THE IMPACT OF STIGMA
ON FAMILY AND FRIENDS BEREAVED
BY A DRUG OVERDOSE DEATH

by

Joshua H. Stout

A dissertation submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Sociology

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Joshua H. Stout

Approved: _____

Eric Rise, Ph.D.
Interim Chair of the Department of Sociology and Criminal Justice

Approved: _____

John A. Pelesko, Ph.D.
Dean of the College of Arts and Sciences

Approved: _____

Louis F. Rossi, Ph.D.
Vice Provost for Graduate and Professional Education and
Dean of the Graduate College

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed: _____

Benjamin Fleury-Steiner, Ph.D.
Professor in charge of dissertation

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed: _____

Tammy L. Anderson, Ph.D.
Member of dissertation committee

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed: _____

Joel Best, Ph.D.
Member of dissertation committee

I certify that I have read this dissertation and that in my opinion it meets the academic and professional standard required by the University as a dissertation for the degree of Doctor of Philosophy.

Signed: _____

Nancy Berns, Ph.D.
Member of dissertation committee

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Chris B.

John M.

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Scott F.

Jesse T.

Scott W.

Blair L.

Demo S.

Brian S.

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Josh S.

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ABSTRACT

As the opioid epidemic has crashed through the American landscape, the immense loss of life has drawn attention to a host of issues related to the causes and consequences of this epidemic. However, limited focus has been given to those in mourning following the loss of a loved one to a fatal overdose. This study explores how stigma impacts the mourning and help-seeking of those bereaved by a drug overdose death. To explore this issue, thirty-five in-depth interviews were conducted with friends, family members, and partners of those who lost a loved one to an overdose. Qualitative analysis of survivors' accounts reveals varying degrees of stigmatization that differs in terms of context. At the institutional level, survivors recalled experiencing stigma in the denial of treatment prior to their loved one's death. Survivors also describe mistreatment by law enforcement. Most reported were stigmatizing experiences of alienation, blame, and isolation by family and friends. Perhaps most important are survivors' accounts of help-seeking. Participation in drug death specific help-seeking (12-Step Fellowship and secular recovery support groups) is described as cultivating safe spaces that foster community and belonging. Survivors who serve in advocacy leadership roles and other support group roles describe a process of negotiating stigmatized bereavement through positive agentic experiences (e.g., acceptance through helping others). Other survivors who are less active in help-seeking activities describe varying degrees of unspoiling identity (e.g., support to share honestly about their loved one's drug overdose death). The implications of these

findings highlight both the importance of expanding access to survivor support groups in marginalized communities most impacted by the opioid epidemic and addressing their stigmatized grief.

Chapter 1

INTRODUCTION

Since the turn of the twenty-first century, the United States has experienced a continual rise in overdose deaths incomparable to any other country. The surge of deaths, totaling over 450,000 in twenty years, has occurred in four distinct waves (Center for Disease Control and Prevention 2020b; Ciccarone 2017, 2019). The first wave of the opioid epidemic began with the prescription pill surge in the late 1990s and early 2000s, when prescription opiates, primarily OxyContin, were the main cause of overdose deaths (Center for Disease Control and Prevention 2011). The second wave emerged as prescription pill users transitioned to a cheaper option, heroin (Fogger and McGuinness 2014; Monico and Mitchell 2018; Rudd et al. 2014). During the mid-and late-2010s, fentanyl – a synthetic opioid nearly one hundred times stronger than heroin – surfaced quickly, crippling communities nationwide, bringing a scourge of overdose deaths (Gladden, Martinez, and Seth 2016; O'Donnell, Gladden and Seth 2017). COVID-19 and increases in polysubstance overdose deaths have brought a fourth wave (Hainer 2019; McCann Pineo and Schwartz 2020; Haley and Saitz 2020). Unlike the previous three waves in which the property of the substance has shifted, isolation and limited access to recovery and treatment-oriented resources have been partially responsible for the increase in deaths in the fourth wave (McCann Pineo and Schwartz 2020).

The impacts of the opioid epidemic have touched certain geographic regions more than others. Overdose deaths were greatest during the first and second waves in

the Appalachian region. As of 2019, West Virginia continues to have the highest overdose death rates in the US. In 2018, the overdose death rate per 100,000 residents in West Virginia was 52.8. Delaware had the second-highest rate of 48 followed by the District of Columbia at 43.2 (Center for Disease Control and Prevention 2020a). It is nearly impossible to find one corner of the American landscape that the opioid epidemic has not impacted. There have been 72,158 overdose deaths in 2019 alone (Ahmab et al. 2020). Such catastrophic loss of life has depended economic challenges in already struggling communities (McGreal 2018) and revealed deeply problematic medical practices (Meier 2018; Keefe 2021).

Research on the opioid epidemic has focused on the efficacy of various addiction treatment modalities (e.g., Moggi et al. 2007; Veilleux et al. 2010), harm prevention and reduction (e.g., Connock et al. 2007; McDonald, Campbell and Strang 2017; Wodak and Cooney 2005), understanding substance use and users (e.g., Jones et al. 2015; Prescott and Kendler 2007; Lindesmith 1968), and examining the causes, conditions, and actors that gave rise to the opioid epidemic (e.g., Kolodny 2020; Quinones 2015, 2021; Smyth and Kost 1998). Additional research has examined the broader impacts of the opioid epidemic on the economy (e.g., Leslie et al. 2019), social resources (e.g., Caulkins et al. 2020), and families (e.g., Daley et al. 2018). One area of inquiry receiving far less attention is how significant loss of life has affected those closest to the departed. This dissertation then aims to contribute to the knowledge of those who have lost a loved one to substance use. Specifically, this project aims to examine the ways stigma surrounding addiction impacts the mourning experiences of those bereaved by such a loss and to provide a more capacious sociological framework for future research on this largely understudied topic.

1.1 Stigma and Substance Use

Society has long constructed labels of difference, defining what is normal/abnormal, good/bad, healthy/unhealthy, and normative/deviant. Although Durkheim was the first sociologist to provide an account of stigma, Goffman (1963) formally introduced the definitional foundation of stigma to sociology in his book *Stigma: Notes on the Management of Spoiled Identity*. Goffman defines stigma as:

> …an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another and therefore is neither creditable nor discreditable as a thing in itself. (1963:3)

Stigma, therefore, is how individuals are categorized, through their interactions with others, as discredited by society. Fundamental to Goffman's theory is that stigma is *interactional*, and it is in relations with others that one is stigmatized. Goffman identifies three types of stigmas: abnormalities of the body, such as disabilities or physical deformities; 'tribal stigma' where someone is stigmatized for their race, nationality, and religion. The third stigma Goffman describes is most relevant to the present study—namely blemishes of an individual's character when someone is perceived as having a:

> …weak will, domineering of unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior. (1963:5)

Interactions with others come to reaffirm this stigmatized label, causing those who carry it to engage in various acts of "stigma management" that conceal or reveal aspects of their "spoiled identity." By highlighting the ways in which those associated

with stigmatized individuals may also be ascribed a stigmatizing label, Goffman calls attention to the process of *courtesy stigma*.

Since the publication of Goffman's seminal study, the study of stigma and its various impacts on individuals has expanded tremendously. At the same time, research on stigma invariably relies on Goffman's central claim that a stigmatizing label reduces the individual "from a whole and usual person to a tainted, discounted one" (1963:3). These impacts have been well recorded in the broad range of literature across a host of topics, exploring how stigma uniquely impacts individuals, their identity, and life chances (For comprehensive reviews of this literature, see: Link and Phelan 2001; Pescosolido and Martin 2015). Not only was Goffman the first to define stigma more broadly, but he also called attention to drug addiction and alcoholism and the attendant stigmatization. Throughout western society, the history of addiction stigmatization is longstanding (Booth 1999; Courtwright 2009; Lindesmith 1968; Musto 2002). Numerous sociological studies have examined deviance and stigma surrounding substance use since the classic works of Becker (1963) and, in the context of addiction, Lindesmith (1968). While I will discuss Lindesmith's work in more detail in Chapter 2, it is important to observe that emotions are critical to the study of grief (Berns 2011) and stigmatized grief. This dissertation will explore emotions in more detail in Chapter 3, however, generally speaking, the contemporary opioid epidemic involves highly stigmatizing interactions and widespread experiences of spoiled identity.[1]

[1] It is important to note that other stigmatized aspects of one's identity may intersect and compound with substance use, such as race, class, gender, ability, and sexual orientation.

Throughout American history, the prohibition of alcohol and drugs has greatly contributed to the stigmatization of substance use (Hari 2015). Since the early 20th Century, especially after the passage of the Harrison Act of 1914 (Courtwright 2009; Musto 1999), addiction (Lindesmith 1968) has been framed in a moralistic dogma of flawed individual behavior. President Nixon's declaration of an all-out "War on Drugs" marked an era of expanded criminalization and stigma. Indeed, harsh criminal laws were implemented that explicitly portrayed substance users as dangerous:

> The declaration and escalation of the War on Drugs marked a moment in our past when a group of people defined by race and class was viewed and treated as the 'enemy.' A literal war was declared on a highly vulnerable population, leading to a wave of punitiveness that permeated every aspect of our criminal justice system and redefined the scope of fundamental constitutional rights (Alexander [2010] 2020: xxviii).

1.2 Stigma and Mourning

Recent research on social stigma and substance use demonstrates the negative impact on families and other loved ones. One of the central findings of this research is that family members of someone with addiction experience a spoiled identity due to courtesy stigma (Guy 2004; McCann and Lubman 2018; Ritches and Dawson 1998; Valentine et al. 2016). Courtesy stigma "involves public disapproval evoked as a consequence of associating with stigmatized persons" (Phillips and Benoit 2013:139). That is to say, the widespread social stigma surrounding drugs extends to members of kin and peer networks (Valentine et al. 2016; McCann and Lubman 2017). In the event of a fatal overdose, stigma may also negatively impact the mourning processes of the bereaved.

Doka's (1999) concept of "disenfranchised grief" is described as grief that often goes unacknowledged or is invalidated by social norms:

> Disenfranchised grief can be defined as the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, politically mourned, or socially supported. Isolated in bereavement, it can be much more difficult to mourn, and reactions are often complicated. It is important to recognize and try to meet the needs of those whose grief is not acknowledged by society, whatever the emotional or financial costs (1999:37).

Disenfranchised grief brings attention to the way certain types of deaths are less socially supported than others. While Doka's conception is clearly sociological, it is most often used in psychological and psychiatric research that focuses on the individual. In understanding disenfranchised grief as a social process, it is then important to situate grief as the result of fatal drug overdose in a more socially interactive context, as first envisioned by Goffman. Given the widespread impact of the opioid epidemic, and the many lives that have been lost, this dissertation seeks to contribute to relatively new and still understudied debates involving the experiences of the drug death bereaved (Stroebe et al. forthcoming; Stout and Fleury-Steiner forthcoming).

1.3 The Present Study

This study is part of a larger program of research to explore the lived experiences of family and friends who lost a loved one to a fatal drug overdose. Specifically, through in-depth interviews conducted with a small sample of such survivors from an area of the U.S. with disproportionately high opioid overdose deaths, I seek a fuller understanding of how stigma shapes the experiences of the bereaved. There are two central research questions that inform this line of inquiry:

How does the stigma surrounding addiction uniquely impact those closest to individuals who pass away from an overdose death? In what ways does this stigma impact the mourning processes and help-seeking behaviors of the bereaved?

1.4 Summary of Dissertation Chapters

The following section provides a summary of the chapters in this dissertation, outlines the content of each chapter, and provides an overview of findings.

1.4.1 Chapter 2 – Literature Review

To explore the lived experiences of those who have lost a loved one to a drug overdose death, this chapter reviews relevant prior research and theoretical frameworks. Specifically, I engage with broader prior research on stigma, bereavement, and meaning making. How stigma impacts mourning for those bereaved by a drug overdose death is my central focus. This chapter concludes by noting limitations of prior research and how the present study contributes to a more capacious understanding of the process of stigmatized bereavement.

1.4.2 Chapter 3 – Methods

This chapter describes data collection, sampling, and analysis. This study utilized 35 in-depth, semi-structured interviews with survivors bereaved by a drug overdose death. Survivors were recruited primarily through help-seeking advocacy groups and snowball sampling. The data collected for this study rendered 24 hours and 17 minutes' worth of audio. All interviews were transcribed and analyzed for emergent themes, employing a grounded theory approach. Demographic information about survivors is provided as well. A statement of reflexivity and positionality is also included, as my biography informs both data collection and the analysis.

1.4.3 Chapter 4 – Empirical Findings: Understanding Stigmatized Bereavement

In exploring how survivors recounted various stigmatizing interactions, this chapter highlights how and in what specific contexts the bereaved experienced stigma. Through this analysis, I highlight how stigmatization creates a compounding effect on the bereaved. This process begins for survivors prior to their loved ones passing. Unable to find them suitable treatment, survivors describe feelings of frustration and self-blame. Soon after fatal overdose, stigmatizing interactions with police officers occur. In describing the mourning process, survivors recall alienating interactions with family and other acquaintances. The findings in this section illuminate a broader process that I call *stigmatized bereavement*.

1.4.4 Chapter 5 – Empirical Findings: Negotiating Stigmatized Identity as an Agentic Process

As a result of experiencing various degrees of stigmatization, survivors engaged in multiple forms of help-seeking behaviors. In this chapter, I explore these various behaviors and agentic practices. Specifically, I examine how survivors' engagement in advocacy, 12-Step Fellowships, support groups, counseling, and religion support the negotiation of stigmatization through these agentic actions. These efforts provided survivors with a space to challenge stigmatizing narratives, find support in their grief, establish a network of individuals who either shared or understood their experience, and use their loss as a way of helping others in their grief and/or substance use.

1.4.5 Chapter 6 - Conclusion

The conclusion discusses key findings from the qualitative analysis, contributions to future research, and limitations. First, a discussion of how this

research expands prior inquiry of the impact of stigma on mourning processes will be presented. The chapter then highlights the importance of a more expansive inquiry into survivors' help-seeking behaviors. This section considers contributions to future research and implications for policy and scholarly debates.

