be eradicated worldwide (Chen et al., 1994). Therefore, public health must continually improve its approach in addressing vaccine Due to the complex decision making process, there are multivariate factors

that contribute to vaccine hesitancy, including structural and political factors, influence of popular culture, and perhaps most influential, the widespread availability of information via the internet. Physicians can respond in a multitude of ways, but they are ultimately the front lines in addressing hesitancy and so should thoroughly consider their actions when interacting with parents who refuse vaccinations. Anthropological study of the decision-making process, the factors that influence public and individual opinion and understanding of vaccines, and the public policy used to navigate vaccine hesitancy will be beneficial in addressing future instances of reduced confidence.

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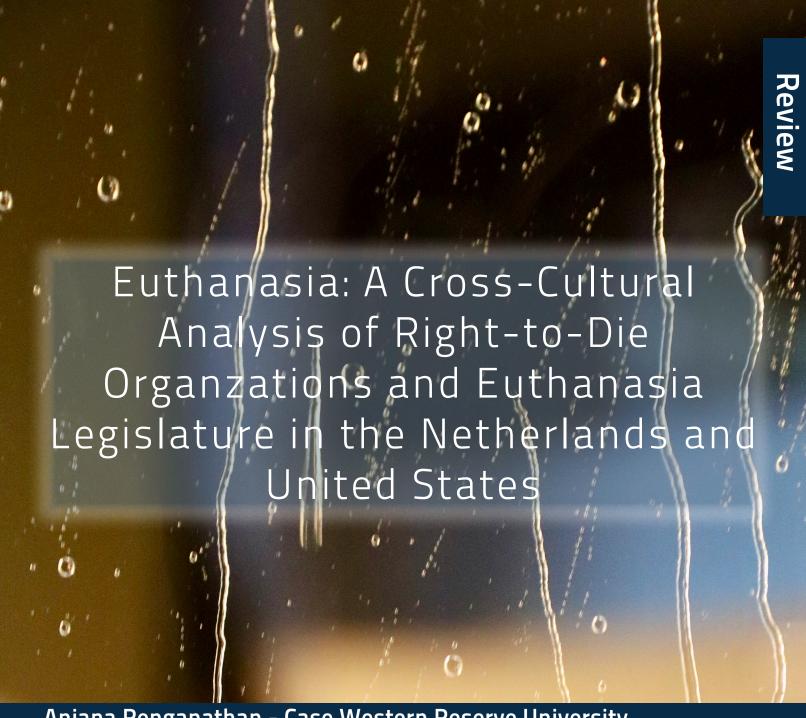
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### Anjana Renganathan - Case Western Reserve University

#### **BIOGRAPHY**

Anjana Renganathan is a senior CWRU student pursuing a Biology major with a Social Justice minor. She's currently interested in topics such as public health, health disparities and plans to attend medical school in the future.

#### **ACKNOWLEDGEMENTS**

I would like to thank my parents for supporting me in all my ventures, including this study abroad trip, my professor, Dr. Stuart Youngner, and the many truly invested people that took the time to educate us on death, a controversial, but universal topic.

American perceptions of euthanasia and culture regarding death, reveal the deeply influential ties health policy holds with history and culture. The Netherlands, and Amsterdam specifically, has had a comparatively colorful history and functional outlook that uniquely qualified it to be the first country in the world to legalize euthanasia. This paper will attempt to cross-analyze American and Dutch pro-euthanasia organizations, giving additional importance to their individual history and cultural values, as well as the health care system they work with and significant media incidents that helped shape public opinion on this controversial topic.

Although the Netherlands has legalized and implemented an organized system of physician-assisted suicide and euthanasia, the idea actually originated from the United States and England in the 1870s stimulated by the medical improvements that nearly doubled expected lifespan in a relatively short amount of time. While a few attempts were made to legalize it in the U.S., all proposals were defeated and it stalled for several decades until its resurgence in the 1930s. Both the United States and England saw the formation of pro-euthanasia societies that generally emphasized the voluntary nature of euthanasia, but also debated eugenics thoroughly (Foley & Hendin, 2002, p. 6). As euthanasia is not limited to the elderly, normalizing the choice to die also opens up the option to people with terminal genetic illnesses and mental illnesses. This 'cleansing of bad genes' is something eugenics is built upon. In a time where the battlefield slaughters of World War I resulted in reassessment of the ethics of life and death, and Charles Darwin's studies on genetics and natural selection had just stirred up a lot of thought, scientists proposed 'negative eugenics' programs to 'perfect' the human race by sterilizing the physically or mentally unfit (Youngner & Kimsma, 2011, p. 31). Extensive financing from sponsors like Rockefeller and Carnegie turned mere parlor talk into devastating action and eventually nearly sixty thou-

