

## ABSTRACT

Perspectives on End-of-Life Decision Making for Adults with Intellectual Disabilities

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This thesis explores different perspectives on the end-of-life care and decision-making process for people with intellectual disabilities through a grounded theory, interview-based research methodology. After learning about the challenges inherent in end-of-life care, particularly in situations where patient input is limited due to factors such as intellectual disability, the perspectives of people who were present with the patient hold value in dictating qualities of the process. A series of semi-structured interviews were conducted, and nine emergent themes arose that illustrated aspects of the process that were either beneficial or harmful to the respondent and the patient and/or loved one. While reviewing and accumulating the findings from these interviews, these themes were compared to the literature surrounding the topic to offer possible solutions. This thesis also examines the need within the medical education system for increased teaching about the treatment of patients with disabilities.

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PERSPECTIVES ON END-OF-LIFE DECISION MAKING FOR ADULTS WITH  
INTELLECTUAL DISABILITIES

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## DEDICATION

To my Aunt Margaret, who inspired me to undertake this project and shaped my life in more ways than she will ever know.

## CHAPTER ONE

### Background and Interest

The end-of-life decision making process is undoubtedly a sensitive and difficult time for anyone involved, but in particular it is hard on those in close relation to the person facing the end of his or her life. This situation, difficult on its own, is complicated when the person at the end of their life may not have the capacity to fully participate in the decision-making process themselves, as is often the case when the person has a diagnosed intellectual disability, dementia, and/or any other complicating condition. There has been a limited amount of research into this particular concern due to its inherent specificity, and as I began to explore this topic during my junior year of college, I realized that it was important to learn more about the benefits and consequences of the choices made in this situation in order to best understand how to treat patients in the future.

#### *Personal Motivation*

My interest in this specific topic came from multiple sources, but it primarily came from personal experiences and things that I witnessed over the span of my life, as well as from interesting conversations that I had already engaged in prior to interviewing any participants. Growing up, I spent quite a bit of time with my aunt Margaret who was born with Down Syndrome and lived out a full life. She was kind-hearted, funny, and she always stood up for others when they needed someone to support them. As I grew and

matured, I realized how much of an impact that her presence in my life had on me and the decisions that I made. She taught me a lot about what loving others truly looks like, and for that I am incredibly thankful. Unfortunately, as I reached my late teenage years, my aunt developed dementia, and she was soon moved into a long-term care facility. When we would visit her after this, I could tell that there was something that was different. As we visited her over the last 5 years of her life, I noticed that there were many aspects of the end-of-life process that made the situation more difficult for her and the rest of my family. She was unable to express her emotions completely, and it was difficult to see her in so much discomfort. Even though the hospice nurses did an excellent job, and she was given medication to make her as comfortable as possible, it was still apparent how excruciating the whole process was. When she passed away, the pain and grief within my family was overwhelming. I was acutely aware of the effects that witnessing her pain and discomfort had had on my family, and after spending some time in reflection, I began to think about the process and what had positively affected my aunt and the rest of my family. At the same time, I thought about the things that were particularly difficult for her, such as moving to the last facility that she lived in at the end of her life. Looking at both the positive and negative aspects of this process encouraged my interest in learning more about the experience of others in a similar situation.

### *Academic Interest*

During my sophomore year of college, a friend suggested that I should take the End-of-Life Care and Bereavement course taught in Baylor's Medical Humanities program. I thought it sounded interesting, and so I signed up to take the course.



Throughout the whole time that I took the class, I learned about end-of-life decision making and many of the issues and complications that can arise as a result of the process. The more I learned about this subject matter, the more the question about my aunt's experience remained in my mind. While I know that no end-of-life process is going to be perfect, and that difficulty is going to be present no matter what the situation, I did learn that there were steps that could be taken to take some of the weight off of the family members and caretakers. I thought about how interesting the application of these steps would be in situations with people like my aunt who have diagnosed intellectual disabilities. With the combination of the things that I took away from the class and the personal experience that I had, I decided that this topic was something that I wanted to explore more.

While this topic expands far past the confines of medical decision making, I thought that this information was particularly important for me to be aware of as someone wanting to go into the medical field. The responsibilities of a physician are numerous, and the knowledge that is expected from physicians is great, but I feel that it is essential to know as much as possible to best treat patients. As I have had conversations with different medical professionals and other people tangentially involved with the care of people with intellectual disabilities, I have found one common statement that has stood out. What I have heard is that, despite having a vast knowledge about how to treat patients, many physicians have little to no understanding of how to treat patients with intellectual disabilities, specifically at the end of their lives. With the exception of physicians who have a particular interest in the subject of disability or physicians who have had family members or other loved ones with disabilities, this topic simply does not

come up enough in the process of medical education. This realization compelled me to think about how important it is that I use my personal experience to learn more about this topic, especially in a way that I may be able to one day talk to my peers and colleagues about it.

### *Current Issues*

The process of end-of-life decision making for people with intellectual disabilities has become increasingly complicated as modern medicine has made it possible for people with disabilities to live longer than they ever have before. While this possibility for longer life brings along with it new opportunities for people with disabilities, it has also introduced extra complications into the decision-making process. With the age of death for people with intellectual disabilities rising significantly and very quickly, healthcare professionals must learn and research this topic as much as they can in order to best treat patients in the future (Doody et al., 2013). One of the concerns surrounding the increased longevity seen in this population is the higher rates of dementia and other health complications at the end-of-life. Dementia complicates the end-of-life process by lessening or removing the possibility of contribution on the part of the person with disabilities in their own end-of-life decision making process (Dassel et al., 2019). While the patient's diagnosed intellectual disability may not cause them to be unable to take part in the decision-making process, the development of dementia may cause this, and this creates an additional stressor on the family members and caregivers. Therefore, it is important that there is an increased awareness for this issue in addition to many other complicating issues that affect this specific population.

As I observed from witnessing my aunt's experience, there were also quite a few simple and easy changes that could have been made in the process to positively impact the caregivers and family members. Environment is incredibly important to both the person with intellectual disabilities and the people surrounding them. Comfort is something that should be a priority in end-of-life situations, both for the patient and the family. Within the current state of the world, which is often focused on fixing issues and working harder, the idea that comfort should be the focus at the end of a person's life may seem contradictory. Particularly in medicine, the faulty idea that placing a patient on hospice care can be equated to "giving up" can motivate healthcare professionals to continue encouraging treatment even when it no longer positively affects the patient's life. This idea can also encourage family members to ask for further medical interventions for their loved one even when they may no longer be beneficial. In the context of people living with intellectual disabilities in particular, but also often in the general population, there can be difficulty in knowing when to refer a patient to palliative or hospice care. Unfortunately, waiting to make this decision has the potential to negatively impact the patient's dying process.