Chapter 2

LITERATURE REVIEW

Research on the bereavement experiences of survivors who lost a loved one to a drug overdose is a relatively new and developing area of empirical inquiry. Most studies focus on individual-level cognitive processes. While the current study takes a broader sociological perspective, the literature review will highlight several important findings from this emergent literature (Stroebe et al. forthcoming). One important observation is the dearth of studies conducted in the U.S. With a few notable exceptions discussed in subsequent sections below, most studies were conducted with survivors from countries outside the U.S. (e.g., England and Norway).

In Part 2.1, I begin by providing a fuller discussion of what is meant by the term "overdose death" and related terminology. Next, I present an expansive review of the literature on drug overdose deaths and other unnatural deaths (e.g., suicide and homicide) and what is known about the experiences of bereaved survivors. As discussed in the introduction, the enormous scale of opioid mortality in the United States presents an important context for studying this inimitable form of death.

2.1 "Unnatural Deaths" and Grief

"Unnatural deaths" typically refer to sudden and unexpected deaths. Sudden and unexpected loss has implications for bereaved survivors. This is because self-

inflicted deaths are explicitly or implicitly violent (Dyregrov, Nordanger, and Dyregrov 2003; Titlestad et al. 2019)[2]. The literature on suicide bereavement, for example, shows how grief is experienced by family of the deceased. Such research tends to highlight three broad but generative ways for understanding suicide deaths. According to Jordan (2001), suicide-bereaved survivors struggle with questions of meaning making, show stronger feelings of responsibility for the death compared to other survivors, and have mixed emotions of anger and sadness towards the deceased. Studies of the impact of suicide on surviving family members, moreover, find disrupted family routines and increased risk of suicidality: "[T]here is considerable evidence that the general stigma that continues to be associated with suicide in our society 'spills over' to the bereaved family members" (Jordan 2001:93). Suicide bereaved survivors experience grief differently than those bereaved by less stigmatized deaths.

Feigelman et al. (2008, 2009a, 2009b, 2011) documents the impacts of stigma on family members bereaved by suicide. This quantitative survey of hundreds of survivors from the northeastern U.S. provides important empirical evidence for how cause of death negatively shapes grief experiences. A focus on survivors' broader attitudes and beliefs is found to be influenced by the longstanding stigma towards suicide in the U.S. Such broader attitudes negatively compound the grieving process of family members. Importantly, Feigelman and colleagues' (2012) book *Devastating Losses: How Parents Cope with the Death of a Child to Suicide or Drugs* provides an in-depth and comparative statistical inquiry. Specifically, this survey focused on 571

[2] See also The END Project (2017)

total parents who lost a child: 462 deaths were by suicide, 24 were due to natural causes, 37 by accidental death, and 48 were drug related deaths. Parents who lost a child to suicide or drug related deaths reported similarly negative and stigmatized grief experiences. Although the survey analysis of drug death bereaved parents is limited by a small sample size, Feigelman et al.'s (2012) research strongly suggests that parent survivors of children who died of a drug overdose experience negative bereavement like the larger sample of suicide bereaved parents. This research also provides insight into survivors' experiences with stigma. Many survivors report feelings of individual responsibility as measured using clinical instruments (e.g., complicated grief scale, traumatic growth, etc.). Additionally, Feigelman et al. (2012) found that parents were stigmatized by other family members and members of their social network. One limitation of this research is it lacks attention to the degree of stigma experienced by drug death bereaved parents. Some parents may endure many years of their child's addiction and non-lethal overdoses. While some help-seeking groups can provide crucial support to parents in cases of protracted addiction before drug related death (See Chapter 5), others may have no resources for negotiating stigmatized bereavement. Still other parents may have children that were in recovery before a totally unexpected death. Additionally, studies have documented how incarceration increases the odds of fatal overdose after release (Bukten et al. 2017), which may also complicate parental grief (e.g., negative interactions with law enforcement). As Templeton et al. (2017) and Guy and Holloway (2007) have observed, it is important to study experiences of stigmatized bereavement with attention to context. The purpose of this study is then to learn *how* stigma surrounding drug overdose death may uniquely impact survivors (Chapter 4) and the ways survivors negotiate such

experiences through help-seeking (Chapter 5). In the next section, I will draw on two reviews of mostly European studies (one systematic and one scoping) of bereaved survivors of loved ones who died of a drug related death. This review seeks to highlight the most salient findings from the existing body of empirical research.

2.2 Studies on Survivors of Drug-Related Deaths

Prior to Feigelman et al.'s research on survivors of drug related deaths, only three relevant studies were published. Given the enormity of the opioid epidemic in the United States, this represents a surprising dearth of prior research. Indeed, the lack of attention to this issue is not because drug related deaths or drug overdose deaths are a rare occurrence (see Introduction). At the same time, this line of inquiry is developing in important and interdisciplinary ways (Stroebe et al forthcoming).

A systematic review of the literature of familial experiences following drug related deaths by Titlestad et al. (2019) identified ten studies. Throughout this analysis, the authors identified three consistent findings. First, families experienced an *emotional rollercoaster* leading up to and responding to their loved one's passing. Second, the bereaved experienced a *lack of understanding by the social world*. Third, families *engaged in activities of meaning making* to navigate their loss. The following sections will explore these three empirical findings in more detail.

2.2.1.1 Emotional Rollercoaster

Titlestad et al. (2019:7) defines this finding as consisting of five descriptive themes: "the consequences of drug involvement, the fear of death, the trauma of death, complex and chaotic emotions, and guilt reflections." First, these studies show how the grief process has begun prior to death. Specifically, family members report years

of uncertainty. This experience is often fraught with feelings of "despair, fear, hopelessness, and powerlessness" (2019:8).

In a study conducted by da Silva, Noto, and Firmigoni (2007), the authors explore how the decedents' addiction may impact the bereaved. Recruiting from key informants and bereavement support groups in Brazil, the authors identified six families for participation in their study. For each family, one member was interviewed using structured in-depth interviews. From those interviewed, the authors observed that two distinct groups emerged those aware of their loved one's substance use and those unaware. Family members unaware of drug use before death expressed profound feelings of "anger, guilt, helplessness, indignation, and shame" (da Silva et al. 2007:305). Alternatively, those aware of the decedents' substance use experienced what the authors call a "veiled preparation" for the death that resulted in "ambivalent situations: pain on one hand and relief on the other hand." (da Silva et al. 2007:304-5).

Two previous studies highlight the complexities of the emotional rollercoaster experienced by drug death bereaved families. A study of five semi-structured interviews with individuals who had lost a loved one to a drug related death in Denmark, Biong and Thylstrup (2016) identified three emergent temporal themes: the period leading up to, during, and after death. They found that the bereaved had a relationship with their loved one that was very negative before their passing. Secondly, bereaved survivors experienced a sense of shock once the death occurred. Survivors also described an emotional turmoil experienced in the aftermath of their loved one's passing. Moreover, survivors described a profound struggle to survive in the time after the death. A similar study by Biong, Sveipe, and Ravndal (2015) employed focus group interviews with 8 individuals and identified three similar

themes: “I would have done anything to help,” “There were things he/she hid from me,” “I felt the abyss beneath my feet.” Both case studies illustrate what Titlestad et al. (2019:8) describe as an emotional rollercoaster: “The family member experiences years of uncertainty, despair, fear, hopelessness, and powerlessness and following this, the drug user often dies.”

A recent study by Feigelman and colleagues (Feigelman et al. 2020) draws on interviews with eleven parents who lost a child to drug overdose death. A unique contribution of this study is the illustration of what is termed a “death spiral.” While the temporal dimension is not explicitly known, the authors describe this experience as “perhaps for the first time, the parent becomes painfully aware of the lethal potential of their child’s drug use” (Feigelman et al. 2020:633). Interviews with the bereaved show that those closest to the deceased experienced profound emotional turmoil watching their loved ones undergo multiple relapses, interact with law enforcement, experience nonfatal overdoses, and struggle with substance use. This death spiral eventually ends in a fatal overdose which, in turn, results in a tangle of guilt, shame, and despair. The death spiral thus leads to what Titlestad et al. (2019) describe as an “emotional rollercoaster.” Taken together, these observations illustrate a complex chain of emotions experienced by the bereaved both before and after the death of their loved one.

Studies also document how the “emotional rollercoaster” negatively impacts the mourning process of the bereaved. Specifically, multiple studies have examined different bereavement experiences but rely on more rigid categorical terms such as sudden and anticipatory loss. Nevertheless, it’s important to clarify this common binary description. Sudden loss occurs when an individual’s death is brought on with

no preemptive warning, typically involving accidents, traumatic incidents, or previously undiagnosed or unforeseen ailments that terminate life suddenly. Research on sudden losses shows the prevalence of mental and physical health problems (Stroebe and Stroebe 1987) and long-term consequences for the bereaved that differ from other forms of loss (Barrett and Scott 1990).

In addition to a focus on sudden losses, other studies in the bereavement literature focus on anticipatory loss. As far back as 1944, Lindemann described anticipatory loss as a death that the bereaved could "see coming" and have, at least some time to prepare (Lindemann 1944). Most studies, however, focus on deaths involving terminally ill patients (Clayton et al. 1978; Friedman et al. 1963; Rando 1983). In studies of bereavement involving drug overdose deaths, anticipatory loss is referred to as "veiled preparation" (da Silva et al. 2007). One difference with the anticipatory loss is that family preparation for fatal drug overdose is veiled or distracted. Bereavement studies also focus on what is termed as "symbolic loss." Symbolic loss refers to a loss that is not a biological death but rather the loss of a system of symbols important to the bereaved (Homans 2000). When a loved one dies of a drug overdose death, families describe the experience as a kind of "double death" where the deceased has long been "lost" before physical death (Oreo and Ozgul, 2007).

While studies of categories of grief (shock, anticipatory, and symbolic) provide some insight, they are not without limitations. This may be especially true in the case of the drug death bereaved. More specifically, such cases of stigmatized deaths may not fit into any category. Experiencing symbolic loss may happen simultaneously with the "emotional rollercoaster" of chronic substance use. If a loved one experiences

bouts of prolonged recovery, feelings of hope obviously complicate matters or even end experiences of symbolic loss. Given the unprecedented level of opioid overdose deaths in the U.S. (see Introduction), relapses are common and may quickly result in sudden loss.

Additional questions complicate the sudden-anticipatory loss dichotomy. If a family experiences the "emotional rollercoaster" of a child's active addiction over a long period of time and has anticipated their death (e.g., taken out life insurance policies, purchased a plot, etc.), does death always fit neatly in the categories of anticipated or sudden? Other studies using complicated grief and other psychological scales find that any experience of temporary relief is overwhelmed by feelings of guilt, shame, and stigmatization (Valentine et al. 2016).

2.2.1.2 Lack of Understanding by the Social World

Titlestad et al. (2019) review of the extant literature on drug death bereavement highlights a second analytical theme. The authors define "a lack of understanding by the social world" as characterized by survivors' reports of stigmatization as a barrier to support and help-seeking. Indeed, this may be the most common theme in the literature.

Case study research from the United Kingdom focused on four drug death bereaved parents (Guy 2004). A common qualitative theme among all survivors involved stigmatized grief that occurred prior to death. Building on previous research, Guy (2004) calls attention to two related experiences described by survivors. First, is feelings of guilt and overwhelmed perceptions of conventional familial roles: "One could not, in the public mind, be a good son, a good mother or a caring father and also be involved in this kind of death" (Guy 2004:50). Secondly, shame and guilt are

described as interrupting mourning practices because survivors had a "sense that grief in these circumstances is somehow wrong…[and] is derived from the deviant nature of the cause of death and also the role that the bereaved may have played in it." (Guy 2004:51). While this research involved only four parents, what is important is its broader Goffmanian insight that cultural and societal views of addiction are stigmatized and taint the memory of their loved one. Such a perspective harms the grieving process by making parents feel deeply culpable for their loved one's death. One limitation of this small case study for the present research, however, is it is not able to provide a fuller account of the degrees of stigmatized grief.

Guy and Holloway (2007) expanded on the 2004 study with interviews from three additional parent survivors in an active grief support group in the U.K. Although these observations are based on only three survivors and therefore should be treated with caution, Guy and Holloway do provide theoretical depth to the limited literature on drug death bereavement. First and foremost, they observe that all drug overdose deaths involve a "problematic social context" (Guy and Holloway 2007:92) that involves negative and misleading media representations that undermine the grieving process. Guy and Holloway argue that consequences go beyond psychological harm alone. Specifically, they demonstrate that the impact of such misrepresentations "threaten the ontological security not only of the individual but also of the wider society" (Guy and Holloway 2007:93). The phrase "ontological security" means the ability to understand matters of life and death on one's own terms. Perhaps most important for the present study is the finding that support group survivors do not experience such attacks as passive victims. As is clear in the present study, survivors are agentic and may engage in meaning making practices and help-seeking and

advocacy work (Chapter 4). A final observation by Guy and Holloway (2007:84) that is also germane to the present study is that drug overdose deaths must be seen as "special deaths" because they represent a "challenge to self-identity and the social construction of the material and social milieu [media] and call into question the reliability of people whose qualities were thought known."

One of the purposes of the present study then to is to analyze a larger sample of drug death bereaved survivors with differing relationships to the deceased. The objective is to contribute a deeper understanding of the meaning making suggested by Guy and Holloway (2007), and Feigelman et al.'s research (2008, 2009b, 2009c, 2011, 2018, 2020).

Other scholars have noted the unique ways this stigmatization is experienced by the bereaved following a drug related death. Nowak (2015) identifies six themes through interviewing eight parents who lost a child to a drug related death: stigmatized grief experience, making sense of the loss, discovering comfort in the loss, identifying helpful support, a transformation of grief, and a transformed identity. Nowak's research shows how stigma experienced by the bereaved creates a sense of isolation. At the same time, this study shows how survivors experienced a transformation of their grief and identity through their participation in support groups and advocacy efforts. Specifically, help-seeking lessened the sense of isolation and provided avenues to make sense of the loss experienced.

Templeton et al. (2017) further note that overdose deaths present different and unique experiences for the bereaved compared to other substance-related deaths. In a study involving 32 interviews with survivors from the UK, the authors identified that the bereaved in their study experienced a marginalization in their bereavement. The

authors highlight five core experiences of the bereaved: first, the families' experiences with their loved one's substance use; second, the families' experiences surrounding the death; third, the official processes surrounding their loss; fourth, stigma experienced following the loss; fifth, participants' engagement in overdose awareness and prevention advocacy. One of the key findings of this study is the challenges of stigma management and the decision to conceal or reveal the nature of a loved one's death.

