

## ABSTRACT

COVID and Coping: A Grounded Theory Study of Isolation and Its Effect on Grief

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Communities all over the world have been grappling with the SARS-CoV-2 coronavirus (COVID) pandemic since early 2020, with countries struggling to maintain their economic, political, and healthcare infrastructures amidst the chaos. As COVID cases are slowly beginning to decrease, researchers are examining a variety of ways that this pandemic has affected the population long-term. One issue that researchers have noted in the general public is the inability of people to freely grieve for a loved one. People who have lost a friend or family member in the pandemic have often been confined to a near-solitary state of grieving due to the quarantine policies currently in place. Thanatologists share the current concerns that researchers and healthcare professionals have expressed, believing that grieving people may be unable to return to their lives after being forced to isolate for so long. This study was designed to explore the perceptions of individuals who have lost a loved one during the COVID pandemic in order to generate a substantive theory on ambiguous loss and perceptions of successful coping. This qualitative study utilized an active interviewing process following a Glaserian grounded-theory design to identify the emerging themes of loss of control, conflict between fear and need, and lack of community. An understanding of these findings provokes further thought into the long-term mental health assistance necessary for the growing number of people who have experienced the impact of losing a loved one during the pandemic.

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COVID AND COPING: A GROUNDED THEORY STUDY OF ISOLATION AND ITS  
EFFECT ON GRIEF

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## PREFACE

This thesis is submitted for the satisfaction of the Honors College program requirements at Baylor University. The research described in this study was conducted by Andrew D. Kim, under the mentorship of Dr. William G. Hoy in the Department of Medical Humanities, Baylor University, between October 2021 and May 2022. To the best of my knowledge the work written here is original, except where references are made to further publications and literary works.

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The interviewees

For shaping this project, and me

## CHAPTER ONE

### Introduction

#### *Context*

“COVID-19 will reshape our world. We don’t yet know when the crisis will end. But we can be sure that by the time it does, our world will look very different.” This statement was made by Josep Borrell, High Representative of the European Union for Foreign Affairs and Security Policy, to address the political and economic factors negatively affecting countries around the world (European Union External Action, 2020). However, another unspoken responsibility is imbedded in this warning: individuals are being neglected while leaders focus on “big picture” issues. More specifically, geopolitical figures have been obsessing with the preservation of their countries’ human capital and population health, the pandemic has been rapidly claiming lives. Those fortunate enough to have avoided serious health complications for themselves and their loved ones during the pandemic may view deaths during this time as unfortunate but expected, nonetheless. They may have the mindset, “It is impossible to save everyone in a pandemic” or “Why should we focus on grieving the dead now, when we have other people to save?”

While some people may have this outlook, it appears that our society may have already been affected permanently. A poll taken in January 2022 stated that seven in 10 Americans believe that “...it is time we accept that [COVID] is here to stay, and we just need to get on with our lives” (Monmouth University, 2022). Many public health experts, like Dr. Davey Smith, Chief of Infectious Diseases at UC San Diego, share this perspective. In a media interview, Dr. Smith stated that “... [I will be] seeing COVID-19

as an infectious disease doctor for the rest of my career...” (NBCNews, 2021). Because there is not a foreseeable end to COVID, the quarantine policies and social distancing will likely be in place long-term. These policies and laws are already causing distress by isolating people from the social lives that they desire. Additionally, with misinformation consistently spreading about COVID, many are struggling because their health issues are being overlooked, overshadowed by the political battles taking place in the media.

Even though cases have begun to decline recently, the world is still experiencing the psychological and emotional effects of COVID. Members of the general public and healthcare fields alike are facing mental exhaustion from the continued threat that COVID presents. Despite the global fatigue toward COVID-related matters, healthcare leaders must set up accommodations for those suffering now; failure to do so will negatively impact how they function in society in the future. Furthermore, if the pandemic is permanent, then COVID-related deaths in isolation will be, too. Considering this reality, future researchers must determine how to implement proper funeral processes and traditions in accordance with the wishes of the deceased and their loved ones, despite the challenges that COVID presents.

### *Prolonged Grief Disorder*

Why is the fact that people are dying in isolation an issue that must be addressed? The problem centers around the concept of *prolonged grief disorder* (PGD). As a mental disorder, PGD can be defined as the abnormal persistence of grief that afflicts an individual’s way of life. The negative consequences stemming from this condition are clearly life-altering: loss of career, motivation, and overall life perspective are just a few



outcomes that could occur due to the changes in personality and motivation. Because of its implications, PGD is recognized in the new revision of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (released in March 2022) as an official mental disorder. Additionally, PGD is still being studied as a new mental disorder. A prior version of the DSM-5 listed PGD under the category of “Conditions for Further Study,” a category reserved for relatively new disorders that psychologists are still researching (American Psychological Association, 2015). Generally proposed criteria states that PGD can occur when the bereaved person has experienced the death of a loved one more than one year ago (or six months for children). Symptoms that can manifest are:

1. Marked difficulty accepting the death.
2. Experiencing disbelief or emotional numbness over the loss.
3. Difficulty with positive reminiscing about the deceased.
4. Bitterness or anger related to the loss.
5. Maladaptive appraisals about oneself in relation to the deceased
6. A desire to die in order to be with the deceased.
7. Feeling alone or detached from other individuals since the death.
8. Feeling that life is meaningless or empty without the deceased.
9. A diminished sense of one’s identity.
10. Difficulty with or reluctance to pursuing interests.

These behaviors immediately following the death of a loved one can be natural; however, when a person develops PGD, they may experience these symptoms for a period of time that is deemed abnormal per societal and cultural norms (Prigerson, et.al, 2021).

Many of the symptoms present in PGD are also present in other mental disorders, such as major depressive disorder, generalized anxiety disorder, and schizophrenia. Additionally, it is important to recognize that the process of grief manifests itself differently in each individual. Therefore, people with PGD may exhibit many of these symptoms, or barely any at all. Some people may take long periods of time to recover from the death of a close friend or family member, while others may recover sooner. However, psychologists have recognized that, when initially normal grieving behaviors continue to occur over an extended time period, the individual may be experiencing PGD. Grief reactions occurring most of the day, nearly every day, are generally diagnosed as PGD, given that the individual is still experiencing these symptoms more often than not (American Psychological Association, 2022). Because of the potential effects on all facets of an individual's life, PGD must be studied as a subject of utmost importance in the coming years.