The end-of-life process also affects far more people than just the person dying. Family members and caretakers, often roles carried by the same person, are faced with the reality of their loved one and/or patient slowly fading away over time. Even with a less attached relationship, this experience can be draining and life-altering. The weight of the person's pain and suffering can begin to weigh heavily on the shoulders of the caretaker, and this has historically led to caretaker burnout and loss of self ("Challenges Faced by Caregivers," 2017). There has been significant research into the caregiver

experience, but a specific focus of this study is to learn about the caregiver experience as it relates to the experience of the patient. This will hopefully add insight to the understanding of the patients' experience, as interviews cannot be conducted with the patients themselves. This inability to interview the patients directly is due to the fact that in order to understand the process holistically, it must be reflected on after the patient has died. Also, in this specific situation, it would be risky and difficult to interview the patients due to their intellectual disability and their state of vulnerability at the end of their lives.

Caregivers and family members provide much needed insight into respect for dignity and facilitated decision making at the end-of-life. Due to both the patient's intellectual disability and other potential additional medical conditions at the end-of-life, there is extra difficulty in allowing the patient the space necessary to have any impact on their course at the end of their life. Caregivers and family members of patients with intellectual disabilities have the additional responsibility to ensure that their patient's/loved one's wishes are granted if they are made known.

While perspectives on the experience of the patient with intellectual disabilities at the end of his or her life are important to consider, it is also interesting to evaluate the experience of the caretakers and family members who saw the patient daily—the people who experienced the process alongside the patient. After reading about different decision-making methods and considerations, I concluded that this was something that I wanted to gain more firsthand perspectives about through interviews. Due to the specific nature and goals of the study, I was recommended to use classical grounded theory methodology.

This would allow for the perspectives I gained to illuminate key ideas and themes that could then be analyzed for further understanding.

### *Chosen Methodology*

The end-of-life decision making process was explicitly discussed in Glaser and Strauss' (1965) groundbreaking work *Awareness of Dying*. Through exploring the impact that sharing information with patients had on their dying experience, they concluded that informing patients of their own dying process appeared to be beneficial in the end-of-life stage (Andrews, 2015). Prior to this exploration, which is recognized as the first study using the grounded theory research methodology to ever be published, the common practice was to shield patients from their own dying process. This work both opened up the conversation about the end-of-life decision making process and formed a groundwork for future grounded theory researchers.

Through learning more about the goals and purposes of classical grounded theory, the interviews conducted in this study were oriented to best align with this methodology. By shaping the questions asked around the particular participant's situation, while still maintaining uniformity and structure in what was being asked, the most relevant information from each participant became apparent. Throughout the course of the interview process, emerging themes in many different categories have arisen. These emergent themes and ideas will be discussed further in Chapter 2. Classical grounded theory concludes when it reaches "theoretical saturation" (Chun Tie et al., 2019), or when there are few to no new emergent themes. Considering the specificity of this study, theoretical saturation occurred fairly early in the process.

Grounded theory advocates for the utilization of the “constant comparative method” in evaluating interview data (Chun Tie et al., 2019). This means that throughout the course of the entire interview process, from the moment that the first interview is conducted until the moment that the last interview is conducted, the information heard is evaluated and compared to both other interview data and the current literature surrounding the subject. When common themes emerge, they are evaluated deeper and the commonalities are then analyzed to be better understood. At the end of the interview process, using this information gained, the task of the researcher is to collect and concisely identify the most important takeaways from the interviews and literature.

### *Historical Background*

When looking at the history of treatment of people with disabilities in the United States, it becomes apparent that social structures have placed serious difficulties on people who fall into the category of having an intellectual disability. After considering the difficulties that many of these patients regularly face, I believe that it is important that this subject is explored more. The marginalization of this community needs to be dismantled from the beginning to the end of their lives, and unless medical schools and other healthcare educational institutions begin including more study about this particular subject into their curriculum, there will continue to be a large proportion of physicians and other healthcare professionals who do not fully understand the complexity and difficulty inherent in the process of treating patients with disabilities. People with intellectual disabilities need more advocates, particularly at the end of their lives when

they unfortunately often cannot advocate for themselves for many different complicated reasons.

Increasing the number and participation of advocates for patients with disabilities is the responsibility of anyone who has the knowledge and ability to support the community. When people do not have a personal connection to someone who has a disability, it is unfortunately quite easy to not pay attention to the issues surrounding this vulnerable community. However, disabilities affect “26 percent (one in 4) of adults in the United States” (CDC, 2019). This statistic demonstrates that it is not just valuable, but essential that the public understanding of treatment of people with disabilities be improved. As mentioned earlier, a good place for this education about topics associated with disability to begin or be furthered is either in university education or medical education. Currently, in light of how large the percentage of people in the United States with disabilities is, it is more important than ever before that advocates work to increase the educational resources about and for people with disabilities.

### *Goals*

Taking into account the information gained from this study, the next question is what it will look like to move forward. The question of how physicians, caretakers, and family members can learn to better understand the wishes of patients with intellectual disabilities at the end-of-life is complex, and even with what has been learned, there is still much to understand. I am hopeful, however, that the things that I have learned through this study will allow me to better understand the treatment of patients with disabilities and to support and advocate for them in my future medical career. I hope that

this thesis will encourage open discussions about this topic and open up the potential for a greater understanding of the entire process. Lastly, I hope that by giving caregivers and family members the space to tell stories of their patients and loved ones with intellectual disabilities who went through the end-of-life care process, they are provided an additional opportunity to share a privileged experience with anyone who reads this thesis.

### *Participants*

For this study, a total of five participants were interviewed. These participants were all women and were within the ages of 54-90 years old. They were recruited using different sources, including hospice contacts, friends of family, and contacts through a home for people with disabilities. Snowball sampling was used, meaning that some participants provided names for future interview participants. This method “is applied when it is difficult to access subjects with the target characteristics”, and it proved useful in this study due to its specificity (Naderifar et al., 2017, p. 2). Four of the recruited interview respondents were direct family members of patients with intellectual disabilities, and one of the interview respondents was a close friend and caregiver of a patient with an intellectual disability. Their unique perspectives offered different insights into the end-of-life care and decision-making process for patients with intellectual disabilities.



## CHAPTER TWO

### Findings

Throughout the constant comparison process, narratives tended to cluster around nine specific themes. These themes centered around three key characters in the process: the patient, their family members, and the staff caregivers. Looking at the entire process from the perspective of the needs of each of these three groups of people allowed for a broad analysis of the situation.

The patients were the primary group that was affected through this process. The patients and loved ones with intellectual disabilities often played a role in their own end-of-life care, whether through participating in the decision-making process or affecting their own care in another way. The patients were also impacted by the presence of family members and caregivers at the time of their death. Lastly, the patients were impacted by the setting and context in which they spent the last moments of their lives.

The family members were also impacted by different aspects of the end-of-life care process for their loved ones with intellectual disabilities. One primary concern is the weight of the decision-making responsibility and the lasting impact that this weight has on the family members. Interactions with the staff caregivers also impacted the experience of the family members positively or negatively. Agreeing to palliative and hospice care also carried a positive impact with the family members, particularly when this occurred earlier rather than later.