Dyregrov and Selseng (2021) utilized an open-ended survey to explore interpersonal communication experienced by 255 survivors following a drug-related death. Stigmatizing discourse surrounding the loss was experienced by the bereaved through friends, family, coworkers, media, neighbors, and professionals. Specifically, the authors highlight that stigma was experienced through dehumanizing labeling of the deceased, claims that the death of the decedent was the best possible outcome or their own fault, and unspoken and implicit stigma. The unspoken and implicit stigma did not meet the criteria for discriminatory, dehumanizing labels, but still left survivors experiencing stigma in their grief. The authors note that this stigma was rooted in a broader social context: "Respondents claimed that hurtful communications came from society because people lack information as to why people use drugs" (Dyregrov and Selseng 2021:6).

A more recent study argues that drug overdose death creates a "special grief" for the bereaved (Titlestad et al. 2020). Through interviewing 14 parents, the authors identified four themes. First, parents experienced a "constant preparedness" in anticipating their loved one's passing. Second, an "emotional overload" was experienced of having a complex range of emotions, such as ambivalence, anger, and

guilt, following the loss of their child. Third, “complex relations” existed between parents and public and personal relationships. Fourth, “stigmatization” was experienced through interactions, and through an internalized self-stigmatization process. Regarding this stigmatization, the authors state:

> According to the parents, society’s attitudes to drug use are reflected in stigmatizing statements, especially in online discussion forums where it is stated that people who have a drug addiction chose this life and need to get a grip on themselves. Many referred to comments that described people who use drugs as an outcast group in society. (Titlestad et al. 2020:160)

Given the prevalence of stigma in these studies, it is essential to examine the theoretical foundations of stigma as it pertains to bereavement in more detail.

2.2.1.2.1 Theories of Stigma

A central contribution of the present study is to center Goffman’s classic sociological framework of stigma. What is especially important about this work is its explicit emphasis on interpersonal interactions. Prior studies of drug death bereavement either implicitly or explicitly pay limited attention to stigma as an interactional process rooted in long standing cultural beliefs (e.g., Templeton et al. 2017; Norwak 2015; Guy 2004; Guy and Holloway 2007; Fielgman 2012). The sociocognitive approach to stigma, as sociologists Link and Phelan (2001) argue, fails to adequately capture stigma in the context of a “power situation that allows these processes to unfold” (2001:382). Building on Goffman’s original framework, Link and Phelan (2001:368) present a more capacious conceptualization of stigma: “human differences are socially selected for salience” in a process of labeling individuals as stigmatized. Importantly, this conceptualization attends explicitly to Goffman’s observation that broader hegemonic beliefs of “us and them” provide the broader

context for understanding the labeling process. Expanding beyond stereotypes, Link and Phelan (2001:375) call attention to systems of power not addressed in Goffman's study: "Stigma is entirely dependent on social, economic, and political power – it takes power to stigmatize." Figure 1 below highlights the levels of social interaction through which stigma occurs:

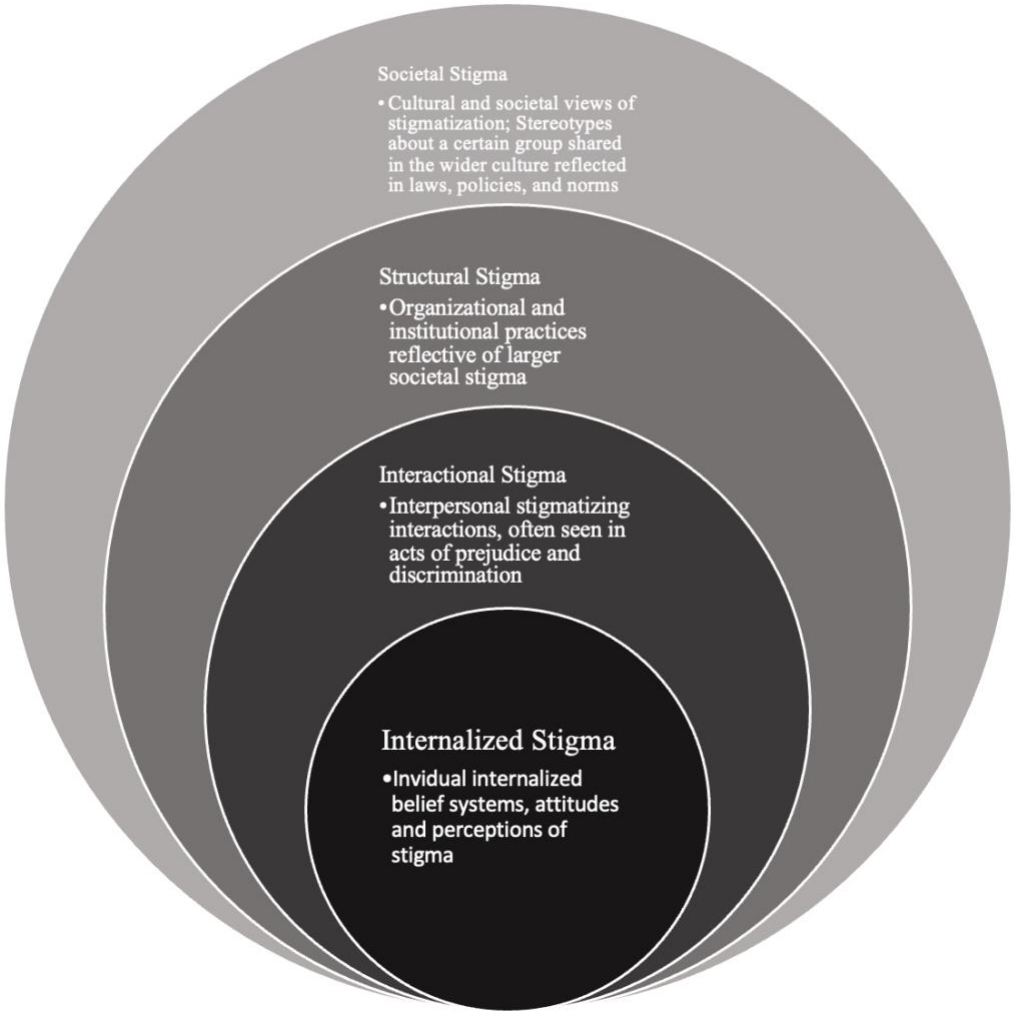

Figure 1: Levels of Stigma

Figure 1 is presented to highlight the importance of conceptualizing stigma as a dynamic process realized at all levels of social interaction. While this observation is not new, it is important to provide clarification. Carrasco et al. (2017) also add additional analytical insight into stigmatized ideologies are rooted in broader inequalities, including the criminalization of addiction. Both a multi-level understanding of stigmatizing interactions and ideologies provides important expectations for this present study. As will be seen in Chapter 4, drug death bereaved survivor's accounts focus on callous or indifferent law enforcement responders soon after death and ongoing stigmatizing interactions with family and others who subscribe to the ideology of addiction as the actions of irresponsible individuals.

2.2.1.2.2 Disenfranchised Grief

It is important to present a more in-depth discussion of Doka's (1989, 1999) influential work. To summarize, Doka's interactionist theory is composed of several interrelated observations. The conception of disenfranchised grief begins with the straightforward observation that relationships to the deceased matter. Those impacted outside of the immediate kin group are presumed to be less affected than next of kin, who have greater relational proximity to the deceased. It is in this social distance to death when grief goes unrecognized, and individuals may experience what Doka terms disenfranchised grief. Another clear example involves the loss of a pet. There is a much higher likelihood that the individual's grief may be unacknowledged or invalidated because such an experience is not "defined as socially significant" (Doka 1999:38). This observation extends to organizational contexts. Regarding work, employers may have varying bereavement policies. While the loss of a family member may result in paid leave from work, the loss of a close friend or significant other who

is not a spouse is likely to be denied support for bereavement. Doka's articulation of "grieving rules" is especially germane to the present study. As will be presented in more depth in Chapter 4, individuals grieve in a way that may be viewed as outside the norms of what is socially acceptable. Perhaps most relevant to the present study is Doka's (1999:38) discussion of "bad deaths" that "create such shame and embarrassment that even those in recognized roles (such as spouse, child or parent) may be reluctant to avail themselves of social support or may feel a sense of social reproach over the circumstances of death." In discussing disenfranchised grief in the context of drug overdose deaths and suicides, Doka does discuss stigma. However, it is presented in somewhat rudimentary way that lacks attention to process (see Figure 1). To be sure, prior research has documented "bad" deaths inseparable from social and moral condemnation from the larger society (Seale and Van der Geest, 2004). Disenfranchised grief is found in studies of deaths from AIDS (Wright and Coyle, 1996), suicide (Simone 2010; Wertheimer 2001) and drug overdose deaths (Feigelman et al. 2012; Valentine et al. 2016).

2.2.1.3 Meaning Making

How the bereaved seek to make sense of the loss, the importance of support from peers, and identifying individual differences in what helps with their bereavement is usefully grouped by Titlestad et al. (2019:8) under studies of "meaning making." Research on meaning making demonstrates how bereaved individuals lose a sense of self (Toller 2008) and how the loss of a member of the family unit redefines family members' understanding of their kinship group (Handsley 2001). In a study of 53 bereaved parents, Toller (2008:312) highlights how "dialectic contradictions of identity" following a significant loss may result in various memorialization rituals

(e.g., celebrating the deceased's birthday, tending to the grave, etc.). These rituals allow survivors to negotiate the tension of a painfully changing self-concept of a parent who lost a child. Indeed, the loss of a child, can dramatically reshape parents' worldviews (Janoff-Bulman 1992) and problematize social roles (Riches & Dawson 1996). If a family member dies of an overdose, it creates particularly challenging, but sometimes necessary, circumstances for the bereaved to rebuild their sense of identity that has been shattered in the wake of their loss (Neimeyer and Sands, 2011). Nowak identified the following emergent theme in her interviews with eight bereaved parents:

> The ability of the bereaved to transform following the drug related death of their child was indicated by a process that brought meaning to the death in a way that honored the decedent and through the discovery of a purpose that ensured a continued and heartfelt relationship with the decedent prevailed (2015:112)

A major limitation in this social cognitive research is a lack of explicit engagement with how stigma is challenged in a process of what I call "unspoiling identity" (see Chapter 5) that focuses on how stigmatized bereavement is negotiated through help-seeking.

Goffman (1963) provided a clear understanding of how stigma can lead to what he called a "spoiled identity." Stigmatized individuals create identities based upon the judgment, discrimination, and devaluation that they anticipate from broader cultural narratives of "us and them." Goffman (1963:19) described this interactional process as a discrepancy "between an individual's virtual and actual identity. When known about or apparent, spoils his social identity" and "has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world." Both perceived or experienced stigma in *interactions* with others creates a spoiled identity that leads to alienation and feelings of isolation from

"normal" society. At the same time, "spoiled identity" lacks sufficient attention to processes of "unspoiling" (see Chapter 5).

Subsequent interaction with supportive individuals also may deepen a sense of belonging. For Goffman, such supportive groups take two forms. First, a primary group of sympathetic others who share the same deviant or "spoiled" identity that can empathize and help individuals feel more normalized, or what Goffman famously termed "the own." Second are "the wise" or "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded…a measure of courtesy membership in the clan" (Goffman 1963:28).

Memorialization practices are clearly important for negotiating grief. The sociology of mourning has long documented the function of mourning rituals. Durkheim's classic work, *The Elementary Forms of Religious Life* ([1912] 2001), demonstrates the importance of such rituals in building social solidarity within small groups. In the context of grief, piacular rites, where a group assembles to mourn the passing of one of its members, may serve to strengthen collective sentiments. Rites of this type bring the group that is diminished by the loss together to reaffirm sentiments of group solidarity.

Another important area of literature from the sociology of emotions focuses on "feeling rules." The unique societal expectations as to what deemed appropriate and customary bereavement practices. Through social interactions with others, individuals internalize how they are expected to feel (Francis 1997). Feeling rules dictate the way one ought to feel in a particular setting and expressive norms emphasize proper or expected behaviors (Hochschild [1983]2012). "In the case of bereavement, feeling

rules tell us how deeply and for how long we should grieve a loss, while expression norms tell us when, where, and to whom we can express that grief" (Goodrum, 2008, p. 425). However, these feeling rules remain ambiguous when considering drug overdose deaths.

When the loss itself is problematic, individuals may find themselves excluded from the mourning and memorialization practices (Doka 1989). Exclusion in this way may lead to disenfranchised grief (see previous discussion above). Importantly, the bereaved feel as though their grieving experience and practices do not align with grief rules of the larger society. One form of memorialization often seen following traumatic loss is "conversational remembering," where the bereaved discuss the life of a deceased loved one or friend (Walter 1996). Conversational remembering itself can be seen as a mourning ritual, as can visiting the graves, displaying pictures and memorials, etc. (Gibson 2008; Valentine 2008). The availability of these resources depends on whether the grief of the bereaved is recognized and acknowledged, which depends on whether they have a supportive and sympathetic social environment in which they can grieve (Simone 2010).

As Goodrum (2008:438) eloquently observes, "Grief both bonds and separates people, and its expression presents a challenge to those experiencing and witnessing it, in part, because the rules and norms surrounding the expression of grief remain unclear." In a study of family members who had recently lost a loved one to homicide, Goodrum found interactions with others become strained because family and friends actively avoid the death, become overly sympathetic, or demand closure. Berns highlights that the social construction of closure creates specific feeling rules regarding loss:

> Closure encourages the idea that grief is bad and therefore something that needs to end. These assumptions, and the larger narratives that carry them, build feeling rules for how we are supposed to respond when bad things happen. (2011:28)

Goodrum's prescient research shows how family members must manage their expression of grief in order to avoid being alienated from positive social interactions: "Feeling grief disrupts our internal order, expressing grief disrupts the social order, and witnessing grief often disrupts social interaction" (Goodrum 2008:429).