sand sterilizations were carried out in thirty states (Black, 2003). These were focused on the "unfit or degenerate, variously defined as criminals, prostitutes, alcoholics, epileptics and the mentally ill" (Foley & Hendin, 2002, p. 7). These laws also disproportionately affected racial minorities like African Americans, and other groups like women, even beyond the original parameters of imperfect humans (Black, 2003). These ideas of race science and cleansing spread from America and strengthened the eugenics movement in Germany, eventually resulting in the book The Permission to Destroy Life Unworthy of Life by Haeckel, Hoche and Binding that proposed that imperfect humans be eliminated for "racially hygienic purposes or because they were a burden to society, or both" (Foley & Hendin, 2002, p. 7). These ideas were much admired by Adolf Hitler, and later were utilized to justify the deaths of millions of people in the Holocaust. In the aftermath of World War II and the revelation of the horrors of the Holocaust. there was a violent abhorrence of eugenics that almost eliminated the entire euthanasia movement. So when it revived in the 1970s, its focus had shifted from eugenics for population cleansing, to euthanasia performed out of compassion for deeply suffering patients. Its reasoning circled back to the original purpose of euthanasia; further improvements in medical care had resulted in "pointless semblance(s) of life" creating a "fear of painful and undignified death" (Foley & Hendin, 2002 p. 8).

During this time period in England, Derek Humphry, a reporter for The Sunday Times of London, helped his wife end her life. Jean Humphry had anticipated a painful, slow death due to breast cancer, but instead was able to die quietly at home with her husband beside her. This event had a significant effect on Derek years after her death, even after he remarried. His second wife, Ann Wickett, after hearing the moving story, encouraged him to share his experience and Jean's Way was published in the U.K. in 1978. While aiding suicide was a crime at the time, the result-

"He made a video of himself injecting Mr. Youk with the lethal concoction and then gave the tape to the CBS show '60 Minutes' to broadcast with an additional interview that dared someone to file charges."

ing investigation during the controversy after the book's publication turned up nothing, and Derek moved to Los Angeles. The interest and enthusiasm about the topic of euthanasia in the U.S. surprised him and inspired him to give up journalism in 1980 to start the Hemlock Society with Ann (Gabriel, 1991). The Hemlock Society was the first right-todie organization established in the U.S. Within twelve years, the organization grew to 80 chapters all over the nation. The organization was involved in several large cases, including that of Dr. Timothy Quill, who had directed a terminally ill patient to the Hemlock Society and then, upon request, gave her a prescription for a lethal dose of barbiturates in 1991. The grand jury ultimately declined indictment of the physician, instigating nationwide discussion on the topic of physician-assisted suicide (Quill 2001). In 1991, the organization also worked with the terminally ill state senator Frank Roberts to pass an "aid in dying" bill that failed but went on to inspire other laws (Childress 2012). Within the same year, Derek Humphry published another book vastly different in content from his previous bestseller. His book, Final Exit, offers thoroughly detailed explanations and instructions on methods of how to commit suicide, including cyanide intake, declining food and drink, and asphyxiation (Humphry, 1991).

A simple Google search shows that Final Exit has been published in 12 different languages, three English editions, and is only banned in France. The Hemlock Society continued to be

active in several different spheres to promote euthanasia and physician-assisted suicide. A ballot measure in California in 1992 to legalize physician-assisted suicide, supported by the organization, failed with a large margin. This could be due to the negative response to the sensationalized suicides attended to by Dr. Jack Kevorkian since 1990. With a nickname like 'Dr. Death' and an idea like the 'suicide machine,' a Volkswagen van equipped with a setup that would allow a patient to start their own suicide with a push of a button, the media loved him. The exposure via interviews and cover stories would have stirred up enough controversy, never mind that he assisted 130 people in taking their own lives (Childress,

"This was only the first of many cases that would show the power of the media and public opinion on a topic that many believe to be a private affair."