The last group of people who were impacted through this process were the staff caregivers, in particular those who worked and formed close relationships with their patients. The presence of these relationships with patients and their family members appears to be valuable, but it also increases the need for understanding the process from the perspective of the caregivers. In particular, there is a need for the option of counseling for staff caregivers after the death of their patients. The last important consideration involving caregivers is the level of awareness among staff caregivers and healthcare professionals about how to best treat patients with intellectual disabilities.

By viewing the end-of-life care process from the perspectives of these three aforementioned groups, the interview findings about the process can be understood better through their effects on these groups of people. The emergent themes identified below reflect this understanding as they explore the most commonly identified findings from the interview process.

### *Patient Autonomy*

In the general population, there is a need for more openness in discussing end-of-life wishes, procedures, and desires. In particular, there is a need for increased discussion of these things throughout the intellectually disabled community. Personal input during the end-of-life decision making process can be an incredibly complex issue when it relates to patients with diagnosed intellectual disabilities. If the patients are high functioning and demonstrate decision-making capacity, there should be considerations made in order to provide some level of patient involvement. In discussions with two interview respondents, I learned that the patients they were connected to had at least a

somewhat significant level of self-awareness, and that they would likely have been able to have input on their own decision-making process if they had been consulted earlier in their lives. This bridges the concept of patient autonomy – and highlights how important it is to understand the implications of the patient’s decision-making abilities. Prior research points to the idea that patients should be allowed to participate at the maximum level that is possible in their situation. In a qualitative study conducted via interviews, Bekkema et al. (2014) discovered that “several qualities were important for respecting autonomy: attention to information needs, connecting, recognizing end-of-life care needs, giving space to show wishes and preferences, and discussing dilemmas” (p. 1). If the patient is provided access to a maximum level of participation in their specific situation, there is a greater likelihood that they will be given the space to demonstrate their own personal wishes and desires.

In an interview with another family member, a similar theme echoed surrounding their loved one’s decision-making capacity. Respondent 1 mentioned that allowing her sister to choose when she was taken off of her feeding tube brought the family so much peace, knowing that this was her sister’s greatest opportunity to exercise her own independence. When the time came for her sister to die, the family had complete assurance that they had respected their loved one and offered her the maximum opportunity for her to express her own autonomy. Therefore, when looking back on this experience, Respondent 1 did not feel regret or responsibility for prolonging her loved one’s suffering. Unfortunately, this was not the case in every interview conducted. In interviews with Respondent 2, Respondent 3, and Respondent 4, the loved ones and caregivers expressed distress in the lack of autonomy that the patient had at the end of

their life. In particular, this was often due to the presence of dementia that had progressed to a state where the patient no longer had the self-awareness necessary to confidently make their own decisions. When asked further questions about the situation, Respondent 3 and Respondent 4 reported that their loved ones likely had the capacity to express their own wishes only a few years prior to the end of their life. Despite this, the uncommon nature of early discussion about end-of-life issues and the discomfort that discussing them can bring on the family had consistently prevented these discussions from occurring early enough. Therefore, the autonomy that the patient once maintained on a daily basis, even with their diagnosed intellectual disability, was taken away from them. The negative effects of this lack of autonomy were clearly felt by the patient in some way, as they were not allowed to truly have a say in the most personal decision they would ever face. More startling however, was the negative effect that this lack of patient autonomy had on the family members and caregivers. Respondent 2 expressed that she dealt with extreme “shame and guilt” through the entire process, as she looked back and felt that she was much too aggressive in her decision-making strategies. Because her sister never had the full opportunity to express her wishes, the participant felt like she may have made a mistake. The worst part of this feeling, clearly spurred on by her sister’s lack of ability to participate in her own decision making, was that she never knew what her sister really wanted. When interviewed five years after her sister’s passing, she stated that she still feels sadness knowing that her sister’s autonomy was taken from her.

The vast difference in post-death comfort among family members, depending on the level of autonomy experienced by the patient, points to the essential nature of early discussion about end-of-life issues with patients with intellectual disabilities, even when

these may feel uncomfortable or like they are too early in the process. As increased patient autonomy was something that linked highly to reduced levels of negative feelings such as regret, it is something that should be a primary concern as end-of-life care is planned.

### *Setting/Context*

Another sentiment that appeared often in the interviews and was additionally found in the literature relating to the topic of end-of-life care for people with intellectual disabilities, was that the setting at the end-of-life was very important in providing comfort to the family and their loved one. Whether the setting of comfort was at home or in a trusted nursing care facility, the place held great importance to the families and patients with intellectual disabilities. In some situations, the setting was somewhere incredibly personal, and the families had very strong relationships with the people present. Even when the setting was more professional, the presence of the same staff and caregivers throughout the entire process provided a sense of peace to the family members and the patient. It was clear from the interviews that the evaluation of setting is important to ensure that the patient is receiving the best possible care.

Setting includes the consideration of more than just the location where the patient spent the last days of their life. It includes the staff caregivers, how common it was for family members to come visit, and how familiar the entire experience was to the patient and their family members. In discussions with multiple interview participants, the value of this familiarity in setting emerged as it brought comfort to both family and the patient. In particular, Respondent 1 discussed the value of allowing her loved one to choose her

nurses, as this gave her one more opportunity to express any sort of decision making. This linked to the importance of setting as well, as by allowing her sister to choose her nurses, she also allowed her to make a choice that would be important in the setting and context of her death. Respondent 2 discussed the value of having her loved one die at home, surrounded by the people that she had spent the last few years of her life with. This choice, allowing her loved one to die surrounded by her friends, impacted her death experience. As the Respondent 2 recalled, “she didn’t have to be afraid then.” This knowledge that her loved one was in a comfortable setting and surrounded by familiar faces when she passed away brought Respondent 2 a great amount of peace.

In relation to caregivers, another theme that presented itself commonly was the value of consistency in the presence of caretakers. It was not simply dependent on how often they were present, but on the fact that the same people were present throughout the entire experience. This brought the patients and family members a great amount of peace. Respondent 4 noted that by knowing that there was a consistent set of nurses that hospice sent to the facility, she was able to feel more at peace when she could not be there. She knew that even if she was not physically present, her loved one knew some of the people who were. This idea was confirmed in an article which stated that “maximizing time in familiar surroundings and establishing trust and continuity are crucial” (Sue et al., 2019, p. 1). Consistency and comfort with all aspects of the setting of death proved beneficial to the patients and their family members.