The unprecedented scale of opioid overdose deaths in the U.S. has mobilized several advocacy groups. These groups share a host of similarities to victim-advocacy groups. Victim-activists take three forms based upon victim status: the individually harmed victim, the bereaved victim, and the general community activist (Weed 1990). Weed (1990) defines the individually harmed victim-activist as advocating against harm directly caused to them. The bereaved victims' role for victim-activists refers to those involved in advocacy that "can claim to have experiential expertise about the suffering of families which serve as a basis of authority for speaking out on the problem." (1990:461). The general community activist is more commonly an individual in the community who wishes to be engaged in an advocacy group – this may be someone from the community impacted by an event or just a concerned citizen. Weed's examination of these forms of victim-activists in Mothers Against Drunk Driving (MADD) present an insightful analysis of how bereaved parents of children killed by drunk drivers become involved in the organization and hold leadership positions within their chapter office.

According to Weed (1990:468) "bereaved victimization may have a stronger impact if people can convince others that their moral outrage at the loss of a family member is justifiable by the family member's innocence." The bereaved individual

engaged in activism may channel their grief into helping similarly situated others. While individually harmed victims and general community activists have been involved in responding to the opioid epidemic, it is evident that a main motivation for bereaved victim-activists involved in advocacy organization is to honor the loss of a loved one. Such advocacy may, in turn, result in healthier grieving and stigma management (see Chapter 5). Nowak (2015) further highlights the ways in which parents bereaved by a drug overdose death sought to honor their loved ones through purposeful efforts to create social changes surrounding drug overdoses. As Titlestad et al. state (2019:8), "In making sense of the loss, the bereaved described that helping others or being politically active were examples of how they tried to prevent others from having to experience the same situation themselves."

2.3 Methodological Limitations of Recent Studies

The drug related death literature provides an understanding of this unique form of loss and grief. However, it is important to examine the methodologies implemented in more detail. Specifically, one fundamental limitation of the drug death bereaved literature is sampling size and a tendency to be illustrative as opposed to a more grounded theoretical approach. In exploring these methodological limitations, I highlight the ways in which the current project addresses these limitations.

2.3.1 Definitional Parameters

The terms drug-related death, substance use-related death, and overdose death appear to hold the same meaning. However, prior research has tackled this definition error to parse out the difference between the three forms of death (Feigelman et al. 2011; Titlestad et al. 2019). These three types of death fall under the umbrella of

unnatural death. In this more expansive definition, death occurs from sudden and unnatural causes, however, each type of unnatural death is treated as subtype. A substance use-related death refers to any death that results from an individual using a mood- or mind-altering substance (legal or illegal). Substance use-related deaths may include alcohol, complications from using steroids, illicit drugs, and psychotropic medications. Deaths classified as drug-related deaths examine deaths that include all the above, excluding alcohol-related deaths. This exclusion has been justified in the literature due to the sudden onset of death that typically occurs with drug-related deaths compared to the sometimes prolonged death of health complications that arise from alcohol addiction (Titlestad et al. 2019). Drug-related deaths are when the:

> …death identified was caused by the intake of substances classified as narcotics i.e., overdose (intentional or unintentional), or was otherwise drug-related (e.g., caused by violence, accident, infectious disease, suicide, or other disorders related to drug use) (Titlestad et al. 2019:2).

It is important to delineate further drug-related deaths from drug overdose deaths (Titlestad et al. 2019). Due to how drug use is often socially condemned (Corrigan, Schomerus, Smelson 2017), some scholars have postulated that bereavement following a drug overdose death may differ from bereavement following drug-related deaths (Guy and Holloway 2007; Templeton et al. 2017), stating that there is a need for studies to examine drug overdose deaths explicitly (Titlestad et al. 2019). Further, it has been observed that heroin carries with it a greater stigma than any other substance (Sattler et al. 2021), making it even more important to limit the exploration of this study to those who have died from an opioid overdose. Aligning with this call, the Overdose Bereavement Project (OBP) examines only deaths classified as drug overdose deaths. This classification excludes deaths defined as suicide, deaths resulting from health complications or accidents surrounding drug use (e.g.,

HIV/AIDS; DWIs), or deaths resulting from purchasing or distributing illicit substances. By contrast, drug overdose deaths occur *explicitly* from a fatal overdose of a narcotic, either intentional[3] or unintentional.

Titlestad et al. (2019) find only a single study (Guy and Holloway, 2007) in their systematic review that focused explicitly on drug overdose deaths. While some included such deaths, that was not the explicit purpose of most studies. Accordingly, the present study seeks to "clarify the cause of death and discuss whether and how this influences the bereavement process" (Titlestad et al. 2019:10).

2.3.2 Location of Study

Of the studies discussed above, only three have focused on drug related deaths in the United States (i.e., Feigelman 2011, 2020; Nowak 2015). Given the widespread impact of the opioid epidemic in the United States, there is an urgent and obvious need for new research. The scale of drug overdose deaths in the U.S. is unparalleled. The objective of the current study than is to contribute to and encourage future research (see Conclusion).

2.3.3 Sample Size

Another methodological limitation of the studies covering drug related deaths is the sample sizes of each study. In the nine qualitative studies examined, the number of participants ranged from 2-32. Almost all these studies have focused principally on the parents (e.g., Feigelman et al. 2011, 2020; Nowak 2015), the children (Grace,

[3] While intentional death from drug-related deaths may be misunderstood as suicide, however this is not always the case. Knowing that such deaths may be an expected outcome can be conceptualized as intentional by some; however, suicidality remains ambiguous.

2012), and the immediate family members, including spouses and siblings (Biong et al. 2015, 2016; da Silva et al. 2007), of the deceased. Two studies to date have examined the effect drug related deaths may have on bereaved friends, spouses, and immediate family (Walter et al., 2015; Templeton, 2017). Notably, Walter et al.'s study of 106 UK survivors is the largest to date. However, this study is not focused specifically on drug overdose deaths. Indeed, it includes all substance related deaths (see 2.2.2 above). Templeton et al.'s (2017) study of 32 survivors from the U.K. is a comparative study of bereavement experiences for drug overdose deaths as compared to individuals bereaved from drug related deaths. These studies from the U.K. provide important insight and expectations for the present study. While the U.S. is obviously not exceptional when it comes to drug overdose deaths, the sheer scale of drug overdose deaths in the U.S. makes clear the relevance of the present study.

To date, there is only one comprehensive statistical analysis of drug related deaths in America. Feigelman et al.'s (2011) survey of 48 parents bereaved from a drug related death in a study comparing stigma to 462 parents bereaved from the suicide of a child, 24 to natural death causes, and 37 to mostly accidental death cases. This seminal study has been very influential in guiding research on how death by suicide and drug related deaths are uniquely stigmatized. However, to date, a mixed-method approach to understanding drug overdose deaths has not been implemented.

2.4 The Importance of a Sociological Approach

Durkheim classic study of *Suicide* (1897) demonstrated the importance of social facts. While psychology and psychiatry have provided insight into the experiences of those bereaved from a drug related death or drug overdose death, viewing stigma as a social fact means attending closely to individual experience as

tethered to social processes. Goffman's classic study of stigma is very much grounded in the Durkheimian tradition. Stigma is widely experienced, internalized, and understood through the process of societal interactions. Yet how stigma is experienced in the context of drug death related bereavement is less understood. As Titlestad et al. state:

> We, therefore, call for further research to explore the consequences of both the emotional overload and the stigma associated with drug related deaths in greater depth and recommend the creation of tailored research questions to explore the prevalence of and process surrounding complicated and disenfranchised grief. (2019:10)

This study seeks to answer this call by highlighting the ways in which stigma is experienced by the bereaved. As an alternative to disenfranchised grief, this study shows how survivors experiences of drug related deaths must be understood as a process of stigmatized bereavement (see Chapter 4).

Titlestad et al. (2019:11) call for future studies that "explore the bereaved people's experiences of lack of help and support." The authors highlight a lack of support the drug death bereaved. Given that stigmatization occurs through an interactional process (Goffman 1963) that is conditioned by unequal power relations (Link and Phelan 2001), in depth qualitative analysis can contribute an understanding beyond polarizing media coverage of drug related deaths (Guy 2004; Guy and Holloway 2007; Valentine et al. 2016).

Chapter 3

DATA AND METHODS

To explore the experiences of survivors who had lost a loved one to a drug overdose, the current study draws primarily on qualitative data collected by the University of Delaware's Overdose Bereavement Project (OBP). Specifically, 35 surveys and in-depth interviews were conducted by both my dissertation chair and OBP principal investigator, Dr. Benjamin Fleury-Steiner, and myself.

3.1 Design and Procedure

The OBP emerged in 2019 to address the lived experiences of families and loved ones bereaved by a drug overdose death. Upon its genesis, the OBP sought to collect both quantitative data through surveys and qualitative data through in-depth interviews. Through his classic research on opioid use disorder, Lindesmith (1968) highlights that is imperative to research lived experience when researching marginalized and stigmatized populations. A lived experience approach is a qualitative phenomenological methodology focused on representing individuals' experiences and choices (Finlay 2009). In taking a lived experience approach, the participant's role is to share their experience with the interviewer, allowing their own choices, occurrences, and recollections to be the collected data. Through semi-structured interviews, we sought to understand the lived experience of those who had lost a loved one to an overdose. To that end, interviews were designed to facilitate survivors sharing their experience as it related to their loved one's substance use, leading up to

their death, their grieving and mourning process, and the impacts of their loss after that (see Appendix A).

While semi-structured, in-depth interviews allow for the capturing of the lived experiences of individuals, supplemental quantitative surveys were critical to the OBP as well (see Appendix B). Pulling from Feigelman et al.'s (2012) metric in *Devastating Losses*, measures were implemented to explore the impacts of grief on the bereaved and help-seeking. Scales were also developed from Earnshaw and Chaudoir's (2009) work on different levels of stigmatization in the context of various relationships.

Although this dissertation does not endeavor on a thorough quantitative analysis of the survey results, these metrics served two paramount purposes for the present analysis. First, the inclusion of these measurements allows me to readily capture survivors' demographic information to examine how these factors may influence their experiences. Collecting this demographic information allows me to identify areas of representation and underrepresentation. Second, these measures allowed me to categorize the qualitative results for closer examination of unique bereavement experiences across certain groups. Each in-person interview began with the survivor completing the quantitative survey followed by the open-ended interview. This order is crucial to the study. Specifically, by first focusing the survivor on the specific details regarding the loss of their loved ones, they are oriented to speaking about the death during the qualitative interview.

This project makes some larger methodological contributions as well. First, it is the largest qualitative study in the United States focused exclusively on drug overdose deaths. While notable endeavors on this topic have been conducted by

Templeton et al. (2017) in the United Kingdoms, and Feigelman et al.'s (2009b, 2011, 2012, 2020) largely quantitative work outlined above, no study to this degree has been conducted in the United States. Given the unique stigmatizing culture surrounding substance use discussed above, the societal climate created by the war on drugs and highest overdose death rate in the world, points to the crucial need for research in the U.S. Finally, this research focuses on stigma as a complex social process (see Chapter 4; Link and Phelan 2001; Prescosolido and Martin 2015; Carrasco et al 2017).

3.2 Sampling and Recruitment

Following IRB approval (Appendix C), the parameters for participation were initially limited to individuals in the state of Delaware whose loss had occurred more than 6 months prior. Eventually, this was expanded to allow us to conduct interviews with individuals out of state, over the phone, and whose lose had occurred more than 3 months prior to the interview. Recruitment began through a local advocacy group that meets once a month. This group, referred to pseudonymously as "Mid-Atlantic Advocacy" or MAA, engages in numerous efforts surrounding substance use. MAA is engaged on many fronts, including legislative reform, naloxone training seminars, educational outreach, recovery housing, and hosting various support meetings for both family and friends of individuals struggling with addiction, with a separate meeting for drug death bereaved survivors. Accordingly, these monthly support meetings became the initial site for OBP recruitment. At these meetings, an announcement was made about the study and fliers with a general description and contact information were distributed, offering participants a $25 gift card for their participation. Each meeting attended rendered a handful of participants. From these initial points of contact, snowball sampling was able to occur. Snowball sampling is when a "random sample

of individuals is drawn from a given finite population." That is to say, participating survivors provide contact information for other interested parties or pass along information of the study to others who may be interested (Goodman 1961:148). Coupled with these efforts, my longstanding work in the recovery community aided recruitment efforts through social media. Survivors active in Nar-Anon, Al-Anon, Narcotics Anonymous, Alcoholics Anonymous, and those who were not actively involved in any peer support groups agreed to participate. Recruiting on these two fronts rendered 35 interviews and surveys. Data collected from these interviews consisted of 24 hours and 17 minutes' worth of audio, and transcription of these interviews rendered 343 pages of single-spaced text. Initially, future recruiting efforts sought to engage with a more diversified sample using stratified sampling. However, due to IRB restrictions surrounding COVID-19 safety procedures, additional interviews were unable to be conducted.

The OBPs sample consists of 35 interviews in total, including 23 females and 12 males. The average age of survivors was between 56-65 years old, with 17 of our survivors being parents to the deceased. Our sample consisted primarily of white, upper-middle-class survivors. Initially, the OBP had hoped to recruit a more racially and economically diverse sample. However, due to the hardships presented by the COVID-19 pandemic, further recruitment was no longer an option. Table 1 below provides an overview of the demographics of survivors in this study. An overview of survivors and their help-seeking practices is provided in Appendix D.

Table 1: Demographics Information of Survivors

Demographics	*Frequency*	*Percent*
Gender		
Male	12	34.3%
Female	23	65.7%
Age		
35 or younger	8	22.9%
36-45 years old	5	14.3%
46-55 years old	5	14.3%
56-65 years old	9	25.7%
66 or older	8	22.9%
Education		
Less than high school	1	2.9%
High School or Equiv.	7	20.0%
Some college	8	22.9%
Four-year college	11	31.4%
Masters/Doctoral/Prof.	8	22.9%
Income		
None	1	2.9%
Less than $20,000	1	2.9%
$20,001-$40,000	5	14.7%
$40,001-$60,000	4	11.8%
$60,001-$90,000	4	11.8%
$90,000-$120,000	6	17.6%
Over $120,001	13	38.2%
Marital Status		
Married	18	51.4%
Divorced	3	8.6%
Never Married	9	25.7%
Widowed	5	14.3%

The average age of the decedent is 32. 74.3% of decedents were male, and almost all were white. The age, race, and gender of the average deceased in our sample is reflective of the national averages as well. 14.5% of survivors in our sample witnessed the overdose of the deceased, and 17.1% were present when the body was discovered. 43.6% of survivors knew of previous non-fatal overdoses of the deceased and 57.4% reported that the deceased had no prior history of non-fatal overdoses.