Applying this knowledge in the context of the COVID pandemic, many individuals are now in danger of developing PGD due to the nature in which COVID is being handled. Those who die from contracting COVID generally succumb to their illness in weeks, if not days. This short timeframe presents the possibility that their loved ones may be unable to see them within the time they are fully conscious and aware. In addition to the quick deterioration rate, the quarantine policies in hospitals are known to be extremely strict, yet unavoidable. Hospital staff must prioritize the safety of other patients of the facility as well as the healthcare staff, which is why stiff policy is necessary. Loose policies could potentially spread COVID further and put the lives of crucial healthcare staff in danger. The World Health Organization (WHO) has estimated

that a median of 115,500 healthcare workers have died during the timeline of the pandemic, even with precautions in place (World Health Organization, 2021). Not only are these deaths tragic, but the additional lives of patients that were lost because of these deaths should also be added to this perspective.

Therefore, those who are admitted to the hospital with COVID are generally not allowed to see anyone except their designated healthcare providers. This denial of entry for any family or friends is the metaphorical nail in the coffin for PGD. In more cases than not, COVID has been incredibly painful for those experiencing intense cases of respiratory issues. For a family member, being unable to see a loved one die can induce a large amount of stress, much less knowing that he/she is in pain during the process.

Common causation for developing PGD is being unable to see the loved one during or after their time of death because it can be difficult to comprehend it if they cannot be physically present to witness the body. If this does happen, feelings of bitterness and regret can arise, making the individual more susceptible to developing PGD. A study in 2014 revealed that 30% of people who experienced >4 traumatic experiences stated that the unexpected death of their loved one was the most severe experience they had ever felt. Additionally, those who did experience the unexpected loss of their loved one were found to have a heightened risk for psychiatric disorder diagnoses such as mood, anxiety, and alcohol use disorders (Keyes et al., 2014). Since this study was conducted long before the COVID pandemic, it is difficult to determine how COVID-related deaths can play into the overall picture of developing psychiatric disorders. However, I suspect that there has been an amplified effect on the public; not

only are COVID-related deaths unexpected, but isolation could potentially serve as an “echo chamber” for these emotions.

### *Isolation*

In 1979, a silver mine located in Kellogg, Idaho suffered from a fire within the workplace. The evacuation took place, but it was not fast enough to save all the miners still stuck in the cave. This tragic incident was called the Sunshine Mine Disaster, which resulted in the deaths of 91 miners. Following this incident, the nearby Idaho community was devastated. Many of the miners had families and loved ones who were left alone after the disaster. Hearing about the sense of isolation that these widows were experiencing, a study was conducted in 1979 that interviewed 44 widows of victims of the 1972 Sunshine Mine disaster. In this study, researchers identified two types of loneliness: personal loneliness, and community under-involvement. Personal loneliness was described as feeling “remote from other people,” while community under-involvement was whether the widows were involved in community social life as much as they liked (Bahr & Harvey, 1979).

While the differentiation between these two terms was not entirely clear, the factors correlating to loneliness were more than evident. From the interviews, these researchers found that high amounts of both forms of loneliness resulted in lower morale, happiness, and perceived quality of life among widows. This study was conducted seven years after the disaster, and the responses of the widows were a clear indication that these individuals were still struggling with their well-being. As discussed previously, this incident falls under the subject of unexpected death. Even forty years ago, loneliness is a

crucial factor in determining whether an individual may freely grieve. Applying this to the present time, psychologists are fearful of the heightened social isolation which may interfere with an individual's bereavement (Vedder et al., 2021).

### *General Reception*

Ever since the start of the pandemic in 2020, healthcare professionals and funeral directors have recognized this growing problem with those experiencing loss caused and affected by the pandemic. However, what does the public think about this issue? Are they worried for their elderly as much as the statistics threaten?

While the main concept of this study is to evaluate public experiences on their grieving process, there are some media sources previously available that summarize the general reception of grief in the COVID pandemic. In fact, there are some personal accounts sharing how their livelihood has already been taken away. *The Irish Times*, an Ireland mainstream media source, posted a collection of stories in which individuals recalled the lives of their loved ones who had recently died during the pandemic (whether they were victims of COVID or not). In these stories, the grieving individuals also narrated what their lives were like after the funeral was conducted. The stories that they responded with were nothing short of eye-opening. Fintan Reddy, one of the interviewees, stated that "In the funeral service...you would be forgiven for thinking we were all strangers...It isn't fair." Another individual, Sarah Wassell, said that "Not being able to see him in his final weeks, let alone hours, was heartbreaking. We cannot hold any kind of memorial...for those who knew and cared for him... (The Irish Times, 2020). These scenarios are not only happening in Ireland, but all over the world. While some

countries may have differing policies on how to handle COVID, one thing is clear: most people have been affected in one way or another.

### *Media Coverage and Political Standing*

Media coverage during the pandemic is an important matter for consideration including the common assertion that politics has played a role in manipulating information. While this study does seek to listen to the narratives that interviewees have to offer, research will stray away from delving into political issues as much as possible.

Nonetheless, it is clear that the COVID pandemic has not lacked coverage; nearly all mainstream media and websites have covered the pandemic at one time. Although current news has moved on from covering the recent rates of COVID on national TV, the danger of COVID is still ever-present. While many were informed of the number of cases and deaths that were encountered daily, there has also been a constant source of misinformation, misguiding individuals' opinions on the severity or existence of COVID. This type of information has proved to be extremely detrimental, as politics have caused this primarily health-based issue into a controversial one. When mourners encounter this clash in opinion, they may experience something called "disenfranchised grief," where those grieving may be unable to express their loss fully because of the cultural stigma surrounding their loved one's death (NPR News, 2021). Not only are these individuals unable to properly host funerals for their loved ones, but they are also pressured to hide the cause of their death from family and friends. Such behavior promotes isolation from their corresponding communities, which has already been seen to be detrimental for those in grief.