### *Decision Making Responsibility*

The actual decision-making that must occur at the end of a patient's life includes some of the more commonly thought of considerations, such as resuscitation orders, but it also includes considerations such as "do-not-hospitalize orders; whether to provide nutrition or hydration by enteral or intravenous routes; whether to initiate or prohibit future interventions aimed at cure" among other decisions (Lang & Quill, 2004, p. 2). Each of these considerations has an individual impact of the patient's experience at the end of their life. Comfort is thought to be of primary concern, but it is often difficult in the moment when emotions are high to objectively view the impact of the decision solely from the patient's perspective. If the caretaker happens to hold a role as a family member or loved one, it is common for the caretaker to inevitably take their own emotional attachment to the person into consideration as well. This can potentially lead to the patient remaining on life support for longer than the patient may desire. The inability to enact control over their own decision-making process has the potential to negatively impact the patient's end-of-life experience.

This subject of decision-making responsibility was something that appeared quite frequently in the discussions with interview participants. When speaking with the respondents, it was stated frequently that the ability to allow their loved one to choose what they wanted at the end of their life was the most comforting situation, but even when this was not possible due to the loved one's mental state, being able to make the decision as a family independently of the medical team brought peace post-decision.

In the end-of-life decision making process, families are faced with many difficult choices. Underlying these complex choices, there is an important choice that must be

made from the outset in situations where the patient does not have the capacity to make the decisions themselves. This decision that the family must consider is whether to make all of the complex end-of-life decisions based on substituted judgement or best-interest judgement (Lang & Quill, 2004). Substituted judgement, which is made much easier when the family has had discussions with their loved one about their desires prior to them facing the condition that has made them unable to make decisions for themselves at the end of their life, involves “determining how the patient, if able to fully understand his or her condition, would make the decision” (Lang & Quill, 2004, p. 2). On the other hand, best-interest decision making involves incorporation of the family values as opposed to solely the patient’s values. While both methods of decision making have benefits and drawbacks, after evaluating the findings from the interview conversations, it appears that the substituted decision-making method appeared to bring more peace to the family after their loved one with intellectual disabilities passed away. This was confirmed by Lang & Quill as they found that “when the family tries to approximate the patient’s decisions as closely as possible, the guilt that regularly complicates such surrogate decision making often decreases” (Lang & Quill, 2004, p. 2).

During the interview, Respondent 3 reported that allowing the family to approximate the decision for the patient brought the family peace and comfort during the difficult time. As a caregiver, the respondent was able to discern how both the patient and the family felt, and it appeared to her that this was the best method of action for them. Another interviewee, Respondent 1, confirmed that when her loved one was allowed to make the decision for herself when she wanted to stop care, it helped the family to feel peace. In contrast, Respondent 2 reported feeling deep regret and guilt after her loved one



passed away due to the fact that she believed she was too reliant on her own medical background in the decision making. This unfortunately made her more aggressive with her treatment plan, and after reflection, she did not know if this was, in fact, what her loved one would have really wanted. The contrast between these two situations reflects both the value of patient autonomy and the value of the decision being as close as possible to what the patient would have desired. The decision-making responsibility has the potential to greatly impact the experience of the caregivers and family members long after their patient and/or loved one has passed away, and therefore, it is an important consideration in evaluating the end-of-life decision making process for patients with intellectual disabilities.

#### *Weight of Decision-Making Responsibility on Family Members/Caregivers*

Another interesting consideration of the end-of-life decision making process for people with intellectual disabilities is the impact that the responsibility of this decision has on their family members. The weight of this responsibility can prove to be difficult for their loved ones, and this can in turn impact their experience in relation to the end-of-life process. It is important to understand that when patients have varying levels of intellectual disability, there is a potential for patient input. However, in more severe cases, there is also the potential that the patient will be completely unable to articulate their wishes at the end of their life. This determination, in addition to the actual decision making, can be difficult for the family of the patient and the caregivers that may support them in discussing the issue.

During the interview, Respondent 5 reported experiencing stress during the end-of-life decision making process due to conflict with the head of the facility that her loved one lived in. As a result of her profession as an attorney and her brother's profession as a physician, she felt equipped to work through the conflict, but it was nonetheless taxing on her and her family. Disagreement over a Do Not Resuscitate (DNR) order led to a difficult weight being placed on her and her family members. She even took the time to express how much more taxing this would have been on a family whose members did not already have intricate knowledge of the end-of-life decision making process. This is confirmed in the literature, which states that "without adequate information from health care providers to inform the decision, families can experience resentment and emotional burden after a decision is made" (Trees et al., 2017, p. 2). While it may seem unfair to assume that healthcare providers should have a very specific understanding of the end-of-life decision making process for patients with intellectual disabilities, it is also realistic to confirm that without their knowledge of the subject, family members and other loved ones of these patients may be left in the dark with little understanding of the ramifications of each decision that they are having to make. Therefore, in order to decrease the resulting weight that caregivers and family members may have to carry, it is important that healthcare professionals have a comprehensive understanding of this topic.

During the interview, Respondent 5 specifically mentioned that while the family waited to make decisions, it was easy for emotions to get in the way of clear decision making. This emotional involvement also has the potential to leave families feeling more responsible if they perceive that they have made a wrong or harmful decision. During my conversation with Respondent 1, she was still clearly emotional following her loved

one's passing, even with the overwhelming feeling that she allowed everything to happen as it should. This clarified the sheer emotional difficulty that making any kind of end-of-life decision carries, even when the patient is allowed some input as her loved one was. It is therefore important that everyone involved in the end-of-life care and decision-making process be sensitive and supportive toward the loved ones and caregivers.

As Respondent 2 discussed her experience and feelings after her loved one passed away, it was apparent that she was still wrestling with the emotional weight of the decisions she made, even years after the fact. This once again clarified the serious nature of the impact that these decisions have the potential to have on the family members of patients. As confirmed by Trees et al. (2017), "how this [end-of-life] decision is managed has important implications for the patient's quality of life at the end and affects family members' emotional well-being long after the decision has been made" (p. 1). It is necessary for healthcare professionals to be sensitive and responsive to family members as well as caregivers as they navigate this emotionally challenging time.

#### *Interactions Between Staff Caregivers and Family Members*

Interactions between staff caregivers and the family members of patients with intellectual disabilities experiencing the end-of-life process are vital in increasing comfort and satisfaction within the difficult situation. These interactions have the potential to increase family comfort if they are positive and stress-relieving, as is the case particularly when the staff caregivers work to form more personal relationships with the patient and their family members. These interactions also, however, have the potential to cause stress and drama within the family, especially in situations where the caregivers are not

sensitive to the needs of the patient and their family. While this may not always be intentional, it is still nonetheless impactful on the experience of the patient and their family members.

In the best of situations, staff caregivers can become close to the patient and form a personal relationship with the patient and their family members. This can be a huge blessing to the family, as the caregiver can help shoulder some of the practical and emotional burdens of being present with the patient at the end of their life. An understanding of the beneficial nature of positive interactions with caregivers often arose during the interview process, and it demonstrated that the interaction with staff caregivers and/or healthcare providers had the potential to completely shape the experience of the family during the end-of-life decision making process. If there was an experience of conflict, which occurred in multiple of the cases for the respondents interviewed, this brought a negative emotional response upon the family members involved in the conflict. This unfortunately increased the experience of stress in an already stressful situation.