2012). In 1999, Kevorkian helped Thomas Youk, a terminally ill gentleman suffering from amyotrophic lateral sclerosis in Detroit, commit suicide. He made a video of himself injecting Mr. Youk with the lethal concoction and then gave the tape to the CBS show '60 Minutes' to broadcast with an additional interview that dared someone to file charges. The resulting court case led to a conviction of 10 to 25 years in prison with the judge saying that the "trial was not about the political or moral correctness of euthanasia", but about "you [Kevorkian], sir. It was about lawlessness" (Johnson, 1999). This was the fifth and last time that prosecutors filed charges against Dr. Kevorkian, and the very public nature of the trials brought a lot of attention to euthanasia. The callousness and up front nature of Kevorkian's call for euthanasia as well as his attitude towards people who disagreed with him led to a lot of negative attention. This was only the first of many cases that would show the pow"This act would allow terminally ill adults who would otherwise die within 6 months to ask their physicians for a lethal dose of medication."

er of the media and public opinion on a topic that many believe to be a private affair.

Meanwhile in 1993, a secondary organization called Compassion in Dying sprang up in Washington, partially in response to the AIDS epidemic that was sweeping the nation at the time. This organization provided resources, support, and advice to terminally ill people. Some of this advice included options for a peaceful death, like abstaining from eating and drinking, ceasing medication, declining medical help, or taking drugs to end their lives. The AIDS epidemic was as well known and worrisome as the Zika virus is now with articles coming out every other week on new victims, cures, and infected celebrities (The AIDS Epidemic, 2001). Barbara Coombs Lee, the president of Compassion in Dying, was quoted saying:

...these were people who were on the front lines at the height of the AIDS epidemic. People whom they loved and people whom they served were jumping from balconies and using guns and doing all manner of horrific things to avoid the terrible death that they had witnessed their partners or their loved ones endure. (Childress, 2012)

Compassion in Dying wanted to help provide AIDS victims with more options so that they could end their lives peacefully with less trauma inflicted to those surrounding them. In 1994, both the Hemlock Society and Compassion in Dying threw their support behind proposed legislation in Oregon, the Death

with Dignity Act. After some legal trouble, the

law was fully enacted in 1997. This act would

allow terminally ill adults who would otherwise die within 6 months to ask their physicians for a lethal dose of medication (Stone & Winslade, 1995). Patients were required to be legal adults capable of making their own medical decisions and of swallowing the medication. The process was well-documented by physicians, had built-in waiting periods, and once the patient acquired the medicine, with the necessary interviews and applications, they were not required to use it immediately. Some patients even died without the aid of the medication. The methods and management were created to suit both the administrative mechanics of the private health care system and the cultural norms of America. The physician-patient relationship is typically not as sustained and intimate as the ones found in the Netherlands, and the emphasis placed on wellness and health is sometimes shifted to financial matters instead. In the United States, some consideration must be given to whether or not a treatment will drive a patient's family into bankruptcy. Additionally, American culture emphasizes individuality, privacy, and freedom of choice, which supports the argument for an individual's right to choose how they die. In 2008, physician-assisted suicide was legalized in Washington with a bill modeled after Oregon's legislation (Childress 2012).

In 2005, End-of-Life Choices (formerly known as the Hemlock Society) and Compassion in Dying, both well-established, accomplished end-of-life organizations, decided to merge to form Compassion & Choices. Today, it is one of the leading right-to-die organizations

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#### EUTHANASIA: A CROSS CULTURAL ANALYSIS OF RIGHT-TO-DIE ORGANIZATIONS

in the U.S. Their mission is to "empower people with information and tools," "advance (end-of-life and health care) policies," and to "authorize and implement medical aid in dying" (CompassionAndChoices. org, n. d. ). Their work extends into advance directives, palliative sedations, research studies, physician training, and aiding the construction of end-of-life legislation. Their history, methods, and volunteers truly reflect an American passion for the right to end-of-life choices.

To understand why the Netherlands would allow such daring legislation on not only euthanasia, but also soft drugs and prostitution, it is important to understand Dutch culture. A combined sense of communalism and individualism, reinforced due to the necessity for effective water management for their coast, characterizes modern Dutch culture (Shorto, 2013). This produced the Dutch character of tolerance, with a generalized concept of "looking the other way" in the face of illegal or improper activity, which, many many decades later, evolved into the modern Dutch concept of gedogen or tolerating definitively illegal activity in other countries such as prostitution or marijuana consumption (Shorto, 2013, p. 262).