Table 2 highlights the relationship between survivors and their loved ones in the sample for this study.

Table 2: Relationship of Survivors and Their Loved Ones

Relationship	*Frequency*	*Percent*
Parent	17	48.6%
Spouse	1	2.9%
Sibling	5	14.3%
Stepparent	1	2.9%
Cousin	1	2.9%
Nephew	1	2.9%
Fiancé	3	8.5%
Girlfriend/Boyfriend	2	5.7%
Close Friend	3	8.5%
Grandmother	1	2.9%
Total	35	100%

3.3 Data Collection and Analysis

All interviews conducted were warehoused on a secure cloud server through Microsoft SharePoint at the University of Delaware. Additionally, all quantitative data was stored and analyzed in SPSS, and all interviews were transcribed and stored in NVivo for analysis and coding. A grounded theory approach was used to analyze the transcripts from the OBP. Grounded theory, as outlined by Straus and Corbin (1994), entails approaching the qualitative analysis process without preconceived thematic codes of analysis in which examination of the data allows for thematic codes to emerge from the narratives provided. Aligning with this methodological approach, all interviews were initially read to discern general themes. Following this initial reading, a secondary analysis for emergent themes is conducted and codes were created in NVivo to identify the frequency and context of these themes in more detail. A final

analysis involves coding each interview to extrapolate findings from the qualitative accounts. Empirical findings are presented in Chapters 4 and 5 below.

Pseudonyms were created for all individuals who participated in this study, all decedents, and all organizations that they were actively members of to protect anonymity and maintain confidentiality. Throughout the analysis, quotations from survivors are used. These quotations were edited slightly for grammatical errors and spelling, and ellipses were added in certain areas to shorten longer quotations for clarity.

3.4 Positionality and Reflexivity

All sociological scholars exist in the social world that they research, meaning that work of this nature can never be value-free (Carr 2000), and that we cannot escape the world we live in to study it (Hammersly and Atkinson 1995). It has become increasingly common for qualitative researchers to consider their own positions in the social world in relation to those they observe or interview. Statements of both positionality and reflexivity are essential for researchers to examine the lens through which they are exploring a social phenomenon and disclose how their values and biography may influence the results of their research. Positionality refers to the ontological assumptions, epistemological assumptions, and assumptions about agency and human nature that a researcher makes based on their own biography, and social and political context (Holmes 2020). Reflexivity involves recognizing the ways in which one's positionality may influence research and proper disclosure as Malterud cogently explains:

> Reflexivity starts by identifying preconceptions brought into the project by the research representing previous personal and professional experiences, pre-study beliefs about how things are and what is to be

> investigated, motivations and qualifications for exploration of the field, and perspective and theoretical foundations related to education and interest. (2001:484)

When discussing positionality, it is important for a researcher to examine how their values, beliefs, and social locations influence the subject under investigation, the participants, and the research process and analysis (Malterud 2001; Grix 2019). The following section discloses my positionality in relation to this study by outlining my own personal biography that has shaped my interest in the subject of bereavement and substance use disorder. It then explores how this may have influenced my interactions with participants, and impacted my analysis. Further, I will address what procedural measures were taken to mitigate certain elements of subjectivity throughout the research process.

During my adolescent years, following the sudden death of my 19-year-old sister and my parents' divorce, navigating grief with grace was not something I was equipped to do. I found myself acting out behaviorally, in constant contact with law enforcement, and eventually institutionalized in a broad array of programs for troubled youth. While beneficial in many respects, such programs also introduced me to a criminogenic setting where I encountered (and in some cases used) a host of illicit substances that I had not been exposed to previously. Throughout various treatment modalities of scared-straight programs, therapeutic boarding school, and residential treatment programs, I quickly found myself labeled as an individual with substance use disorder. This label itself allowed me to shift the onus of responsibility internally from a narrative of "I have behavioral issues – I am the problem," to a medicalized view of, "I suffer from substance use." With this new paradigm, at the malleable age of 17, I began my journey of recovery through a 12-Step Fellowship.

Throughout my undergraduate and graduate careers, I remained immersed in the recovery community until the Fall of 2020. While there were moments during those 12 years where I would have a "slip" and drink – thus breaching the abstinence only approach found in 12-Step programs – my recovery was a salient part of my identity. This involvement in 12-Step programs shaped my world view. The tenants and spiritual principles of the 12-Steps were my moral compass and shaped my world view. Perhaps most importantly is the fellowship I found became both my primary arena of socialization through those formulative years and my social network as an adult. I would often leave my evening classes in graduate school and rush to the "front lines" of being in a meeting, taking a new member to treatment or detox, sitting with men and doing step work, or attending some 12-Step related event. Immersion in the recovery community placed me in contact with hundreds of individuals I never would have interacted with outside of the academy, from housing insecure individuals to high level politicians, all sharing the same two goals: stay sober and help others.

During this point of my journey, the third wave of the opioid epidemic crashed through the state of Delaware. I lost a romantic partner to a fatal overdose and many close friends between 2017 to present with the rise of fentanyl. The loss of my partner, coupled with research interest in grief, influenced by my early life experiences with loss, became the catalyst for my interest in this research topic. While I no longer consider myself a member of the 12-Step community and have forgone the abstinence only approach to recovery, my continuing long-term sobriety from illegal substances, the experience of losing my partner and close friends and family members, and my own treatment and recovery journey shaped both my interest in the topic, and my interpretation of the data.

Much debate has occurred regarding researchers occupying insider or outside status among the groups that they are researching. Merton's definition clearly outlines what is meant by insiders and outsiders: "Insiders are the members of specified groups and collectives or occupants of specified social statuses: Outsiders are non-members." (1972). Further, debate has centered around the benefits being an insider may bring to gaining access, and the way this status can positively impact the research process through having unique insight of the group studied (e.g., Sanghera and Bjorek 2008; Geertz 1973; Holmes 2020), and the unique disadvantages as well, such as being too close to the subject(s), and assumptions about what material may be "obvious" (Holmes 2020). To be sure: "The insider/outsider dichotomy is, in reality, *a continuum with multiple dimensions* (emphasis added) and that all researchers constantly move back and forth along several axes, depending upon time, location, and topic (Christensen and Dahl 1997:1)." Ultimately, insider/outside status can be fluid given the various interactions and contexts of qualitative research, acting as a "double-edged sword" (Mercer 2007). It is useful then to understand the researcher's status as straddling the position of insider/outsider (Mohammed 2001). Given my status as an insider in both the recovery community and as a bereaved individual, coupled with my outsider status as an academic who researches substance use and grief, continually addressing my positionality though reflexivity became critical to the research process.

Savin-Baden and Major (2013) identify three areas in which positionality ought to be identified. The first regards locating oneself about the subject of study. As outlined above, the topic chosen is one that I have personal experience with. In navigating the loss of loved ones to overdose deaths, I experienced grief, stigma surrounding my grief, and processes of memorialization (both in the creation of sacred

spaces and advocacy). All these experiences, coupled with my biography above, have the potential of influencing my findings. The collaborative nature of this project allowed me to readily examine my theoretical approaches and understanding of the topic at hand to ensure that my approach/viewpoint was rooted in the data and not my own assumptions. Further, the preexisting research discussed above was used to guide the analysis. The second area for identifying positionality is locating oneself in relation to the participants – in several instances, survivors knew of my loss and/or of my involvement in the recovery community, had prior interactions with me, or I had known their loved one. To mitigate the impact this could have on the interview process, any survivors that I may have known were interviewed by Dr. Ben Fleury-Steiner, while I interviewed survivors whom I had no connection to. It should be noted that some individuals bereaved by the passing of my late partner were included in our sample – accordingly, Dr. Fleury-Steiner conducted these interviews. There was one instance where I was interviewing a married couple and upon being shown a picture of their loved one, I realized that I had known this person from 12-Step meetings – I did not divulge my knowledge of their passing and maintained outsider status through emotional labor until the interview was concluded. The third area of positionality refers to locating oneself regarding the research process. To ensure that my biography was not influencing the analysis of this data, frequent conversations with my advisor occurred to explore the ways in which we both were interpreting the data. Further, as demonstrated below, my findings and interpretations were put into conversation with preexisting research and well-established theoretical frameworks.

Chapter 4

EMPIRICAL FINDINGS: UNDERSTANDING STIGMATIZED BEREAVEMENT

In contemporary society, the stigma of drug addiction persists (Nieweglowski et al. 2018). As discussed above, a drug overdose death may be perceived as self-inflicted (Feigelman et al. 2012; Titlestad et al. 2019; Valentine et al.2016). Other studies show how those bereaved by a drug overdose death experience a sense of stigma (Dyregrov and Selseng 2021; Feigelman et al. 2011, 2018, 2020; Guy 2004; Guy and Holloway 2007; Nowak 2015). However, there is less attention to how individuals experience stigma. Link and Phelan (2001) observe that many psychological studies of stigma overstate individual experience. Specifically, Link and Phelan describe stigma existing "when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" (2001:377).

As mentioned in the introductory chapter above, preexisting theoretical frameworks of grief and bereavement tend to place bereavement into "normalizing psychology" (Prior 1989) through terms such as "disenfranchised grief," "complicated grief," or other definitions that dichotomize normal and pathological forms of grief. Such frameworks do not adequately capture the experiences of those bereaved by a drug overdose death "because this group may already feel outside the norm, such models and concepts, which imply that it is mourners not society that are the problem, may further confirm the sense of marginalization" (Valentine et al. 2016:292). Larger

cultural narratives stigmatize substance use as socially deviant (Becker 1963; Downes 1977; Murji 1998) and criminal (Chiricos 1996; Kruis, Choi, and Donohue, 2020; Reinarman and Levine 1997; Young 1971). Other studies of cultural narratives of good/bad parenting led individuals to experience a sense of shame after the death of a child (Duncan and Cacciatore 2015). Therefore, it is crucial to understand the unique way that the bereaved may feel stigmatized through various interactions surrounding the loss of their loved one in the context of these societal belief systems. As Seale highlights in *Constructing Death*, "In the ebb and flow of everyday interactions, as has been conveyed so effectively by in the work of Goffman, there exist numerous opportunities for small psychic losses, exclusions and humiliations, alternating with moments of repair and optimism" (1998:193). Thus, the social process of stigmatizing interactions needs to be explored. More so, these interactions need to be understood through a sociological lens that examines the cultural and social underpinnings that give rise to these micro-level interactions.

Survivors were asked to describe positive and negative interactions with others following the loss of their loved one. Throughout these interactions, survivors describe incidents where they felt supported in their grief, love for the deceased, and ways they did or did not provide certain forms of care for their loved one while they were actively using substances. Alternatively, these accounts also demonstrate how stigma is experienced by the bereaved and occurs through multiple interactions. In experiencing these multiple interactions, the stigma experienced by the bereaved has a compounding effect (e.g., intensifies the negative effects of stigma). Throughout these interactions and experiences, the bereaved receive various signals that their loved one was marginalized because of their substance use, sending the message that the loss

experienced by the bereaved is less legitimate. This follows the logic of arguments outlined above that certain "normal" types of death are worthy of compassionate sentiments, while "bad deaths" receive less social support and empathy (Doka 1999; Seale and Van der Geest 2004). Research on stigma typically has focused on one stigmatized characteristic or examined stigma in a particular setting. The findings below highlight how the stigma experienced by the bereaved took multiple forms in various settings.

Prosocial support and interactions have been shown to aid individuals in their grieving process (Aoun et al. 2020; Cacciatore et al. 2021), while lack of support has presented barriers to grief (Feigelman et al. 2009a, 2012, 2020). As those in mourning experience more stigmatizing interactions, they are likely to experience greater degrees of stigmatization. More specifically, individuals are more likely to feel alienated in their grief and judged by others. I refer to this process as the stigmatized bereavement process. The stigmatized bereavement process refers to how a series of interconnected interactions increase the degree of stigmatization experienced by the bereaved, which impacts their bereavement and mourning processes. The following sections explore how the bereaved experienced stigma through their interactions with others and institutions.

4.1 Anticipatory Grief and Barriers to Treatment: "When you're the bad guy, you don't get help." – Eric, Father

The stigmatization process experienced by survivors begins before their loved one's drug overdose death. As discussed in Chapter 2, such anticipatory grief is a looming shadow of the loss to come. Survivors are stigmatized by blocked access to treatment for their loved ones. Specifically, they describe strong feelings of frustration

because they are unsuccessful in finding potentially life-saving treatment for their loved ones. For some, this pre-bereavement experience leads to experiences of self-blame or guilt that does not dissipate. How such barriers to treatment are described takes different forms; in some cases, treatment is described as fatally flawed. Some survivors believe a lack of suitable treatment resources led directly to their loved one's death. Others are less strong in their beliefs - rather than expressing that barriers to treatment caused their loved one's death, survivors described profoundly flawed systems of rehabilitative care as doing little to address their loved one's addiction. Consistent with prior research, barriers to treatment are a common experience for individuals struggling with addiction (Yang et al. 2017; Cunningham, Sobell, and Chow 1993; Link et al. 1997; Luoma 2011). When treatment is denied altogether, stigma can be thought as occurring at a structural or systemic level that "encompasses both public and private sector policies, with consequences that restrict opportunities for those with drug dependence in unintended ways and may restrict access to and diminish the quality of care" (Wogen and Restrepo 2020:54).

Nicholas and his wife Kelsey sought treatment for their son after he had been caught using pills in their home. Upon not finding a suitable program available in Delaware, Nicholas and Kelsey found a long-term inpatient facility out of state for Ryan. Upon returning home, Ryan eventually relapsed. While attempting to get their son Ryan help following this relapse, they experienced roadblocks when getting him into a detoxification center. The father, Nicholas, recalls:

> He did have some challenges in treatment. *Number one was finding appropriate treatment.* When he was addicted to both heroin and methadone, there was no place in Delaware that would detox him under those conditions. We had to find a medical detox which we eventually did. We sat down at the computer and worked at that. *So, I think it was*

> *a big, big challenge finding help and finding good help.* The last place he went, several months before he passed away, told him they had a bed for him, and when he got there, they wouldn't accept him.