In my conversation with Respondent 1, she remarked how having a relationship with many of the staff caregivers brought her a sense of calm every time she entered the facility where her loved one was. By knowing that the caregivers knew her loved one well, she felt a sense of safety and trust in the midst of a difficult situation. In contrast to this, however, Respondent 5 remarked that due to conflict with one of the staff members at the facility where her loved one was, she felt stress when she went to visit him. Another staff member also treated the loved one of Respondent 5 in a way that did not align with her preferences or values, and this caused conflict and stress for the family to the extent that the family requested that their loved one be removed from her care. From

this conversation, it was clear that Respondent 5's experience was very different than the experience of Respondent 1, and the interactions with staff caregivers played a role in this difference.

Interactions with staff members have the potential to remain completely professional, but due to the sensitive nature of this specific situation, often staff caregivers can become incredibly close to the patients and their family members. In this situation, "both the family and the care staff at the ID care service are often deeply emotionally involved over a long period of time", and this can increase the connectivity between the family members and the staff (Nienke Bekkema et al., 2015, p. 7). This situation was expressed by multiple interview respondents as they recounted the value of their relationships with the staff caregivers. Familiarity was helpful in creating a comfortable environment, but relationships allowed for the family members to truly know that the caregivers loved and valued their loved one. One study termed care staff for people with intellectual disabilities "the other 'family'", and this accurately reflects how strong the bonds have the potential to become with staff caregivers (Nienke Bekkema et al., 2015, p. 7). This can be a great advantage to the family in this difficult time, and it can also be a valuable and life-changing relationship for the staff caregivers. Therefore, it is important that caregivers working with patients with intellectual disabilities have an awareness of the positive impact that their relationships with the patients have the potential to have on the family members in addition to the patients themselves.

### *Agreeing to Hospice/Palliative Care*

Hospice and palliative care are advantageous in many situations for patients at the end of their lives. In situations where the patients are competent to participate in the decision-making process themselves, it is fairly common for them to have a say in when this referral to palliative care and hospice services occurs. While having patient insight into this timeline can be helpful, there are many situations in which patients may not be capable of communicating that they would like to move to palliative and/or hospice care. One example of this can occur when patients have a diagnosed intellectual disability or other complicating condition that prevents their participation in their own decision-making process. In this case, it is particularly important that the family members be properly educated about the benefits and advantages that early referral to these services have historically had on the patient experience.

Over the course of the interviews with caregivers and family members of patients with intellectual disabilities who went through the end-of-life decision making process, respondents frequently commented on the value of palliative care in providing comfort to both the patient and their family. In particular, multiple respondents commented on the value of early referral to hospice and palliative care. Respondent 5 commented on the value of referral to hospice care, and she reported that the pain medication her loved one was offered through the service brought comfort to him and the family members. Knowing that her loved one was adequately cared for by hospice providers brought her peace, as she knew that all of the pain was being addressed properly with medication. Respondent 4 also commented on the comfort that the hospice providers' presence brought her, especially at times when she could not be physically present with her loved

one. Because she knew and trusted the hospice workers who were caring for her loved one, she felt more comforted when she had to leave her loved one's side.

In another discussion about hospice care, Respondent 3 commented on the lack of proper knowledge in the general population about the value of palliative and hospice care and the differences between the two services. Palliative care and hospice care can often overlap, but they serve two distinct purposes for the patient. Palliative care serves the patient with the primary goal of palliation of symptoms and increased patient comfort. Palliative care differs from hospice care in that "you do not have to give up treatment that might cure a serious illness" (National Institute on Aging) . Hospice care, on the other hand, requires referral from a physician to confirm that the patient is in a state where they will most likely die within the 6 months following referral. A common public misunderstanding of the differences between these two services may lead families to be fearful of a referral to palliative care for their loved one, as they may see it as giving up treatment for their loved one. Through proper education and clarification, families can be made aware of the benefits of palliative care and the distinction between palliative and hospice care. As Respondent 3 commented, education about the value of these services would allow for families to access these services earlier, and this could provide support with both the patient's physical pain and the pressure that families often feel to never leave their loved one's side during the end of their life. Knowing that there are trusted caregivers present with the patient at all times is very important for peace, and this was echoed in my conversation with Respondent 4.

Palliative care has proven to be valuable, but "unfortunately, palliative care is often only offered late in the course of disease after curative measures have been

exhausted” (Fink, 2015, p. 597). Movement toward earlier referral to palliative care through proper education of the public has the potential to bring more peace to families, and in particular, this would help support family members of patients with intellectual disabilities by bringing them an extra system of support and understanding.

### *Counseling for Families and Staff*

Something else to be considered when evaluating the circumstances surrounding end-of-life decision making for patients with intellectual disabilities are the lingering emotional impacts on the family and the caregivers and how to specifically address them. After their loved one or patient has passed away, it can be difficult to work through the grief process while additionally dealing with the emotional and psychological toll that intricate involvement in the end-of-life decision making process took on them. In a statement from the APA, they recommended psychological care for families not just before and during the end-of-life care process, but also “after the death of the patient, with bereaved survivors” (American Psychological Association, 2005). This recommendation was echoed in interviews with multiple respondents, as they reflected on the value of counseling for both families and staff caregivers.

During the conversation with Respondent 3, she remarked that through her work with the patient, she had developed a strong friendship with him and the rest of his family. As a result of this strong bond that she shared with the patient, she expressed that counseling was an important resource for her and her colleagues, along with the family members. In many circumstances, the staff caregivers may have worked with the patients for many years, and as a result, it is important to accommodate for the caregivers in a



similar manner to accommodating to the family members. Respondent 3 had worked with her patient for over ten years, and therefore, she needed time and space to grieve just as the family did. The current standard for counseling is “a bereavement assessment with family members/friends of the deceased within 38 days of the hospice patient’s death” (Ghesquiere et al., 2019, p. 3). There is also access to counseling for “informal caregivers”, but this does not usually include the hospice staff caregivers, and therefore, there is not space built in to care for and counsel this group of people after the death of a patient who they may have been close with (Ghesquiere et al., 2019).

Respondent 4 also spoke to the importance of taking care of the family as well as the patient, both during the end-of-life care process and after their loved one has passed away. This increased family support was expressed to be positive for Respondent 4, but it also added another layer of caregiving to the staff responsibility. As a result, the staff members were then tasked with helping the families through the grieving process in addition to needing to work through the process themselves. Even with professional training in their field, this process can still be incredibly challenging and stressful for the staff caregivers.

In the interviews, multiple respondents noted that more counseling for families and staff who worked with the patients would be beneficial for all involved. In particular, due to the high level of interaction between the caregivers and the families and the patient due to the patient’s intellectual disability, it is important that bereavement counseling be available to anyone who was close to the patient and desires counseling services.