### *Countering Grief and Support*

While there have been many negative consequences of the existence of COVID, groups of people have begun methods to counteract such harm. Seeing the need for people to connect to others, support groups online have been formed so that those in grief can reach out online when they have no one else to contact. While this movement is commendable, it is evident that online groups are nowhere near as effective as consolation from close friends and family (Uden-Kraan et al., 2011).

### *Summary of Purpose*

In summary, COVID and its quarantine/isolation policies are dangerous to a person in grief. When someone we love dies, we are thrown into a whirlwind of emotions that may be difficult to comprehend. Being unable to see them as they die places us in a state of uncertainty; some cannot fully admit that their loved one is dead without seeing the body. Along with these bottled feelings, they are then forced to socially distance themselves, isolating themselves from social support and healthy grieving practices. These people will not be able to experience the comforting touch of another family member or the comfort of witnessing the body at a viewing. Instead, these are replaced with anonymous support group meetings, online funerals, and consolation through brief phone calls and texts. The purpose of this study is to explore the perspectives of those who have experienced the loss of a loved one during the pandemic to create a theory outlining the impact that COVID has had on those in grief.

## CHAPTER TWO

### Literature Review

#### *Grounded Theory*

One of the qualities of the Glaserian grounded theory analysis (further detailed in Chapter 3) is the recognition of implicit bias during the design of the study. “An effective strategy is...to ignore the literature of theory...in order to assure that the emergence of categories will not be contaminated...” (Glaser & Strauss, 1967, p. 37). As stated, researchers must be careful not to cover too much material in the literature review, for fear of obtaining preconceived categories before qualitative analysis begins. While the researcher must understand why the study is being conducted and how to generate proper theory, they must be wary of being unconsciously swayed by any literature similar to the study being conducted. Fortunately, the COVID pandemic is a relatively new occurrence and therefore has less research compared to diseases that have lasted for many years. More literature review will be done in the later chapters of theme exploration once coding has been complete.

While experiencing grief is different for everyone, there are certain preliminary aspects that should not be taken away. Grief is an extremely complex yet universally experienced phenomenon, and one that many find challenging to overcome. For most people, grief is commonly associated with the loss of a loved one, manifesting itself through physical, emotional, and spiritual means. To be aware of one’s own mortality can be frightening, to say the least. However, as scary as it may initially seem, grief is unavoidable. So, if everyone will eventually encounter this subject, why should they be so secretive about it?



Some readers may ask, are funerals that important in the process of grief? The response to these questions is thoroughly addressed in Hoy's *Do Funerals Matter?* Not only does the book break down funerals into their vital components, but it is also stated that "...funerals remind us of the truly endearing values, of the relationships we share and the people whose lives we touched, as well as...recall the people whose lives have touched ours" (Hoy, 2018, p. 181). The physical funeral assists in visual healing as well as providing the necessary traditions to regulate emotions that people experience while the funeral is conducted.

It is clear that basic emotions (sadness, anger, fear, contempt, surprise, etc.) are not enough to convey what many feel as "grief" on a scientific basis because of the social implications and variety of symptoms that can manifest depending on the specific situation. It is difficult to describe and quantify such feelings and thus makes it elusive for researchers to study. Therefore, how are we to explore grief, much less the ambiguous nature of grief that manifested during these recent years of the pandemic? These qualities are taken into account in this study by utilizing Glaserian grounded theory. As a qualitative method of study, the steps require the researchers to dedicate ample time for constant comparison of such qualitative variables. This specific methodology and details mapped in this study will be discussed further in the Methodology section.

## CHAPTER THREE

### Methodology

#### *Restatement of Purpose*

Before elaborating on the methodology, it is important to keep in mind the purpose of this study. Without distinct visualization of the problem at hand, it is difficult to determine the correct methodology and proper techniques to get to the final conclusion. To reiterate, the purpose of this study is to explore the perspectives of those who have experienced the loss of a loved one during the pandemic to create a theory outlining the impact that COVID has had on those in grief. In order to address this question, this qualitative study utilized an active interview format, outlined by a Glaserian grounded-theory study to generate certain emerging themes from the data. A simplified overview of the study includes:

- Interviewing 10 individuals who have recently lost a close family/friend
- Conducting a constant comparison analysis on the data collected
- Grouping categories into an encompassing theory to answer the purpose

#### *Qualitative Research*

While a large portion of academia focuses on quantitative research, there are cases when numbers cannot apply to certain fields of research. For example, it can be difficult for studies to quantify human experiences and emotions. While researchers can create surveys asking participants to rank their emotions from “1 to 10,” they are not representative enough to embody the complex functionality of the human mind. Instead of quantitative research, this study takes the path of qualitative research: more

specifically, the grounded theory research methodology. First established by Barney Glaser and Anselm Strauss, these two first developed the methodology of grounded theory as detailed in their book, *The Discovery of Grounded Theory* (1967). As experts in the field of sociology, Glaser and Strauss noticed that much of the current research conducted in their era consisted of verification of already existing theories. The process of developing new theories in sociological fields was obscure and outdated, which caused these two to eventually craft and propose the now popular methodology of grounded theory. The key aspects of this process generally consisted of:

1. A systematic method of obtaining data
2. Conducting constant comparative method of analysis
3. Creating an overarching theory

This type of study is most effective when the field being studied is generally lacking in detailed knowledge. For example, even though COVID has been thoroughly analyzed on the molecular level, there has been not enough time and resources necessary to see its long-term effects on societal and psychological outcomes. Grounded theory studies are effective in this area because it involves looking for emerging themes from collected data, rather than from previously established theories. Because the researcher is searching for novel categories, they must also consider the life story of those being interviewed within the study. The role of the researcher is to not record their findings objectively. Instead, they are tasked with interpreting individuals' life stories to craft a theory matching the reality that they have witnessed through these spoken words (Glaser & Strauss, 1967).

Another topic that must be addressed is the type of grounded theory that was conducted. In this study, the Glaserian grounded theory was utilized, compared to its Straussian grounded theory counterpart. The difference between these two studies is mainly the amount of previous literature research conducted before the active interview process. In Glaserian grounded theory, it is thought that literature review prior to the active interview process would result in the researcher gaining pre-conceived notions during the coding and categorization process. Straussian grounded theory is considered to be more reformative in its approach to data analysis.