This account highlights that the father faced barriers to finding help for his loved one. First, barriers were experienced through not finding an appropriate treatment center in the state, resulting in Ryan having to access treatment out of state. Second, being denied entry to treatment after being told a bed was available served as another barrier. The mother, Kelsey, expands on this by highlighting that they are not the only ones who have experienced this:

> And we hear story after story after story – "You're not using the drug now, so why do you want to come in here? You can't come in here. Go use and get high. You're not threatening to kill yourself." *There are so many roadblocks for people that are trying to get help that I think it deters a lot of people* and really discourages a lot of people, and I wish there was something we could do to help, but I'm not sure where to go with it.

Kelsey describes the challenges for someone who is in recovery to access treatment. If the individual in need is not an immediate threat to themselves or others (e.g., "You're not threatening to kill yourself"), then intervention may be deemed unnecessary. When such barriers are confronted, the stigmatizing cultural script of "unworthiness" is made salient. Additionally, this message may be sent to family members because of their association with the person seeking treatment. Hahn (1983) highlights the ways individuals with disabilities are stigmatized through what he calls a "disabling environment." Here, stigma is experienced through institutional exclusion. Such disabling institutional environments fail to support marginalized groups. By contrast, these institutions stigmatize by denying treatment or support services (Link et al. 1997). Expanding this further, when families or friends are blocked from accessing

resources for their loved ones or are faced with a lack of resources, they may also experience a sense of otherization.

One mother describes attempting to get her daughter help during a crisis shortly before her daughter's fatal overdose. Chloe recalls that she "…went down and got her and I drove her to 5 facilities here in Delaware for the door to be shut in our face. There's no room; there's no beds; come back tomorrow morning at 7:30 when we start discharging." Following this experience, Chloe began exploring other treatment options. At the time, her husband was terminally ill and on hospice care, expected to pass in the coming weeks. Chloe sought a treatment center that would allow her daughter to leave for a few days to be with family in the event of her father's passing. Unfortunately, Chloe was unable to find a facility willing to make these accommodations. Shortly thereafter, Chloe lost both her husband and her daughter.

Experiences such as these impacted the belief that survivors would be able to get their loved one's help. Brittany describes how her son Alex was struggling with substance use and mental health while in high school. During this time, Brittany and her husband Sean tried multiple outpatient treatment options to get help for their son. As Brittany explains, "…our expectations just kept getting lower and lower and lower, and we didn't know what to do. And we didn't have, nobody we went to, I mean he must've had so many different therapists and then psychiatrists..." Further, Sean recalls that certain outpatient settings did more harm by introducing Alex to other users. Experiences such as these left Sean and Brittany and other survivors in this study feeling discouraged by the ways they were unable to access appropriate care for their loved ones.

Laura had continued experiences of being administratively discharged from treatment centers due to behavioral problems pertaining to her co-occurring mental health issues. Her mother Karen and stepfather Samuel voiced countless experiences of sending her to multiple facilities out of state to address her substance use, only to have to spend exorbitant amounts of money to send her to programs specifically oriented towards the treatment of her dual-diagnosis of mental health and substance use. Karen and Samuel eventually found a facility out of state that reassured them they were equipped to address Laura's dual diagnosis, and that they would not administratively discharge her for behaviors associated with her mental illness:

> The sad part about it was they kept telling us [that] they were the right place for her to be, because they dealt with the dual diagnoses, but when she got too hard to deal with, they kicked her out. So, we said to ourselves, and we said to them, "what kind of place is this when you tell us you're the specialist in dealing with dual diagnoses, but you're finding fault with her for having the dual diagnoses?" The very behavior they didn't like was related to her condition. And they kicked her out and had to send her somewhere else. We had to bend over backwards to get in her there. So, it was just very hypocritical. That was my one beef with that place.

Finding adequate and supportive treatment was not an easy process for Samuel and Karan, nor was it for many other survivors in this study. Facing denial when trying to get a loved one help can be incredibly demoralizing. Being told that your loved one is too problematic can be stigmatizing, leaving individuals feeling their loved one is "less than" due to the problems they are presently facing.

Eric recounts how his son Gavin was denied treatment because of the types of substances he was currently using and how they had to lie about his use to receive care. Gavin had approached his father Eric and stepmother Susan during high school

saying that he had a problem with cocaine and needed help, at which point they immediately sought to get Gavin treatment:

> *Initially, he was denied treatment because they said cocaine is not addictive.* Once it leaves your system, you know there's no physical effect left over from it. They said, "Well, you know, if he had problems with alcohol, too, that would be a different story." "Oh yeah, he's got an alcohol problem!" So, the experience was that with a lot of things, *it's a shame that you have to really stretch the truth or even lie to get the right thing to happen.*

Gavin's experience highlights how survivors did not receive support in getting help for their loved ones. Denial of treatment based on the type of substance creates a hierarchy of care. Certain users are viewed as more worthy of receiving care than others. In facing this repeated structural stigma of being denied access to treatment, and not finding adequate treatment suited for their loved one's circumstances, family members and friends of a loved one experienced stigma.

Experiences of courtesy stigma were reflected in survivors' feeling unsupported in their help-seeking decisions. As Nancy states, "It was not a supportive community when we were making those hard decisions, except for a couple of close friends. You quickly figure out who your friends are." Throughout seeking help for their loved ones, survivors often felt as if they were alone in the process, unable to turn to their friends or other family members for support, compounding the stigmatizing experience they were facing through structural stigma. This can be understood as courtesy stigma, for survivors did not share the discrediting label of their loved ones in most cases, but were treated similarly in their interactions- e.g., undeserving of support or help.

Another way structural stigma was experienced was through a lack of available services. Prior work has highlighted that stigma surrounding certain mental health

conditions is often experienced through how mental health facilities are typically placed in isolated environs set away from other people (Rothman 1971). Creating spatial separation between the "sick" and "normal" populations sends a clear message of otherization, similar to the "disabling environment" mentioned above. A handful of family members voiced that adequate substance use treatment services were not available in Delaware, often leading them to seek treatment in other states. Audrey's husband Wyatt lost his job after being arrested on drug charges and fell deeper into addiction as a result. During this time, Audrey sought to get Wyatt help, and describes how she was able to secure her husband's detoxification in Delaware but had to send him out of state to receive long-term treatment:

> He couldn't stop shaking if he wasn't drinking. So finally, I got him in rehab down at [Delaware Detox and Psychiatric]. I found another rehab in [out of state] that did bed-to-bed. So, he did seven days in the rehab over Christmas at [Delaware Detox and Psychiatric], and then they had me take him to the airport, the ticket was waiting there for him. I basically walked him on the plane [out of state].

Returning home after treatment out of state, Wyatt began using again, leading Audrey to take him back to Delaware Detox and Psychiatric. During this stay, "the people weren't friendly, they weren't helping him at all. They gave him these different drugs that I hated that just made him totally a zombie." After Wyatt left this facility, he died from a fatal overdose the following evening. Similar to Karen and Samuel's experience, finding the proper treatment for their loved ones close by was difficult, and often experiences with out-of-state programs were viewed as playing a part in their loved one's death, rather than helping them with their addiction.

The structural stigma experienced by lack of access was often compounded by the experiences friends and families had once their loved ones received treatment.

Notably and tragically, Kathleen describes how the barriers in Delaware, and barriers created by insurance companies, contributed to her son Tanner's death. Kathleen's son had a work-related injury, for which he was prescribed opioids. Through pain management treatment, Tanner became addicted to opioids:

> He died [out of state] because I sent him; he went to [Out-of-State Rehab] because there was no place in Delaware for a man in his 30s. He went to [Out-of-State Rehab], and I actually had to get relinquished at the time to help pay for it because Tanner had Medicaid but Medicaid wanted him out of there in seven days and that was ridiculous.

Kathleen, in fighting to get her son help, was first met with barriers of being unable to get him to help close by, only to be told that he would receive just a week's worth of treatment covered by insurance out of state. Rather than being supported in getting her son help, Kathleen had to fight with the insurance company to extend his stay so that he could complete the 28-day program. Her attempts were successful, however, the barriers she had faced were still a source of frustration. Structural barriers such as these left survivors like Kathleen feeling unsupported in struggling with their loved one's substance use by treatment providers and insurance companies. Therefore, the lack of adequate resources contributed to how family members experienced structural stigma. This experience was further amplified when the services received were inadequate or presented other barriers.

An example of inadequate service contributing to experiencing structural stigma was also found in multiple interviews. Families and friends often talked about how various programs did not provide adequate care or services for their loved ones or were unsafe/unsanitary environments. Jennifer sought to get her son Eugene help multiple times - a process that she describes as "doing all the wrong things" in trying

to “force him” to get sober. Jennifer recalled that he was afraid to go to detox, and one time when she was able to convince him, she and her son were treated terribly by the staff. Upon locating the detoxification center, Jennifer described it as a “crack house” in a “really bad neighborhood.” Upon entering the facility, Jennifer observed unsanitary conditions at the detoxification center that they were attempting to utilize:

> We went in there because we were looking for help for him to detox. *There was a rat running across the floor*, and the guy that was there I went to high school with. It was so weird. And he’s saying, “Look what you’re doing to your mother,” you know, “Look at her,” because I was crying, I was upset. Well, [Eugene] ran out the door and took off. He took off, so we left.

Jennifer explains that because of this interaction of public shaming experienced by her son, coupled with the issue of cleanliness presented by seeing a rodent, her son left the treatment center and was no longer willing to go into detoxication. However, once adequate treatment was found, Jennifer states that Eugene loved it. Indeed, she recalls that he thrived in the structure and routine and expressed the desire for employment as a treatment professional. This example highlights how structural stigma occurs not just in blocked access or separated locations of treatment centers but also through interactions, for Jennifer’s interaction with the individual at the first detoxification center of shaming her son was negative, leading him not to enter treatment. In contrast, Eugene had a positive experience in treatment when interactions with others in these settings were positive.

All the above components of structural stigma demonstrate how seeking treatment for a loved one or sending a loved one to a rehabilitation center often served as a moment of stigmatization for the bereaved prior to their loved ones passing. In these interactions with treatment structures, family members experienced the

pernicious effects of the structural stigma that exists surrounding substance use. Given their proximity to the stigmatized individual in these interactions, the bereaved experienced a courtesy stigma. More specifically, stigmatizing interactions with now deceased loved ones produces a secondary effect on survivors. Thus, even though they do not carry the stigmatizing label of being someone struggling with substance use, they do experience negative emotions that undermines grieving. Specifically, in being denied access to treatment, feeling alone or unsupported in seeking treatment, and witnessing insufficient or unsanitary treatment conditions, survivors experience stigma in the lack of institutional supports for their loved ones.

4.2 Interactions with Police: "Could you please be nice to me? My son's dead." – Sarah, Mother

Many survivors in our study had direct contact with law enforcement at their loved one's time of death. During the interviews survivors were asked to describe these interactions. While not all interactions were negative many, as will be presented in sections to follow, were.

There is a long-recorded history of the way stigmatization of substance use has been codified into law (Musto 1999, 2002) and perpetuated by police officers (Kruis et al. 2020). Prohibition also creates barrier to implementing rehabilitation services (Hari 2015; Morone 1997). Notably, the criminalization of drugs has often utilized stigmatizing imagery and labels to legitimize the "war on drugs" (Alexander [2010]2020; Hari 2015; Kruis et al. 2020). In this way, law enforcement officers may act as stigmatizing agents of social control—police make explicitly moralizing judgments that demoralize and otherize people struggling with drug addiction

(Murphy and Russel 2020). The negative consequences of drug war policing may spill over into kin and social networks.

Patrick and Penelope described their interaction with the police immediately after their son Nolan died. Nolan did not have a long-term prior history of using opiates. Although he had been in recovery for alcohol abuse, he did not suffer from long-term opioid addiction. However, he was prescribed pain medication after a medical procedure, and physical dependence quickly took hold. Indeed, only a month later, Nolan died of a fatal drug overdose. Below is an account of Patrick and Penelope's interaction with police officers at the time of Nolan's death:

> Patrick: Nolan was on his sofa. He fell forward, so he was leaning over his coffee table covered. I stayed until they [paramedics] took him out in a body bag.
>
> Penelope: His girlfriend, Lily, felt like the police wanted her to come inside [Nolan's apartment]. She was really upset. She said they treated her like a heroin couple. She didn't even do drugs.
>
> Patrick: She hardly drank. She would have a glass of wine with dinner when they went out, but that was about all.
>
> Penelope: She said they treated her terribly.
>
> Patrick: She was totally shocked that Nolan had done this. . . The police questioned me. *The officer was like, "So, he's a long-time user?" And I said no, as far as we know, this is the first time he used it. And he goes, "That's impossible. He's probably been using it a long time."*

There are a few critical insights to glean from this interaction. First, the girlfriend experienced courtesy stigma by being viewed as a drug user in association with someone who had died from an overdose. Rather than providing support, the police labeled her as a criminal. Secondly, the officer brought Nolan's substance use history into question. The officer expressed the view that only long-term users die from a fatal

overdose. That is to say, the officer relies on a stereotype of drug overdose deaths. Lastly, in discussing his son's death with the police, the father describes law enforcement as unsympathetic. It can also be inferred that the officer is labeling Patrick as a "bad father" for not knowing the presumed extent of his son's drug addiction. Patrick's experience is stigmatized by association.