### *Presence at Time of Death*

Whether or not the family members and/or caregivers were present at the time of the patient's death was also a common theme that appeared to dictate how comfortable the respondents were after their loved one's passing. When the respondents had the ability to be present at the time that their loved one or patient died, they reported feeling more peace in the moments afterward. When this was not possible, knowing that someone who knew their loved was present, such as a friend or another family member, brought a similar sense of comfort. While it is often difficult to accurately predict the moment when someone is going to die, it is important that hospice care staff and those present with the patient do their best to inform the family when the patient is close to death.

Respondent 5 talked about how she missed the passing of her loved one due to another obligation, but she did have the opportunity to be present the night before his passing. The fact that she was not able to be there when he died was difficult for her, but the knowledge that she had been there, and that other friends and family members were there at the moment when he passed, still brought her a sense of comfort. Respondent 4 reported a similar situation, in that she was also not present when her loved one passed away, but she had been visiting her earlier in the morning on the day that it occurred. While she was also saddened that she was not there when her loved one died, she also reported feeling comfortable with the knowledge that there were caregivers present who knew her loved one. It is difficult for family members when a loved one is dying for many different reasons, but one reason is the inevitable fact that they cannot be with their

loved one all of the time when they are nearing death due to other extenuating life circumstances that are out of their control.

In contrast to the experiences of Respondents 4 and 5, Respondents 1 and 3 were present at the time of their loved one and/or patient's death. Respondent 1 was present when her loved one passed away, and the family called one of the nurses whom their loved one had been close to during her time in the care facility to inform her that she was passing. The nurse left what she was doing to come say goodbye, symbolizing the strength of the relationship that she had formed with the patient. About this specific situation, Respondent 1 remarked that she "could not have asked for a better group of people to have taken care of her [loved one]". Everyone being present with her loved one and caring for her even at the end brought Respondent 1 peace. Respondent 3, who was a caregiver and friend of the patient, was also present at the time of his passing. She remarked that her ability to be present at the time of death was "comforting to the patient and caregiver", who in this situation happened to be herself. As she spoke more about the powerful impact that her interactions with the patient had on her life, it made her statements about her own presence at the time of the patient's death hold more meaning. Clearly, the ability to be present at the time of death was a very helpful advantage for her as she began the grieving process for her friend.

While it is valuable to make every effort possible to have the family present at the time of the patient's death, this is often difficult to ensure due to the complicated nature of death. Because of the challenges, "family presence at the time of death is a process of end-of-life care, requiring coordinated effort and thoughtful attention to family needs" (Lewis & Williams, 2012, p. 455). It is important that the staff members at the care

facility and the hospice nurses work with the families to do their best to be present with their loved one, as this brings comfort and closure to their loved one, the family, and the staff caregivers. It is believed that “family presence at time of death is associated with quality of death and dying”, and therefore everything that can be done to increase family presence at the time of death should be advocated for when possible (Lewis & Williams, 2012, p. 455).

### *Level of Awareness of Healthcare Professionals*

Another interesting insight that arose through the interview conversations related to the knowledge and understanding that healthcare professionals had about the end-of-life care process in general, and specifically in relation to patients with intellectual disabilities. Speaking about physicians in particular, multiple interview participants expressed frustration and disappointment about the lack of desire that many of the physicians that they encountered had toward learning and knowing more about how to best treat patients with intellectual disabilities. Respondent 2, who interacted with physicians often, expressed that many of the physicians who treated her loved one “had never seen anybody like her”, and therefore did not have the knowledge necessary to guide the family members in their difficult decision-making journey. While some level of unfamiliarity with a topic this specific is to be expected, it is important that medical education institutions work to incorporate teaching about the treatment of patients with disabilities more holistically into their curriculums.

Respondent 3, who worked as a caregiver professionally, expressed that the lack of physician knowledge about this subject was often related to an absence of interacting

with people with disabilities in their life outside of their work. This was an interesting insight that points to the importance of work with people with disabilities for anyone hoping to enter a healthcare related profession.

Respondent 2 also spoke in depth about the impact that physician knowledge, or the lack thereof, about treating patients with disabilities had on the experience of her loved one. As someone involved in a healthcare profession, Respondent 2 spoke about the value that her experience with her loved had on her care of patients. She also spoke about the general lack of knowledge among all medical personal treating her loved one in terms of specific considerations to be accounted for when treating patients with intellectual disabilities. In particular, she remarked that they may have encouraged her to keep her loved one alive too long, and in response to this she stated that “death isn’t the enemy people in medicine think it is.” Unfortunately, in this specific situation, the lack of knowledge among medical professionals about treating a patient with intellectual disabilities at the end of their life ended up leaving the family member, Respondent 2, with a sense of discomfort and guilt after the passing of her loved one.

Taking into account the experiences of these respondents, it is important that healthcare professionals have a satisfactory understanding of the complications that can arise in the treatment of patients with disabilities, and therefore, it is the responsibility of both the providers themselves and the educational institutions that train them to ensure that all healthcare workers are sufficiently trained and knowledgeable about this subject. This preparation and understanding has the potential to greatly impact the experiences of patients with disabilities and their family members in either a positive or negative way, and therefore, this should be elevated in importance of study.

## CHAPTER THREE

### Discussion

#### *Interpretation of Results*

Throughout the interview process, different emergent themes arose. These themes clarified the most important and impactful aspects of the end-of-life care and decision-making process for patients with intellectual disabilities. Through reflecting on the current research on this topic, it is clear that the process impacts the patients, family members, and caregivers differently. Despite this variation, there is also a significant amount of commonality among the experiences reported by the respondents. Among these reports, nine common underlying themes emerged. These themes were: the value of patient autonomy, the importance of setting/context, the delegation of the decision-making responsibility, the weight of this responsibility on the family members, the interactions between staff caregivers and family members, the time when referred to palliative and hospice care services, the counseling availability for families and staff, the benefits of presence at the time of death, and the level of awareness of healthcare professionals. Each of these themes reflected an important aspect of the care process that either served to benefit or harm the patient, family members, or staff members. By identifying the pieces of the care process that were beneficial, it is now possible to understand these in the context of future care. It is also helpful to know and understand the pieces of the process that were hurtful to any of the three parties involved, as knowing about these problems is the first step toward finding solutions to them.

The patients were the group most directly affected by the end-of-life care that they received. In evaluating the patient experience, patient autonomy, the importance of setting/context, and the benefits of presence at the time of death arose as especially important due to their immediate impacts on the patient. When questioned during the interview process, the respondents often reflected on these three themes by discussing the impacts of these factors on their patient and/or loved one.

The family members were also heavily impacted throughout the course of end-of-life care process. The family members in particular were affected by the decision-making responsibility and its resultant weight on them during and after their loved one's passing. Another factor that deeply impacted the families was the timing of discussion and agreement to palliative and hospice care. The interactions that the family members had with the caregivers also appeared important in their experience.