### ***Study Design***

While designing this study, the main question that is necessary to keep in mind is:  
*How do the current COVID policies affect those who are experiencing grief through the loss of a loved one?*

### ***Subject Selection***

Participants were located by reaching out to the local Waco community through advertisement. Utilizing word-of-mouth and various forms of social media (Facebook, Instagram), individuals who have lost a loved one during the pandemic were contacted. The criteria for a subject to be applicable were broad. If the individual had someone close to them (family, friend, etc.) die during the timeline of the pandemic (2020-current 2022), they were qualified for the study. Using snowball sampling and purposive sampling, these individuals were then contacted through the use of email to schedule an interview time and location. Respondents were given the choice between a zoom meeting and an

in-person meeting. A sample email and phone script for initial respondent recruitment are attached in APPENDIX.

### *Compensation*

As compensation for participating in the interview, each participant was awarded a \$25 gift card. No other compensation was given to participants. Funding for the gift cards was acquired from the Baylor Honors College Grant. Prior to this grant, the initial compensation was designed to be a lottery, with gift cards being given to only 3 of the participants. Once the grant was received and the IRB amendment was approved, the additional funds were included in the official proposal.

### *Research Design*

After reading and agreeing to the Consent Form for Research (see APPENDIX), the interview began with a summary statement introducing the purpose of the study and the general areas of inquiry to ascertain the participant's willingness to continue the interview. Basic demographic information was also collected for classification purposes only.

This study consisted of open-ended questions as part of a semi-structured interview, beginning with questions from the interview guide (see APPENDIX). Participants were also given opportunities to discuss matters the participants perceived were not addressed adequately in the interview. The field notes were saved following the conclusion of the interview, but the interviews themselves were not recorded to assure

confidentiality and candor (Glaser, 1999). No personally identifying information was included in the field notes.

Following Glaser & Strauss' (1967) protocol, the interview field notes were then coded for emergent themes and compared using the grounded theory's procedures of "constant comparison," which evaluated each interview to what was heard in earlier interviews. If this study proceeds according to previous research, these codes will reach "theoretical saturation" before all interviews are conducted. In theoretical saturation, Glaser & Strauss (1967) and Glaser (1999) suggest the threshold is reached when additional data collection seems to be offering no substantially new perspectives. Nevertheless, each interview was conducted to the fullest until it was determined that the interview respondent had given a full narration of their experience. Again, questions in the interview guide assured that there was a satisfaction of data necessary for the topics of interest in this study.

One essential difference between classic grounded theory and other qualitative data analysis methodologies is that in GT, the literature review is conducted alongside interviews and is seen as data in its own right (Glaser, 1999). Typically (as in this study), a preliminary literature review is done to assure a salient question in need of further study; an extensive review of the literature is reserved for the period during and following interviews so that previous results do not "cloud" the researcher's judgment. This concept is also known as internal consistency, which is vital in ensuring validity grounded theory research (Glaser & Strauss, 1967; Blumer, 1938).

### *Risks*

The potential risk of harm to research participants was minimal. The only major consideration was that subjects could potentially experience negative feelings about their own experience, such as the memories of their loved ones, potentially evoking sorrow and nostalgia in the process.

To counteract this potential issue, subjects were informed that they were not obliged to answer any of the questions asked of them. The participant had a right to answer only those questions with which they felt comfortable with. They were also informed that they may terminate the interview at any time if they feel uncomfortable: the compensation would not be revoked if they did so. Recommendations to employee assistance programs and other professionals for follow-up care were also offered to any participants who desired so in the interviews.

It is believed that potential risks are partially mitigated by participants' willingness to participate in the study; a narrative retelling of experiences is widely regarded as a helpful step in processing intense emotion (Worden, 2018). Furthermore, the individuals participating in the study were told that their perspectives contributed to a more significant understanding of the effect of COVID and grief during the pandemic.

### *Privacy and Confidentiality*

No respondents are identified in this study, and no personally identifiable information is included in the findings. Consent Forms and research protocols were maintained by the PI permanently. All field notes were stored in a locked filing cabinet remote from the file containing the names and email addresses of respondents (only kept

for the purposes of the compensation distribution). Only the corresponding respondent code number was indicated on the field notes. These notes and identification codes are stored by the PI for a period of not less than three years following the presentation of the findings. Exemption from IRB review was submitted as a request through IRBnet.org, where the Baylor Institutional Review Board reviewed and exempted the proposal prior to interviewing. The researcher was only permitted to begin interviewing once exemption was given.

### *Data Collection*

Grounded theory study is an inductive process, where the data that is collected from individuals is open to interpretation and categorization (Glaser & Strauss, 1967). In the general research overview detailed above, it was stated that the created list of questions served as an open-ended guideline for a “semi-structured” interview. While the questions themselves served as a good foundation for many of the topics that were needing to be addressed, much of the data collection stemmed from the conversation itself. In similar words, Glaser and Strauss stated that the beginning of research consists of “open-ended conversation...which respondents are allowed to talk with no imposed limitations of time. Often the researcher sits back and listens while respondents tell their stories”...(Glaser & Strauss, 1967, p. 75-76). The interviewer should only interject with further questions when an emerging theory is noticed during the flow of conversation.

Additional notes were taken on more factors than just the literal content of spoken words. The tone of voice, slang, and body language are some aspects that are also necessary during the interview. This type of interviewing is also known as the “Active



Interview” process, where researchers are taking into account a holistic view of the interviewee to get the most detailed perception of the individual and the meaning behind their stories (Glaser & Strauss, 1967). The interviewer is not only responsible for recording these details; they then must properly analyze and code them for interpretation.

#### *List of questions*

The full list of structured questions is listed in the APPENDIX. It is important to note that the number and types of questions per interview varied depending on individual circumstances. The first few interviews conducted utilized more of the questions from the list. However, in the later interviews, the non-relevant questions were discarded to make room for discussion on concepts that more commonly appeared.