Another survivor provides insight into how this stigma informed his interaction with police at the time of his girlfriend's death. Both the survivor and his girlfriend were in long-term recovery. Prior to Jeremy and Hailey getting sober, they had multiple contacts with the police related to their substance use. Once she did not arrive home for dinner after attending an Alcoholics Anonymous meeting, Jeremy began driving around looking for Hailey. Upon finding her unconscious in her car in a parking lot, Jeremy administered Narcan and instructed Hailey's father, who was with him, to call 911:

> County Police Department showed up first. They saw me, they were about to put me in handcuffs because they knew me from my past. Hailey was lying on the floor. They almost treated her as if she wasn't even there at this point. Her dad's very quiet, soft spoken and he wasn't speaking up, so I started yelling. And then a State Trooper pulled up. I can picture his face . . . First thing he said was "Jeremy, I believe we have paperwork for you." And I was like, "Well fuck you. Find the paperwork. Right now, she's on the floor" … *Yeah, they looked at us like scumbags, which is awful because at this point, I was coming up on two years clean at this point. Even after she passed away, I tried to contact them. It's like one of those things like you haven't seen me in two years, yet you've seen the hundred-pound crackhead I was, and you see me in my own car, sober as fucking dirt trying to take care of my girlfriend, and you're sitting here still calling me a junkie.*

In this account, paperwork refers to an active warrant. This exchange highlights how the officer was more focused on the criminalization of Jeremy than the medical emergency at hand. Jeremy describes not being treated with basic dignity at a moment

of a devastating tragedy. Instead, the officer labels Jeremy as a "junkie" even though, in his colorful phrase, he was "sober as fucking dirt." This exchange highlights two things: how courtesy stigma is transferred to survivors at the time of death and how members of law enforcement are focused on drug overdose deaths as a crime scene. Jeremy's account is also reflective of the "drug couple" stereotype experienced by Nolan's girlfriend.

Jeremy's past interactions with police also shaped his experience at the time of Hailey's death. Past experiences with law enforcement shaped other's accounts of such interactions. The deceased's drug addiction history often involved prior contact with law enforcement and survivors were viewed as suspects involved in a crime. Although Sarah's account differs from Jeremy in one obvious way—she has no prior history of substance use—she has had multiple interactions with police because of her son Marshall's addiction which, evidently, resulted in multiple arrests:

> They were kind but mind you, I said to them, and I'll never forget, "Could you please be nice to me? My son's dead." Because they were never nice…I believe they were out to get him over stupid stuff. Just because they knew he was an addict. My son didn't rob, he didn't rob stores or hurt people, but he would cross the railroad tracks because we lived by the railroad tracks, and they'd follow him, and then they'd arrest him for crossing the railroad tracks because that's against the law. You were on the railroad tracks…really? And they would throw him in jail for a couple of hours just to break him. And when he broke probation, they came to my house looking for him. They were so disrespectful coming to my house, and they were like, "We want him now," like he was a criminal. He wasn't a criminal . . . And I'll never forget that . . .

The stigma ascribed to her son by the police fosters negative expectations *at the time* of Marshall's death. While she describes the police as showing some kindness, her

past experiences lead her to still distrust the police. Sarah was worried that the police would treat her with animosity rather than sympathy.

For other, negative police interactions are perceived as possibly hastening a drug overdose death. Jennifer's son Eugene had a long history with the police, ranging from a previous hostage situation at their house in which SWAT was involved, to dealing drugs. Eugene spent multiple years in prison while alive and had been in the criminal justice system since he was young. Given this lengthy history of antagonistic relations with the police, Jennifer apparently learns from Eugene's girlfriend Terry that the police, who she also suspects are corrupt, may have beaten Eugene and emergency care was deliberately delayed:

> And they wouldn't let her [Terry] in the room. They closed the door. I don't know what they were doing, and I worry about that because policemen didn't like him. There had been some big scam where policemen - they were all taken off the force, but they were going in to confiscate drugs and take [INAUDIBLE] away, and they were keeping it, using, whatever. And I think they had done that to Eugene, and then his case was totally dropped because of that. *So, there were these policemen that had these grudges with him, so I'm thinking, they wouldn't let her in the room, and I'm thinking, did they beat him up? What did they do?* Because she heard a thunk. And when she finally was able to look in the room, he was on his knees, which he would never be because his knees were real sore. She said that Eugene was conscious, but he couldn't talk to her. And police came first before the ambulance, and they were in there a long time, and then the EMTs. Why would that be? And I tried to get the police report and everything, but I couldn't get it.

While Jennifer did not have direct engagement with law enforcement at the time of death, she learned of this encounter when her son's partner [Terry] called to inform her of her son's passing. Like Sarah's experience, she believed that law enforcement viewed Eugene as a criminal. What distinguishes her story is the belief that police may have harmed Eugene and impeded emergency medical care.

These experiences of the bereaved highlight two ways in which interactions with police create a stigmatizing experience. The first involves the courtesy stigmatization of survivors due to their close relationship with the deceased. The examples above highlight that this is most strongly experienced by significant others, especially if the partner has a history of substance use themselves. Second, interactions where police are completely unsympathetic to the deceased. In these interactions, they show little sympathy for the family who are treated with indifference and even as possible accomplices to a "drug crime." Because criminalization dominates these interactions, law enforcement officers construct family members of the deceased as enemies in the drug war.

Law enforcement officers take the cultural narratives of substance use as a moral failure based on bad individual choices as commonsense (Murphy and Russell 2020). Prior research has, moreover, highlighted a lack of social support when deaths are viewed as being "at the hand" of the decedent thus "[b]laming children for their own demise is another direct assault on the survivor, suggesting that the deceased is unworthy and does not rightfully deserve to be honored and remembered" (Feigelman et al. 2012:65). This labeling, in turn, has led family members and adult peers to feel that law enforcement was not supportive of their grief. For most, the first interaction after the loss of their loved one with someone outside of their immediate family is with law enforcement, meaning that the stigmatization experienced at this moment may act as a guide for how they perceive future interactions regarding their grief. Drug war policing leads many officers described by survivors to approach substance use in a manner of moral regulation and social control (Murphy and Russell 2020). These

approaches carry forward into the interactions that members of law enforcement have with the bereaved, resulting in a display of a callous indifference towards their grief.

4.3 Alienation: "When your child dies of a drug overdose, you feel like you're alone." – Brittany, Mother

One of the primary features of stigma is that it creates a separation of "us" from "them" (Link and Phelan 2021; Morone 1997; Devine, Plant, and Harrison 1999). The stigma surrounding substance use has a long history of creating systems of exclusion and alienation (Ritsher, Otilingam, and Grajales 2003). Prior studies have highlighted that the families of loved ones with addiction experience this through courtesy stigma and alienation (see Chapter 2). Indeed, Doka's work on disenfranchised grief is instructive here. Specifically, this research illuminates how bereavement must be contextualized in "socially difficult circumstances" (Doka 1989, 1999). Survivors' accounts illuminate how stigma surrounding substance use is often a profoundly alienating experience. Family and friends also act as agents of stigmatization. Specifically, they actively alienate the bereaved as stigmatized outsiders versus "everyone else."

For those survivors in intimate relationships with the deceased, stigmatization is profoundly alienating. Rose was engaged to Mel, who continued to have periods of time where he was sober, followed by a string of relapses. The experience of watching Mel vacillate between sobriety and relapse was traumatic for Rose, who described Mel as an entirely different individual depending on if he was sober or using. In recalling her fiancé's death, Rose describes this judgment and disconnect:

> Someone asked me one time, "How could you love an addict?" I wanted to take my hands around their throat… I'm like, "Are you kidding me? Do you know anything about this population? They're

> incredibly traumatized and incredibly hurting. They need people like me to love them." I didn't love an addict. I loved a man who struggled with some demons.

This exchange otherizes Rose for her positive feelings towards a loved one struggling with substance use. In describing the questioning, her love for a person struggling with substance use is met with a disbelief meant clearly to stigmatize them as outsiders. Rose attempts to counter this narrative by bringing attention to Mel's identity as not defined by his struggle (stigma). Rose's narrative is also one of resistance. She discredits the agent of stigmatization in this interaction as lacking understanding of substance use and addiction.

Other survivors also recounted how those who actively stigmatized their loved ones lacked knowledge, understanding, and exposure to individuals with substance use. Maggie lost a close friend and coworker named Erica, who had been sober for 18 months before experiencing a fatal relapse. Maggie recalled that Erica was the coworker with whom she was closest to and a friend that she spent a lot of time with outside of work. After Erica's passing, Maggie felt alienated in interactions with her coworkers. Maggie, who is older than her co-workers that she refers to as "girls," recalls the following experience:

> Well, I mean that's a person that's speaking that's never understood addiction. There are a few girls who [said] "Didn't she overdose?" I knew her nephew…Roger had a terrible heroin problem. He's been clean probably for five years or maybe longer…But she's like, "Ugh, well, didn't she overdose? So, she obviously wasn't recovered" [in a judgmental tone] It's like, "are you kidding me?"

Prior research has highlighted that even when individuals with addiction reduce use or abstain, they still experience stigma (Link et al. 1997).[4] Maggie's experience highlights that her friends' sobriety was overshadowed by her fatal overdose. Maggie explains that she now feels alienated in the workplace, "It's just not, you know, the group, it's a very divided group. Erica was my person, so now I'm person-less. I don't necessarily have anybody that I hang with." This example further highlights how stigma makes its way into the workplace of bereaved friends, leaving Maggie feeling alone in an environment where she once found support in her friend Erica's presence.

Alienation often occurred in more overt ways as well. Survivors frequently reflected on how friends and families were not supportive of them. This occurred both at times before and after their loved one's death. Jennifer, the mother who lost her son Eugene, supported her son financially and emotionally during his struggles with addiction. Her family strongly opposed this decision and ended all contact with her. Throughout Jennifer's interview, she discussed moments where she had reached out to various family members for support while her son was using and did not receive any. She recalls a time when he was in the hospital shortly before he passed when nobody reached out:

> Not one person came to sit with me in that hospital to visit him. I was so annoyed. I actually got … the "Get Well" cards [and] I [mailed] them to family members I wrote "These are cards for you to mail to

[4] "In support of our hypothesis, we found that two aspects of stigma that we identified-perceived devaluation/discrimination and respondent reports of discrimination experiences-continued to affect the men in an untoward fashion even though the men generally improved, presumably in response to the positive effects of treatment." (Link et al. 1997:186)

> Eugene, so he thinks somebody gives a shit." You know, if it was their son - I sat there *alone* nine days.

Jennifer's experience of alienation continued even after this painful experience of isolation. She described her other son speaking ill of her at Eugene's funeral: "He was outside the funeral home [telling] people that I was a bad mother and [that I] don't pay attention to my grandkids." Jennifer describes, through tears, her anguish at how her family essentially abandoned her and the alienation that continues into the present:

> I don't think I'll ever forget that. If my sister's daughter or son had died, my mother by hook or by crook would have gotten a ride and been over there for her. But nothing for me. Why? Because Eugene was an addict? Because I had an argument with my family members? They need to let that go…I couldn't believe it! [crying]

The alienation Jennifer experiences is directly linked to the stigma of her son's addiction and her family's condemnation of her as an unfit mother. Later in the interview, she explains how this situation has gone on for five years, "I lost my living son because he's being an ass." Jennifer's account is another dimension of alienation experienced by survivors. Specifically, a legacy of stigmatization leaves survivors with profound feelings of isolation from family members that may last for many years. The grief of losing a son to an overdose death is compounded by the grief experienced by the loss of living sons and other family members who blame the survivor.

As an alternative to experiences of family members abandoning bereaved parents and other loved ones, some survivors push others away. Yet the outcome is similar (e.g., they express feelings of alienation as they grieve). Another mother, Kathleen, who lost her son, Tanner, describes how the lack of support by her mother had a negative impact on their relationship:

> When Tanner died, my mother didn't even come to my house for 15 days after he died. She finally called me, and said "What are you doing?" And I said, "Well, I'm writing Tanner's obituary." I was

> crying and the only thing she said to me was, "Well, don't include me or dad in the obituary." And I said, "Oh really?" *And she said, "Yeah, no, don't, please don't include us." And I said [in a stern voice], "Okay, mom, you don't want to be included in my son's obituary? You won't be included in mine either."*

Kathleen's mother and father want no association with their deceased grandson. For Kathleen, this painful interaction resulted in an act of self-preservation. Like Jennifer, Kathleen describes a similar outcome to Jennifer – namely, the severance of close family relationships with her parents. Interactions such as this highlight the unique way stigma surrounding substance use acts as a barrier of support for the bereaved. Kathleen describes a subsequent alienating experience when her mother came over after the death of Tanner:

> I really don't have a relationship with my mom, and it's a shame. She finally came over after weeks after Tanner's death. She sat on my couch, and all she could say was, "Thank you, Jesus, for taking Tanner, thank you, Jesus." And I turned to her and said, "You know what, Mom, I'm not really thanking Jesus right now. Um, you have no idea what I'm going through, and if you don't stop, I want you to leave." And she just got up, and she left.

Clearly, Kathleen does not have a close relationship with her mother anymore. Rather than receiving support, her interaction with her mother is fraught with feelings of alienation. While her mother's religious faith may have been intended to provide comfort, for Kathleen, it obviously backfired. Instead of providing the support that her daughter needed, moreover, she leaves. While the intention may not have been to stigmatize, the impact that the mothers' words had was stigmatizing for Kathleen. The reference to her mother's hasty departure is clearly an alienating experience for Kathleen.

Some survivors even highlighted how they were blamed for their loved one's death. Rather than receiving prosocial support in their mourning, the bereaved

experienced alienation through blame. Chuck's fiancé Lexi had a strained relationship with her family. Chuck describes feeling closer to Lexi than her family, emphasizing the strained relationship Lexi had with her parents and that he had lived with her in a different state for the past few years while the family was elsewhere. When Lexi passed, her mother blamed Chuck for her death:

> She thought that I had something to do with it regardless. Everything was always my fault with her mom, who wasn't in her life for twenty-eight years. You know, but whatever. I get it. That's what people do. I'm an understanding person, and they need someone to blame and pin it on, so I get it.

Ideally, community and support can be found in those who share mourning sentiments in times of grief. However, when individuals are viewed as somehow responsible for their loved one's death, they may be alienated from those with whom they could find support. Specifically, Chuck did not find support nor an experience of shared grief with Lexi's family. On the contrary, he was blamed for her passing. At the same time, in a gendered response that is quite different than female survivors, he draws on the story of a strong man willing to be blamed for his overdose death.

Chloe experienced equal blame when approached by friends and acquaintances about the death of her daughter. As she previously described, Chloe had sought to get her daughter Eustice into treatment. During this process, Chloe went to multiple treatment centers and was unable to get her daughter admitted. She describes how she was blamed by others for not getting her daughter into treatment:

> I had one friend tell me three weeks after Eustice died that she should've been in rehab a long time ago. Now, this is a friend that babysat her for many years and has a son who lives at home because he doesn't wanna go to jail for smoking pot. And you're gonna sit here and tell me I should've had Eustice in rehab a long time ago?