The caregivers were also impacted due to their close contact and relationships with their patients. The caregivers, in particular when they became friends with their patients, were emotionally impacted. Therefore, the option of counseling is important for caregivers within the grieving process. The level of awareness among staff caregivers and healthcare professionals about treating patients with disabilities is also important when considering the caregiver perspective. Lastly, the caregivers were also impacted by their relationships with family members of the patient.

Hopefully, the findings expanded on in the above section will serve not just to inform my future practice, but also to help others understand the different dimensions of care in order to best serve future patients.

### *Limitations*

There were multiple factors that limited this study and its resultant findings. First, due to the COVID-19 pandemic, all of the interviews were conducted over the phone, as opposed to face-to-face which would have been preferable. In particular, this may have had an impact on the comfortability of the interview participants as they discussed these sensitive topics. Not being able to sit face-to-face prevented the respondents from being able to gauge my own response to their answers and it prevented me from being able to fully gauge their emotional state during the interview.

Another limitation is the lack of men interviewed in this study. As all of the interview subjects were middle-aged or older women, this inherently shaped the perspectives that were received in a particular way. While this most likely did not have a huge impact on the findings, I believe that in future studies it would be valuable to try and include men in the cohort of interview participants.

A final limitation of the study is the small sample size of interview respondents. Despite recruiting subjects over a series of months and employing snowball sampling, only five interview respondents were ultimately recruited. This was not ideal, but despite the limited sample, many different perspectives were still shared that offered unique insights.

### *Future Research*

I also believe that there are many important aspects of this topic that still necessitate further exploration. With the specific nature of this study, it has only touched on a few important findings relating to end-of-life care for people with intellectual



disabilities, and I see room for future increased understanding of this topic through more complex studies and studies that interview a broader, larger cohort of participants.

I believe that this topic is important to medicine and the treatment of all people with intellectual disabilities, and therefore, I am hopeful that the library of research relating to this specific topic will continue to grow as awareness of the issues surrounding end-of-life care for people with intellectual disabilities grows.

### *Conclusion*

The conversations that I had the privilege of taking part of through this thesis project have illuminated both areas of great success and areas where improvement is still needed. I feel honored to have had the opportunity to engage with and learn from so many wonderful people through this project.

## CHAPTER FOUR

### Moving Forward/Future Application

As I was thinking about what topic I wanted to study for my thesis project, many different factors pointed me toward the study that I chose. However, it was a specific aspect of this study that truly compelled me to understand the importance of further study of this topic. As I asked questions, shadowed, and gained knowledge from healthcare experiences throughout my college pre-medical studies, I learned more about the lack of medical education surrounding disability. The time spent in medical school discussing the topic of disability is far less than is necessary to train physicians fully on the subject. I also learned about the negative attitudes often held by physicians toward people with disabilities, and the extra danger of this when physicians are not personally aware of their own subconscious negative biases. Lastly, I learned about the importance of peer education from students and faculty who do have knowledge about treatment of patients with disabilities. From this study that I have been privileged to perform, I now plan to use the information gained to help encourage discussions with my future peers in medical school, to further explore the topic independently, and to use what I have already learned to best treat patients in the future.

Recently, as the topic of disability education has been talked about more frequently, medical schools around the country have been examined to determine how adequately they are teaching students about the treatment of patients with disabilities. After spending time learning more about the medical school curriculum and the lack of presence of teaching about disability in most medical schools, I have been compelled to understand why this is so, and I have also been motivated to discuss this when I enter

medical school this upcoming summer. A study examining the presence of disability education at Tufts University School of Medicine offered some insight into this subject. Minihan et al. (2004) stated that “medical schools should play a pivotal role in efforts to produce physicians who are knowledgeable about the needs of patients with disabilities, yet only a handful of medical schools offer formal content about disability and this rarely reaches a broad cross section of students” (p. 1). The acknowledgement of the shortcomings in the realm of medical education about disabilities is the first step in improving them, but there is much more work that still needs to be done to address the negative effects of this lack of disability education.

Another issue that needs to be addressed in the medical field is the unacknowledged negative biases that physicians and other healthcare workers often have toward people with disabilities. While many physicians would like to believe that they do not struggle with biases, there is great evidence that biases deeply affect health outcomes among different groups of patients. It has been found that “even unrecognized perceptions can influence physicians' judgments and interventions, and have profound effects on the treatment process” (McColl et al., 2008, p. 132). Therefore, it is important that these perceptions be known and understood before physicians begin to treat patients who may have diagnosed disabilities. The impacts of biases can be clearly seen when looking at the treatment outcomes of other marginalized groups, and they must be addressed in order for them not to be furthered. According to one study looking at doctors' treatment of patients with disabilities, the researchers found that “one-fifth of doctors did not take adequate account of the disability, while another fifth tended to attribute everything to the disability, and therefore did not explore new complaints as

thoroughly as was warranted” (McColl et al., 2008, p. 133). Both of these extremes can be harmful to the patients being treated, and in the case with patients with disabilities, it is even more vital that physicians be aware of the needs of patients when they may not be able to communicate them themselves. Because “physicians may also fail to assess specific health vulnerabilities facing many people with disabilities which require particular attention” (Minihan et al., 2004, p. 1), it is essential that all members of the healthcare team work to increase attention to specific issues surrounding the treatment of patients with disabilities. It is difficult to force the full responsibility of this education onto those who may already have knowledge of the subject, but as of right now, with the current lack of medical education surrounding the treatment of patients with disabilities, it is the best option to advocate for the highest standard of care for all people. There has been a lot of movement recently to address serious healthcare disparities, and in the realm of disability, “disparities have been associated with poor health care provider understanding of disability, as misunderstandings lead to inappropriate assumptions and a decrease in quality of care” (Rogers Julie M. et al., 2016, p. 2). This can happen any time from the beginning of life all the way to the end of life, and it is clear from my conversations that often misunderstandings resulted in discomfort for patients with disabilities and their families at the end of life. In order to best confront this issue moving forward, the standard and amount of physician education about treating patients with disabilities must be increased.

Until medical schools and other healthcare education institutions can shift their curricula to include more discussion and teaching surrounding patients with disabilities, it is important that students and faculty members who do have an understanding or interest

in the subject should make sure to increase peer education and non-curriculum related teaching. This may look very differently depending on the school and person, but it has the potential to have a large impact on the treatment of patients, and therefore, it is very important. At the Mayo clinic, a panel was assembled to discuss issues relating to disability education in 2016. They found that after the panel discussion, “the disability curriculum has been well received”, and that “the most important part of the session development was the involvement of the local disability community” (Rogers Julie M. et al., 2016, p. 3). While this was a step forward in increasing education for this specific community of students and faculty, steps like this need to be taken at all medical education facilities in the United States and abroad. While medical institutions slowly increase their education on this subject, it is important for students and faculty who do have knowledge and interest in this specific field to advocate for these patients and help educate their peers and students.