#### *Constant comparative analysis*

A major strategy necessary to forward grounded theory is the method of comparative analysis (Glaser & Strauss, 1967). Using this method, researchers can control the way they analyze qualitative data by evaluating common themes that emerge from a majority of the interviews conducted. The definition of constant comparative analysis is fairly evident, as it is stated in the name. This method evaluates consistency by creating patterns across interviews while determining a systematic comparison of the codes detailed in each. Starting from the first interview, memos are collected to be compiled into larger categories, which can later be summarized as an overarching theory grounded in data.

### *Coding*

Glaser and Strauss mention, “The sociologist must engage continually in some systematic coding [by] usually just jotting categories and properties on the margins of his field notes...” (Glaser & Strauss, 1967). Following this method strictly, footnotes and memos were made in the margins as interviews were conducted. This process could be described as adaptive, constantly evolving as categories are being shaped and refined to fit the core of a developing theory. This step is vital in the process of coding, as researchers can easily fall into the trap of collecting large amounts of unnecessary codes if they are not consistently trying to fit the “puzzle pieces” together.

### *Identifying categories*

A category can be defined as a core subject that can be connected to the theory’s main story (La Rossa, 2005). Over time, the categories that are proposed should become clearer and more defined as each interview connects to them. The actual categories developed within this study will be mentioned in the findings section. As more interviews were conducted with additional interviewees, the length of each interview was shortened because of the development of categories seen throughout a majority of the conversations conducted.

### *Limitations*

While this study serves as a great fit for grounded theory, there are some difficulties present due to the openness that this methodology offers. The most obvious limitation is shared with other forms of qualitative research, which is the opportunity for

error and bias. The influence of the investigator is present in all steps of grounded theory, from the interview to the development of codes to the coalescence of themes (Chapman et al., 2015). While the end goal is to create a theory based on the grounded reality of others, it is not possible to create a truly unbiased account of analysis as long as such influence remains. However, it is important to note that consistency is still upheld due to the interviews being conducted by only the PI. Since there were no other investigators involved in the interview process, each coding process was done by the same person, hence the consistency allowing effective use of constant comparison.

#### *Verification, consistency, and reliability*

It is evident that qualitative data is heavily reliant on the nature of the interviewer and the participants. However, the manufactured theory still needs to have a degree of consistency per the interviews conducted. Glaser and Strauss stated in the preface of their book, “Although our emphasis is on generating theory rather than verifying it, we take special pains not to divorce those two activities, both necessary to the scientific enterprise” (Glaser & Strauss, 1967, p. viii). This means that when the theory is re-introduced to each interview, it should encompass the vital points coded during the interview. If the theory is presented but does not appear to apply to a past interview, the researcher must reevaluate their data and propose a new theory that can account for the previously excluded data. Many times, researchers are required to refine their categories numerous times in order to find connective themes across the various coded data. Only when a common central framework emerges can researchers be satisfied (theoretical saturation).

## CHAPTER FOUR

### Findings

Upon constant comparative analysis, three unique themes were found to perforate across all the interviews completed. Each theme will be discussed in detail, along with examples of related codes in interviews pertaining to the categories. These themes are:

1. Loss of Control
2. Conflict between Fear and Need
3. Lack of Community

#### *Theme 1: Loss of Control*

This theme emerged quickly from some of the earliest interviews that were conducted. As interviews accumulated, it was evident that each respondent felt they were unable to thoroughly grieve during the time of death.

When speaking to the respondents, two distinct timelines emerged when speaking about control: before the loved one's death and afterward (i.e., funeral, celebration-of-life, etc.). The first time period is the lack of control that the respondents experienced prior to the death of their loved ones. A question that was commonly asked by the interviewee was, "Did the pandemic restrict any customs that you planned prior to their death?" (See APPENDIX). Often the response was, in some form, "yes." Many of the cases interviewed had their loved ones either in a hospital or medical institution miles away from their home. Respondent 3 stated that her mother resided in a local hospital for 40 days prior to her death. This shows that even before death, quarantine policies in healthcare institutions that restrict visitations have caused some to experience a loss of

control over patient autonomy. While patient autonomy is widely accepted in the healthcare field, there are some instances where it is impossible to prioritize such. For example, in the case of COVID, accommodations can be made to make the patient comfortable, but moving them to a hospice center or care facility would endanger the elderly who would inevitably come into contact with the virus at these populated locations (Abbott et al., 2020). Unfortunately, this means that those who are infected are typically unable to determine the location where they die. In a majority of the respondents' cases, the loved one unexpectedly died in either a hospital or local ICU. Control over the place of death is important and should be a major consideration in comforting those experiencing death (Seal et al., 2015).

The second timeline to consider is after the death of the individual and how the loss of control is still a dominant theme throughout. In this case, the focus falls on how the body was handled in terms of funeral procession and planning. When asked, Respondent 10 stated that he was highly discouraged from planning a funeral, which eventually prevented him from hosting a funeral at all. This individual stated that he felt stifled and that the funeral homes were "out to get him" (Respondent 10). This case with Respondent 10 was abnormally severe, as the other respondents were able to at least host a physical funeral. However, objections were raised when questioning whether the funeral was carried out as they preferred. Respondent 1 directly said, "[the funeral] was supposed to happen one way, this wasn't how it was supposed to be" (Respondent 1). Another interviewee stated, "...I didn't give him a proper sendoff...I still regret it every day" (Respondent 4). It is shockingly clear how displeased many of the respondents were with the funeral. Whether it was due to the number of attendees, the attitude of the

funeral staff, or the financial constraint, COVID has played a large factor in hindering the ability of many individuals to host a proper funeral. Studies have shown that the body's presence at a funeral can be vital to entering a period of transitioning from life to death. This concept is known as the body's *liminality*, where witnesses can escape the limbo of considering their loved one as "...no longer alive...but...not yet safely dead" (Hoy, 2013, p. 115). Without a proper viewing of the body, some people may eventually be stuck in this "in-between." This is an unhealthy position to be in, as the individual would continue to struggle with accepting that their loved one is gone, lengthening their grief and exposing themselves to the dangers of PGD as discussed earlier. As another respondent summarized, "...I wanted her to die easy, not with these tubes stuck in her. I wanted to see her die drinking a margarita on a beach..." (Respondent 2).