In 1973, the Netherlands decriminalized soft drugs. Soft drugs are 'less damaging' to health, and include marijuana and hash. Hard drugs have more obcious and severe side effects, such as cocaine, ecstasy, and heroin. However, criticism from neighboring countries led to legislation being put back into place. This is where infamous Dutch tolerance, or in this case, gedogen, comes into play. It should be noted that while soft drugs are legal, this is only because the Dutch government believes that they have no significant, immediate negative impacts on users. Hard drugs are illegal and not tolerated, even by coffee shop owners, and they are liable if customers bring illegal drugs into their stores.

The legalization of prostitution in the Netherlands followed a similar slant. The legislation regarding prostitution mainly involved zoning into specific neighborhoods and making sure it was kept off of the street and in buildings, reducing risk for both sex workers and citizens. In the 1980s sex workers formed their own advocacy group, the Red Thread, which would go on to empower and support a tolerated yet unsupported profession for many years (Shorto, 2013, p. 263). For example, in a discussion with Ms. Majoor, while public health care is characteristic of Dutch health care, 'sex worker' is not a profession listed on the jobs eligible for it, so most sex workers go without public health care" (Majoor, personal communication, May 10, 2016).

In the same wave of social liberalization that led to the legalization of marijuana and prostitution, euthanasia is also allowed in the Netherlands. However, euthanasia had been happening quietly all over the country many years before this. In 1971, Dr. Postma and her husband euthanized her mother, who had suffered a brain hemorrhage, was severely handicapped, and had repeatedly pleaded for her daughter to kill her (Sheldon, 2007). Dr. Postma proceeded to inform the nursing home director who alerted the health inspectorate. In 1973, the court found her guilty under an anti-voluntary euthanasia law, but they only gave her a symbolic punishment of a week of suspended prison sentence with a year's probation. This symbolic punishment, when the law actually demanded a 12-year prison term, stemmed from the public opinion she had been morally in the right, which is an example of Dutch tolerance. Also in 1973, the first Dutch right-to-die organization was The Nederlandse Vereniging established. voor een Vrijwillig Levenseinde (NVVE) was founded due to the public outcry surrounding the court case. The organization seeks to educate, lobby, facilitate research, and support other initiatives for euthanasia and assisted death to this day.

Two other cases after Dr. Postma's set a precedent for euthanasia in cases of "voluntary request[s] from a person suffering unbearably with no reasonable alternatives for relief" (Hendin, 2002, p. 225). Finally in 1984, another case of physician-assisted suicide reached the Supreme Court, after the physician's acquittal had been reversed by an appellate court. The court overturned the conviction and sent it back to the appellate court to consider the case for euthanasia as a medical necessity for a patient. The Royal Dutch Medical Association (KNMG) sent a request for a change in the euthanasia legislature before the court even decided to acquit the charges against the physician. Unlike the U.S., the laws allowing for euthanasia did not spring from patients demanding a right to die, but rather a physician's right to ease unbearable suffering. This is a significant distincion that determines many of the differences between the American and Dutch in the two different euthanasia systems. It is noted that these laws are more self-regulation of the medical profession with additional helpful public and governmental support rather than a government initiative that included assistance from the NVVE. The Dutch characteristics of tolerance and community, as well as their strong liberal nature during this period and relative lack of publicized negative incidents, allowed for the legalization of euthanasia.

Unlike the United States, the government provides health care to the majority of its citizens, with a mandatory General Practitioner assigned to each patient. This system cultivates long-lasting, intimate relationships between physicians and patients. This results in a more accurate judgment of suffering and a greater understanding of, and need to, ease a patient's pain. It should be noted that the lack of negative incidents includes the absence of both eugenics since the ideas did not catch on as strongly in the Netherlands as they did in the U.S. and media incidents like that of "Dr. Death" which occurred in the U.S. In short, a lot of the issues that the U.S. went through

with euthanasia, the Dutch simply did not have. This could be due to the fact that the movement originated with physicians, or due to a Dutch perspective on tolerance and community. However, this is more likely a multi-layered combination of social and political reasons.

The U.S. and the Netherlands are both unique nations, with their own distinct histories, cultures, health care systems, euthanasia organization, and legislature. With a controversial idea like physician-assisted suicide and euthanasia, there are bound to be complications and "slippery slope arguments". No one organization or set of laws will be perfect and people will continue arguing about these topics so long as they're human, inherent contrariness, mortality and all. But, as I hope this paper suggests, as long as we maintain the ability to argue freely and control the laws that determine our lives, we will have euthanasia legislation that supports and protects the fragile and human act of dying.

#### EUTHANASIA: A CROSS CULTURAL ANALYSIS OF RIGHT-TO-DIE ORGANIZATIONS

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