As I move forward with my own medical education that will be starting this upcoming summer, I intend to use what I have learned from this study to best support and advocate for patients with disabilities. If I notice that the education about treatment of patients with disabilities is lacking, this is something that I plan to work to change. While I know my abilities to do this as a student may be limited, I still plan to do the most that I can within my position in the institution. Furthermore, once I do become a physician, I plan to continue educating and learning from my peers about this important subject. In particular, I will use what I have learned in this study about the treatment of patients with disabilities at the end of life to support and advocate for future patients and their families who may face this situation.

As discussed earlier in this paper, I believe that people with disabilities are one of the most vulnerable and marginalized communities in the world today. Especially with the rise of practices such as selective termination of fetuses that present with genetic markers of disabilities, it is more important now than ever before the healthcare providers take the time to think about the implications of their care of people with disabilities. If healthcare providers believe that the lives of people with disabilities are as valuable as the lives of every other group of people in the population, then it is essential that they work to advocate for them in all aspects of care. This includes more than just supporting the birth of people with disabilities, as care continues throughout the lifetime of these patients. This includes care at the end of these patients' lives, and as I have learned through this study, there are still many things that can be improved in the care of people with intellectual disabilities at the end of life.

## APPENDICES

## APPENDIX A

Table of Interview Respondents

Interview Participant	Details	Relationship to Person with Disability
Respondent 1	54-year-old female	Sister of patient
Respondent 2	64-year-old female	Twin sister of patient
Respondent 3	50-year-old female	Close friend/caregiver of patient
Respondent 4	90-year-old female	Mother of patient
Respondent 5	77-year-old female	Older sister of patient



## APPENDIX B

### Interview Questions

#### *Contextual Questions*

- What is your relationship to the loved one, and how did your interactions with them shape you?
- In what capacity were you caring for the person?
- How long did you care for this person before they died?
- How would you describe their decision-making capacity when you first met them? When they reached the end of their life?
- Were you or other caregivers/family members present in the last moments of this person's life?

#### *Experiential Questions*

- In the days leading up to their death, how would you describe their state of being?
- What things contributed to the person's dignity at the end of their life? What aspects of care seemed to lessen the person's dignity?
- How involved was the loved one in their own end-of-life decision making? How involved was their family?
- How did the person's intellectual disability affect your experience of caring for them at the end of their life?
- What aspects of care contributed most to the person's comfort?
- What aspects of care contributed most to the family's comfort?

#### *Hypothetical Questions*

- Is there any way that you believe the end-of-life process could be made better for people with intellectual disabilities?
- If you could identify one aspect of the process that benefitted the person and their family the most, what would it be?
- Is there anything else you think it would be helpful for me to know?

## APPENDIX C

### Consent Form

Baylor University  
**Medical Humanities**

#### Consent Form for Research

PROTOCOL TITLE: Perspectives on End-of-Life Decision Making for Intellectually Disabled Adults

PRINCIPAL INVESTIGATOR: Caroline Hughes

SUPPORTED BY: Baylor University

**Purpose of the research:** Honors Thesis

**Study activities:** Participating in this study will involve taking part in an interview exploring end-of-life decision making for adults with intellectual disabilities. The interview will generally ask about your observations and experience from your position as caregiver. The interview will last between 30 minutes and an hour. It will be conducted in person, over the phone, or through a video interview platform.

**Risks and Benefits:** The risks of the study are very low. Speaking about a sensitive subject such as death may be difficult for some of the caregivers, particularly those who may have been family members of the deceased person.

The interviews will remain professional and the participants will be reminded that they do not have to answer a question if they do not feel comfortable. The participant may also end the interview at any point if they are no longer comfortable with proceeding. The names of study participants will not be disclosed.

The participants may gain from participation in this study the satisfaction of furthering discussion on this topic. They may also find the reflection that the interview questions will encourage beneficial in the grieving process. The hope is that the information acquired through these interviews will be beneficial to the greater disabled community by emphasizing the necessity for better understanding of the end-of-life process.

**Confidentiality:** Random case numbers will be assigned to each participant in order to ensure confidentiality. Any information that could be used to personally identify a participant will be kept apart from the field notes.

Signed consent forms will be kept in a locked file cabinet, and emails communication will be printed and then deleted. The print copies will be stored alongside the consent

forms and any other paper documentation in the locked file cabinet. All field notes and other information will be destroyed two years after first presentation.

Authorized staff of Baylor University may review the study records for purposes such as quality control or safety.

**Compensation:** N/A

**Questions or concerns about this research study:** You can call the researcher(s) with any concerns or questions about the research.

Caroline Hughes  
2613 Graduate Row  
Waco, TX 76706  
Phone 713-471-6548  
[Caroline\\_Hughes1@baylor.edu](mailto:Caroline_Hughes1@baylor.edu)

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One Bear Place #97202  
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Phone (254) 292-9900  
[Bill\\_Hoy@baylor.edu](mailto:Bill_Hoy@baylor.edu)

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), you may contact the Baylor University IRB through the Office of the Vice Provost for Research at 254-710-3708 or [irb@baylor.edu](mailto:irb@baylor.edu).

Taking part in this study is your choice. You are free not to take part or to stop at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential. Information already collected about you cannot be deleted.

By continuing with the research and completing the study activities, you are providing your consent.

APPENDIX D

IRB Approval



Baylor University

INSTITUTIONAL REVIEW BOARD – PROTECTION OF HUMAN SUBJECTS IN RESEARCH

**NOTICE OF EXEMPTION FROM IRB REVIEW**

Principal Investigator: Caroline Hughes  
Study Title: Perspectives on End-of-Life Decision Making for Intellectually Disabled Adults  
IRB Reference #: 1668672  
Date of Determination: October 16, 2020  
Exemption Category: 45 CFR 46.104(d)(2)

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The above referenced human subjects research project has been determined to be EXEMPT from review by the Baylor University Institutional Review Board (IRB) according to federal regulation 45 CFR 46.104(d)(2): Research involving the use of educational tests, survey procedures, interview procedures or observation of public behavior.

The following documents were reviewed:

- IRB Application, submitted on 10/14/2020
- Protocol, dated 10/07/2020
- Consent Form, dated 10/07/2020
- Interview Questions, submitted on 10/07/2020

This exemption is limited to the activities described in the submitted materials. If the research is modified, you must contact this office to determine whether your research is still eligible for exemption prior to implementing the modifications.

If you have any questions, please contact the office at (254) 710-3708 or [IRB@baylor.edu](mailto:IRB@baylor.edu)

Sincerely,

A handwritten signature in black ink, appearing to read 'Deborah L. Holland'.

Deborah L. Holland, JD, MPH, CHRC, CHPC  
Assistant Vice Provost for Research, Research Compliance

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