### *Summary*

Prior to the commencement of this study, I participated in William G. Hoy's End-of-Life Care course, a senior-level class in which students discussed important factors that played into the lives of those nearing the end of their life. One class period that stood out to me was the discussion on the importance of hospice and palliative care. A poll was conducted in 2017 regarding public opinion on hospice care. Among the 70% who knew what hospice was, a large majority (~85%) had a positive opinion of hospice care (Hamel et al., 2017). Why were hospice and palliative care so important? During this discussion, we eventually touched on one of the many reasons why these types of care are crucial: the concept of control during death. For many, it brings comfort to the dying and their loved ones when they are aware that death is approaching. As grim as it may sound,

visualizing a general sense of the amount of time that someone has left to live can serve as a form of comfort (Abbott et al., 2020).

One of the prominent issues commonly associated with hospice was that discussing death was a “taboo,” a concept that people avoided in everyday conversations (Bellamy et al., 2022). A grounded theory study was conducted in 2013, breaking down the processes that people undergo when attempting to discuss death. The study found that there were three general categories of dying-control discussed, which were *closed dying*, *open dying with reversible medical control*, and *open dying with irreversible medical control* (Thulesius et al., 2013). Each person generally fell into one of the three categories, depending on how open they were to discuss palliative care, sedation therapy, and euthanasia. While some geographical locations are more readily comfortable for discussing control of death, it is clear that a majority are still hesitant because of the preconceived negative emotions. Because people were struggling to discuss controlled measures of death pre-pandemic, it can only be presumed how much COVID has discouraged this type of discussion. It was noted that some respondents felt unprepared for the death of their loved one, which felt “untimely” (Respondent 2, 3, 6, 7). The pandemic has caused families and friends to be both physically and emotionally distanced from each other, making communication for these types of conversations more difficult. Respondent 7 was quarantined at the time, so she was unable to be present during the planning of her mother’s funeral during the pandemic. Since then, she stated, “...I never really had a chance to experience what was involved in planning [my mother’s] funeral. I wanted to do more for her, but it was out of my control” (Respondent 7). As Hoy says in his work *Do Funerals Matter?*, funerals help families and communities navigate the early

process of grief (Hoy, 2013). Respondent 5 stated that she never had the time or methods to communicate with her mother about how she would like to die. Her mother was too mentally unwell to make use of phones or email; when she died, Respondent 5 conducted the funeral as best as she could to respect her mother, but still questions, “Is this what she really wanted?” (Respondent 5). Later in the interview, Respondent 5 stated that this thought has stuck with her ever since her mother’s death. While this respondent was technically in control of the funeral and the celebration of life afterward, she felt that the meaning of the funeral and the significance of the celebration were out of her control.

This topic of control touches on almost all facets of end-of-life care. Ranging from hospice care to the end of the funeral procession, people are comforted when they know that the deceased received the respect they wanted and deserved. Respondent 4 stated that one of the biggest problems during the entire process was that he was unable to give his loved one a proper send-off.

Volandes’ *The Conversation: A Revolutionary Plan for End-of-Life Care* proclaims that we must approach the physician-patient conversation about end-of-life as straightforward as possible (Volandes, 2015). This aspect of control may be new to some. However, speaking to these individuals, it is obvious that most prefer to live in their home as long as possible until hospital care was necessary, even if they have not discussed it with anyone else. Hospice is not a place where people go to resign from life; it is a place to live the rest of it fully. However, with quarantine policies in place, some are unable to attend hospice centers, as their lives may be in danger if they go. COVID has provided physical restrictions from accessing proper healthcare for the elderly, which individuals perceive as a loss of control.



With the ongoing pandemic, society's perspective on death will be changed after the virus has swept through the entire world. In Hoy and Harris' article about the unintended consequences of COVID, it is stated that the emotional health cleanup will cause citizens to reevaluate the vulnerability of hospitals and nursing homes (Hoy & Harris, 2020). With people struggling to regain both physical and mental control of their lives, people are becoming aware of making necessary preparations in case of a premature death. As long as COVID has the spotlight in the world news, people will be constantly reminded about the fragility of life and how easy it is to lose control when a loved one dies.

### *Theme 2: Conflict between Fear and Need*

This next theme emerged towards the latter half of the interviews. At first, the categories of "fear" and "need" were thought of as independent from one another. However, around the sixth or seventh interview, these two categories tended to coincide in similar sentence structures, if not the same ones. Ultimately, it was decided that these categories should be combined into one theme due to the common appearance of this topic as well as its interconnectedness.

#### *Fear*

This category was fairly easy to evaluate in respondents, as fear can be expressed both literally and with non-verbal expression. When telling their story, it was not uncommon for interviewees to openly admit their fears. The most common statement across all the respondents was fear for the safety of their loved one, prior to their death. Respondent 1 was fearful that their mother was in pain from COVID as she was lying on

her deathbed. Respondent 8 was less expressive with her emotions at first, but when asked how she felt after describing her mother's death, she stated that she feared for the unknown future and how she was supposed to live comfortably without her mother. Part of the reason why fear was such a common occurrence was the abruptness of the deaths that a majority of these respondents encountered. Since the relationship between psychiatric disorders and experiences of unexpected death was correlated, it is safe to assume that fear could be one of the relating factors in this study (Keyes et al., 2014). In the context of COVID, the fear of losing a loved one in a painful situation puts an extreme amount of pressure on the relative, which comes into conflict when it meets a need for socializing.

### *Need*

What qualifies as a need? In this study, we are not discussing physical needs, such as the necessity of food, water, and shelter. Instead, respondents have described situational needs, which are important for supporting their mental wellbeing. For example, Respondent 4 expressed the need to attend her grandfather's funeral. If she was unable to attend to this need, she stated that she would have likely been devastated, as the funeral was a crucial factor in helping her mourn.

During the 2003 SARS outbreak in Asia, people who were affected or had close relatives who were affected were at risk for a range of psychiatric issues, including depression, anxiety, panic attacks, and even suicidality (Carvalho et al., 2020). In a similar situation with COVID, such symptoms could be expected from those currently infected. Because of how crucial it is to uphold mental health, individuals who are at risk

of infection need to address these “needs” so that they are able to avoid such negative consequences from taking over their lives.

### *Conflict*

The categories of fear and need are self-explanatory. However, in these interviews, the two categories frequently clashed with one another. Respondent 5 mentioned how she had to decide whether to take her mother to the hospital or keep her at home. Because her mother was showing severe illness after being infected, the respondent had to make a decision between fear and need. Should she take her mother to the hospital, in case that her mother might get the worst of COVID symptoms? Or should she keep her mother at home, because it was likely that she would be unable to visit her mother once she was accepted into the hospital? Even at the time of the interview, the respondent was still unsure if she made the right decision to drop her off at the hospital. These difficult decisions are the types of choices that these respondents had to make on a daily basis. This constant weighing of fear versus need can be a burden and takes up the mental capacity that individuals need to mourn for their loved one.

### *Theme 3: Lack of Community*

This theme, similar to Theme 1, also rose fairly quickly across the span of the interviews. After all, almost all traditional funerals have some aspect of community integrated into it. Whether that be family, friends, or the surrounding community, it is fairly common for individuals to gather for an opportunity to mourn.

### *Types of Community*

It is important to highlight the types of communities that the interviewees were involved with, as each response varied in the groups who they were associated with. The most common/close groups consisted of immediate and relative family members such as parents, grandparents, and siblings. In a few respondents, the topic of community support groups was brought up. These gatherings varied from Facebook groups to church communities, but it was clear that each individual had multiple networks to rely on in case they were struggling.

### *Disappearance of Community*

It is not difficult to visualize the effect that COVID had on tight-knit communities. Quarantine policies and social distancing made it extremely difficult for groups of people to gather in small locations, such as houses, churches, and funeral homes. When a community member suffered a loved one's death, the best that these communities could do was to communicate through various forms of technology and long-distance communication (Respondent 3). While some groups hosted virtual gatherings to gain some semblance of togetherness, Respondent 5 stated that the friendly neighborhood feel was gone ever since the pandemic happened.

Out of all of the themes discussed, the lack of community is the one that respondents mentioned the most. Every single respondent mentioned their close circle of friends/community at least three or more times. This highlights the fact that communities are crucial in upkeeping mental health; without these groups, people are becoming even more isolated. Respondent 6 discussed the disparity in attendance between the virtual and

in-person numbers for the funeral that they hosted. Because many were quarantined indoors during the 2021 COVID spike, only eight individuals attended the in-person funeral. The rest (~40 people) all attended through Zoom, with only half able to show their faces on screen. The entire process for Respondent 6 felt “unmeaningful.” Some of the attendees had known his father for 45+ years, but because most of them were virtual, it didn’t feel impactful enough to honor his father.

### *Development of Theory*

Following the categorization of themes, grounded theorists seek to develop an overarching theory from the emergent themes in the data collected. By taking into account all three themes (loss of control, conflict between fear/need, lack of community), the theory that emerged from the data is: participants experienced a failure of narrative cohesion.

This theory comes from connecting aspects of the three themes mentioned- loss of control, conflict between fear and need, and lack of community. In every respondent who was interviewed, each of these three themes appeared at least once during the coding process.

Narrative cohesion can be strictly defined as the way in which a story brings together themes to create flow and understanding of relative concepts. Applying narrative cohesion to a study of grief, in order to understand the process of someone dying, certain components of their life must be understood: how they lived, how they died, and how they are remembered. By removing one of these “building blocks,” the story completely falls apart, as the flow is disrupted. For example, if an individual lacked a proper

explanation of how their loved one died, they are unable to complete the envisioned story, leaving unanswered questions. Another example is if a funeral is not carried out to the fullest of expectations. Those attending the funeral may not be satisfied with how their loved one is being remembered. If funeral traditions are foregone due to social distancing policies, the narrative of their loved one will be unfinished. This would then leave attendees with a lingering sense of regret for not concluding their loved one's life properly.

The loss of narrative was directly witnessed in some moments during the interview. For example, one of the respondents was asked to compare their feelings before their loved one's death, to post-mortem. Their response to this was, "...I...don't know, I haven't had the time to think about this really...I just kind of disconnected my life before and after [her] death. It happened so fast..." (Respondent 9). This is a clear example of when a respondent is unable to create a connecting story. In this respondent's case, the planning of the funeral was unsatisfactory; the flowers, food, and time of the burial were all heavily restricted and dictated by the funeral home. This individual was able to picture the "before" and "after" but could not bridge each side, which led to an unfinished narrative of her mother's death. Since then, this respondent has noted that the "funeral" that was given has instilled a sense of disbelief; she still cannot believe that her mother is gone.

## CHAPTER FIVE

### Conclusion

#### *What was learned*

This study is important because it seeks to advance the understanding of long terms issues that arise when quarantine policies prevent individuals from saying goodbye to their loved ones. In addition to the economic hardship and lack of community, the pandemic has been an extremely stressful period for the majority of the world's population. This study will help increase awareness for those in grief during the pandemic and provide foundational knowledge for a deeper discussion on strategies to inhibit long-term emotional damage.

#### *How it Impacted Me*

I have no doubt that the information I have learned in this study will be applicable in medical school and beyond. Whether I take a career involving end-of-life care or not, death and grief will always play a part in whatever healthcare field I enter. As an active interviewer, I have learned how to interpret others' stories and develop meaningful connections through active listening. I have developed a strong awareness of the importance of mental health and found a voice in advocating for those that are still being affected by the pandemic today. As long as bereavement is still prominent in society, I will always be open to learning more about the perspectives on death.

### *Future Works*

This Glaserian grounded theory study contributes to the foundational data regarding long-term effects on the mental health and wellbeing of those affected by the pandemic. Generating theory on grief consequences of the COVID pandemic is the first step towards solving these issues. A recent study created the Complex Grief Scale, which can be utilized to diagnose whether someone is at risk for developing PGD (Prigerson et al., 2015). Studies have shown that this scale shows significance in diagnosing symptoms related to PGD. If this scale was possible to be implemented in the public, it would be possible to provide support to those who need it early on before their lives are affected to a great extent.

### *Conclusion*

Through the coding and categorization of data collected by the active interview process, the themes of loss of control, conflict between fear and need, and lack of community arose, which ultimately led to the proposal of the theory of failed narrative cohesion in bereaved individuals.



## APPENDIX A

### Consent Form

#### Baylor University **Medical Humanities Program**

#### Consent Form for Research

PROTOCOL TITLE: “COVID and Coping:” A Grounded Theory Study of Isolation and its Effect on Grief

PRINCIPAL INVESTIGATOR: Andrew D. Kim

SUPPORTED BY: Baylor University

**Purpose of the research:** The purpose of this study is to evaluate the effect of COVID quarantine and isolation policies on the process of coping with grief and loss of loved ones. We are asking you to take part in this study because I believe your perspective will provide a helpful and unique contribution to this study.

**Study activities:** If you choose to be in the study, you will be asked to join me by telephone or video conferencing software for an interview and conversation. I anticipate our conversation will be between 30 and 60 minutes long, but you may make it as long or as short as you want.

**Risks and Benefits:** To the best of our knowledge, there are no risks to you for taking part in this study other than you getting tired or fatigued. You can rest at any time and we may stop or postpone the interview if you desire. Please tell me if you want to do so at any time. It is possible you will benefit from participating in this study if you feel emotionally supported by having your story and perspective heard by another. We believe caregiving professionals and other universities who learn from the gathered results of this study will enable them to provide healthier and more accurate care to the bereaved in the future.

**Confidentiality:** A risk of taking part in this study is the possibility of a loss of confidentiality. Loss of confidentiality includes having your personal information shared with someone who is not on the study team and was not supposed to see or know about your information. The researchers plan to protect your confidentiality with utmost diligence.

We will keep the records of this study confidential by making sure that your name and other specific identification details will not be included with the interviewer’s field notes from our interview. To further protect your confidentiality, we will make no video or audio recordings of our conversation. The only other demographic information we will

include with the field notes is your age range (young adult, middle-aged adult, older adult). We will make every effort to keep your records confidential. However, there are times when federal or state law requires the disclosure of your records.

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

By law, researchers must release certain information to the appropriate authorities if they have reasonable cause to believe any of the following:

- Abuse or neglect of a child
- Abuse, neglect, or exploitation of an elderly person or disabled adult
- Risk of harming yourself or others
- Alleged incidents of sexual harassment, sexual assault, dating violence, or stalking, committed by or against a person enrolled at or employed by Baylor University at the time of the incident

**Compensation:** There is a \$20 compensation for your time, which will be distributed through the form of an Amazon gift card. Other forms of compensation may be pursued if gift cards are unavailable. The compensation will be sent after the interview, which will most likely be done during or after February 2021.

#### **Questions or concerns about this research study**

You can call us with any concerns or questions about the research. Our telephone numbers are listed below:

Mr. Andrew D. Kim, Undergraduate Student  
Medical Humanities Program, Baylor University (M-F, 8:00 AM – 5:00 PM)  
One Bear Place, # 97202, Waco, TX 97298  
Phone (281) 216-4688  
Email [Andy\\_Kim1@baylor.edu](mailto:Andy_Kim1@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 to not 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 consent.

## APPENDIX B

### Interview Structure Guide

**Introductory Statement:** Thank you for coming today, and for agreeing to participate in this study. My name is Andy Kim, and I am the principal researcher that is conducting this interview. Today, I will be asking you questions to better understand how grief is being processed differently during the age of the pandemic, due to the loss of a loved one. This interview is open-ended; I am not expecting any certain answers, as I wish to explore your own story and thoughts. I highly value any comments or ideas that you make. I will be mostly asking about your personal experiences with losing a loved one, and how the pandemic has affected it. I will also be asking about your funeral experience, and things that you have witnessed happening to others in a similar situation. If at anytime you do not wish to disclose further information, or want to end the interview, just let me know. If you feel that you need more time to process your thoughts or emotions before explaining a topic, please feel free to let me know as well. I am here to hear your story, so please take as much time as you need.

#### **Introductory questions:**

What is your age? Gender?

What is your relationship with the deceased individual? How long has it been?

What do you think about the pandemic? (death/infection rate, severity, public response, govt response, anti-vax, etc.)

#### **Main questions:**

Will you tell me a bit about the life you had with the deceased individual?

When this individual passed away, how did you initially feel? How about currently?

Did you host a funeral for your loved one? Did the pandemic restrict any usual customs?

- Tell me what elements were meaningful to you when you were experiencing this loss. What made them more or less meaningful?
- If this loss had happened two years ago without the pandemic, would the funeral have been the same?

Were there any methods that you actively undertook to cope with grief? Explain?

- (Follow-up) In what way has [subject] helped you cope with the loss?
- Did the pandemic hinder any methods that you would have pursued?

At what point in your life did you experience a sense of closure from this loss? If you haven't, what is preventing you from doing so?

There have been cases where people have conducted virtual/Zoom funerals, where friends and families attend online, or through a computer. What are your thoughts on this?

From literature, there are cases where people have been seen to mourn for extended period of time during the pandemic. Why do you think that might be the case?

Do you see isolation/quarantining as a problem for grieving and funerals customs? Why do you think so? Did you personally lean on anyone else during this time?

What do you see as the biggest problem of losing a loved one in the pandemic? How do you think this can be changed?

- Follow up this question if needed.

Has financial problems from the pandemic hindered your process of mourning for your loved one? If you had unlimited money, what would you change about the funeral experience?

Do you think the current COVID policies on business and social life are fair? Have you faced any pressure when planning for the funeral? What would you change about the policies, if anything?

Is there anyone else you know that is in a similar situation? What have you seen others do to cope with loss during this time?

If someone came to you asking for advice and informed you that they just lost a loved one, what would you tell/advise them to do?

What else should I know about people who have experienced loss in the pandemic?

APPENDIX C

IRB Exemption Letter



Baylor University

INSTITUTIONAL REVIEW BOARD – PROTECTION OF HUMAN SUBJECTS IN RESEARCH

**NOTICE OF EXEMPTION FROM IRB REVIEW**

Principal Investigator: Andrew Kim  
Study Title: COVID and Coping: A grounded study of isolation and its effect on grief  
IRB Reference #: 1846802  
  
Date of Determination: December 10, 2021  
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 12/04/2021
- Protocol, dated 10/25/2021
- Consent Form, submitted on 12/04/2021
- Counseling Resource Sheet, submitted on 12/07/2021

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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