> ...She wasn't the only one, didn't do enough to save my child. *One man, who I considered a friend, blamed me.* He has a daughter prostituting for her drug money. What are you doing for your own daughter? You're not even involved in her life, and yet you wanna tell me I didn't do enough to save my kid? See ya, friendship done. I don't need to hear that stuff if you can't support me.

In these interactions, Chloe is obviously denied support from her friends. Moreover, she is targeted as a failed mother, who bears responsibility for not doing enough to prevent Eustice's death. Cultural scripts of good/bad parenting and the stigma surrounding substance use present an alienating experience for the bereaved. Rather than receiving support, individuals like Chloe are left to defend their decisions and parenting. As Feigelman et al. (2012: 65) observe, "…direct blame toward parents are especially troubling to the survivor because they reinforce the parent's own self-accusations of ineffectiveness in saving their child's life."

Alienation also was present in larger narratives of the decedent dying by suicide. As discussed above, deaths by suicide or drug overdose death receive less social support (Feigelman et al. 2008, 2009a, 2009b, 2009c, 2011, 2012, 2020). Typically, these deaths receive less support because they are viewed as "bad deaths" (Seale and Van der Geest 2004) resulting from individuals' choices, alienating the bereaved from receiving sympathy or support in their grief. Mary lost her son Chester shortly after he completed an inpatient rehabilitation program. Although Mary works in the treatment industry, she expressed that she felt she could only talk to Chester's fiancé about his death because of how others viewed his death. As Mary describes a cautious approach to discussing this with other people, "Certain people I have issues discussing it with feel as though he did this to himself. And in one respect he did, but in another, he didn't." Ingrid, the fiancé of Mary's son, further recalls the decedents' father stating at the funeral, "he did it to himself, I guess he got what was coming for

him." This experience shows how stigma surrounding substance use – notably the stigma of individual choice or moral failing – impacts sympathetic sentiments. Statements like that of Mary's ex-husband left survivors feeling that they could not speak to others about their loved one's death, for they would be met with the dismissal of their grief through stigmatizing statements that they, "did this to themselves."

From these experiences, stigma is described by the bereaved through the ways that others alienated them. As previously discussed in Chapter 2, stigma is not separate from "social inequalities in life circumstances" (Link and Phelan 2001:371). One such social inequality experienced by those who lost a loved one to a drug overdose death involves a lack of support or sympathy for their grief. As the examples above show, alienation is made salient in subtly different ways: *First, individuals may experience exclusion from social networks.* Survivors' experiences highlight how this is often the result of a family member's lack of understanding of substance use. Rooted in stigma, this lack of understanding creates moments where individuals find themselves defending the decedent rather than receiving support for their grief. *Second, individuals may experience isolation from family.* Families were not always a unified front when mourning the loss of a family member to a drug overdose death. Instead of the "us" versus "them" stigmatization being reserved for those with addiction, this otherization was experienced by those who grieved the loss of a family member by those whose actions had an alienating impact. Some of the individuals engaging in alienating actions were grieving as well (such as Kathleen's mother above), highlighting that it may not have been their intention to alienate their friends or family members, but this became the impact of their responses to grief. Experiencing this otherization left individuals like Kathleen alienated from their families. *Third,*

alienation occurred through blame being placed on the bereaved. Rather than receiving sympathy or support in their grief, individuals who experienced this alienation were depicted as culpable for their loved one's death, often leaving them having to defend their past actions, decisions, and, indeed, how they grieve in the present. *Fourth, alienation occurred through the bereaved receiving messages that the decedent either did this to themselves or "had it coming."* Narratives such as this are rooted in the longstanding cultural stigma of substance use as a personal or moral failing (Courtwright, 2009; Dyregrov and Selseng 2021). This ideology of individual responsibility undermines social support individuals need during these profoundly difficult times of mourning (Doka 1989, 1999; Feigelman et al. 2011, 2012). *Lastly, this alienation compounds mourning sentiments.* How alienation is experienced can combine with this last form across all the ways discussed above, creating a "double-loss" for the bereaved. Those experiencing this alienation are often left mourning both the loss of their loved one and the loss of relationships and support of others.

4.4 Lack of Social Support: "They don't respect it. Some people don't respect an addict that has died over someone that has died from natural causes or someone that has died from cancer." – Nancy, Mother

Aside from feeling alienated from prosocial support, survivors often felt they could not turn to others for care. While alienation focuses more on interactional stigma, this section will explore beliefs internalized by the bereaved rooted in the culture of stigma surrounding substance use. As Valentine et al. (2016) highlight, the culture of stigma toward substance use in society often leaves the bereaved feeling that they cannot seek support. Cultural belief systems of stigma are also reflected in individual beliefs, often serving as a barrier to help-seeking behavior. As Tan et al. (2020:2) observe: "Stigma affects an individual's help-seeking intentions

and behaviors, insomuch that a person considering treatment may be discouraged from doing so due to the anticipation of potential discrimination." Survivors in this study avoided potential stigmatization. Survivors thus engage in forms of label avoidance (Schomerus & Angermeyer, 2008). Corrigan and Wassel (2008:44) define label avoidance as "dodging a group altogether to escape the negative effects of public stigma and self-stigma." This section will examine how stigma about substance use resulted in the bereaved engaging in label avoidance. Specifically, survivors in this study reported they hid the nature of the death from others, attempted to keep their loved one's addiction a secret, and chose not to pursue help-seeking practices in their grief.

Decisions to hide a loved one's substance use, or that their death was from an overdose, demonstrate how the bereaved engaged in label avoidance. Notably, they did not want the memory of their loved one to be associated with substance use, nor did they want the courtesy stigma ascribed to them. Brittany lost her son Alex after years of trying to get him help through various treatment centers and programs. Brittany and her husband Sean had discussed hiding how Alex had died. Brittany describes how she kept the nature of her son's death a secret, as well as her concern that revealing it would alert others of Alex's substance use:

> I only wanted to hide the fact that he had died of an overdose, because then they'd know he had a drug problem. And not everybody knew that we battled with the drug problem. I felt very vulnerable. It was very hard.

Brittany and her husband Sean also hid their son's death from the neighbors for as long as they could. The stigma surrounding substance use thus contributed to their decision to hide how Alex died, for - as they state - they did not want others to know their son had a drug problem. More broadly, this can be seen as Brittany and Alex

seeking to prevent a stigmatizing label being ascribed to their son, and in turn, avoiding the associative courtesy label of having a child who uses substances. Concealing the nature of the death in this way further highlights the impact of stigma on the bereavement process. Rather than the possibility of reliance on communal support in their grief when it was available, some survivors felt they had to actively hide the death.

Penelope and Patrick, who had experienced the stigmatizing interaction with police discussed above, described a similar decision-making process in discussing their son Nolan's death. Nolan, having worked in the treatment industry at the time of his death, and having had multiple years of sobriety before his passing, was well known in the recovery community. While Penelope and Patrick eventually chose to share the nature of his death, they voiced fear of how he would be remembered if people knew he died from a drug overdose.

> Penelope: We could probably try and make the cause of death something else, but we just decided it would be the biggest help if we were just honest.
>
> Patrick: I think I wanted people to know that he wasn't some street drug addict.

Two elements must be highlighted in this statement. First, is the acknowledgment by Penelope that disclosing the nature of Nolan's death would allow them to access more support than if they kept the death secret, highlighting that help-seeking was possibly viewed as more important than label avoidance is evident in their statements. Second, Patrick chose to share that Nolan died of an overdose because he was afraid that people would stigmatize Nolan as a deviant "street addict." Because Nolan did not have a long history of substance use, indeed the news that he died of an overdose came as a shock to his parents, and those with whom he worked with in the treatment

industry. Patrick felt it was important to share that his son was prescribed opiates by a doctor and not engaged in the stigmatizing images of the street addict, represented as knowingly using dangerous street drugs.

Parents were not the only bereaved group that deliberately chose to conceal the nature of their loved one's death. Rose, who experienced alienation following her fiancé Mel's death discussed above, expressed that she wanted to preserve a particular image of her fiancé. Doing so signals the ways that she felt she might not have entirely been supported in her grief. Rose expresses concern about the extent of information to share about Mel's harmful and abusive behavior:

> My family knows the wonderful parts about Mel because I won't let them know that this man relapsed six or seven times while we were together. And I won't tell them about the horrible stuff. And I still won't let anyone think bad about that man because he was my Mel…And I loved him.

Rose chose to hide that her fiancé had been actively using prior to his death and that he had relapsed multiple times. This decision is based on not wanting to diminish her family's memory of Mel. Both Rose and Patrick highlight how the bereaved engaged in label-avoidance for the deceased. Notably, both sought to preserve a certain image of their loved one when discussing them.

Amy had a close relationship with her grandson throughout his life and leading up to his death. She apparently sought to keep her grandsons' addiction a secret: "I have some friends, and I will say that people that have nothing to do with drugs don't understand it. . . they think that they can just stop." This pervasive stigma has been discussed throughout this dissertation. It is essential to emphasize how the belief in substance use as an individual choice can create a barrier to social support for Amy.

Knowing that they held a stigmatizing view of addiction, survivors decide not to pursue grief support from kin or social networks.

If survivors cannot depend on loved ones and close friends, then it is safe to assume they may pursue grief support groups. However, avoidance of stigmatization may also prevent individuals from pursuing such alternatives. Patrick and Penelope describe how fears that Nolan's overdose death would not be accepted prevented them from attending a grief support group:

> Penelope: Yeah, somebody had told us about [a grief group] for people who have lost a child. But we were afraid because I remember talking to our counselor about it, and she said, you know it could be somebody that just lost their infant child to cancer or something. She said you could go to a meeting and be the only ones that lost somebody to drug addiction. I don't know that I ever would say that people look down on you, but I think people with suicide feel the same way.
>
> Patrick: You did it to yourself.
>
> Penelope: You did it to yourself. They did it to themselves. It's not like we lost our child to cancer or an accident. And I might be wrong there, but I think that's what kept me from going through.

Echoing Amy's sentiments in the previous section, Patrick and Penelope felt that others would not understand their grief due to the cultural stigma of substance use being an individual choice/failing. The above sentiments demonstrate that they were concerned that their grief would not be supported due to the nature of their loved one's death. Cultural, structural, and interpersonal experiences of stigma all shape how stigmatization becomes an internalized belief system (Tan et al., 2020). Here, it can be seen how this internalized belief system prevented Penelope and Patrick from potentially receiving support in their grief.

What about parents who did pursue group support? According to one survivor, Jan, she did decide to hide the circumstances surrounding her son's death:

> I also went to [a grief group] and that was probably the *least* helpful. Probably because almost everyone else there had lost a spouse or a parent, and it was very different. I didn't discuss how my son died there. The facilitator there had lost a daughter in a car accident, so at least there was one other person who had lost a child.

Jan's experience further highlights the decision not to disclose the cause of death when a drug overdose is involved. Even in the context of formal help-seeking, stigma can act as a barrier for individuals receiving grief support. Jan, Penelope, and Patrick also demonstrate the particular ways that grief is disenfranchised in the lives of parents. This analysis provides context for understanding how stigma surrounding a drug overdose death reflects both the barriers to support survivors experienced and overarching cultural beliefs in drug related deaths as an individual choice. Disenfranchised grief is perceived by parents as less grief-worthy than non-substance-use-related sudden losses or destigmatized anticipated losses such as cancer.

Beyond this broad sentiment, disenfranchised grief is realized in the survivors' help-seeking experiences. These experiences differ from alienation. Specifically, survivors internalized the belief of stigmatization, serving as a deterrent to help-seeking behavior. As Titlestad et al. (2019) observe "Along with stigma comes social isolation, which is internalized as an intense feeling of shame" (p. 9). While in the next chapter I will explore positive help-seeking experiences, for these survivors a support group was avoided or negotiated by concealing how their loved one died. These findings demonstrate that the bereaved experienced a courtesy stigma from their loved one's substance use, limiting their willingness to turn to various forms of support – or to be transparent about their loss when seeking support – due to anticipated stigma. Studies on suicide bereavement have highlighted similar experiences (e.g., Dyregrov 2011; Goulah-Pabst 2021; Young et al. 2012).

4.5 Feeling Rules: "But you know, we're not supposed to mourn, you're supposed to get over it; you're supposed to get through the first year" – Kathleen, Mother

Feeling rules and expressive norms served as another arena where the bereaved experienced stigma. Agents of stigmatization emerged in "policing" feeling rules of survivors by providing criticisms of their grief process and expressions of mourning sentiments. Although it may seem that this is separate from the stigma associated with substance use, those bereaved by a drug overdose death often experience a sense of not being able to display their grief outwardly - they experience a "social censure" due to how their loved one died (Valentine et al. 2016:294). Survivors in this study commonly experienced various instances of social censure in expressing their grief. These episodes of social censure are rooted in the discussion of feeling rules above. Because cultural norms exist about what feelings should be felt and displayed following a loss, social censorship becomes compounded for the drug overdose death bereaved.

One survivor coped with her grief through humor and being direct. Claire lost her roommate and close friend, Erica. As mentioned earlier, Erica had been sober for 18 months before her death. Claire, in recovery herself, works in the treatment industry - a space one would assume to be less stigmatizing. Claire recalls the stigmatization experienced through coworkers enforcing feeling rules and expressive norms:

> It's probably more with coworkers than family just because my family also deals with things through humor. That's like a - but I have had coworkers - and I'm just very blunt and very cut and dry like this is what happened. And people will be like, "Oh my God, Claire!" And I can't think of a specific example. I don't know. I can't think of a specific example. *I'll just be like, instead of "Passed away," I'll be like, "She's dead. She's died." And people will be like, "You gotta be more gentle with it."* And I'll be like, "Why?" That's what happened.

> But again, *I think there's that stigma of death, and you have to be gentle, you have to deliver it the proper way, and I don't agree with that.*

Three critical things can be highlighted in this example. First, coworkers enforce expressive norms by telling Claire what is and is not an appropriate way to discuss her loss. Feeling rules refer to the internalized emotions one is expected to feel in each situation, and expressive norms refer to how these feelings are supposed to be displayed. Situations such as this can further alienate the bereaved by signaling that they are not supported in expressing their grief. Second is the direct mention of stigma surrounding openly discussing death. While the stigma surrounding substance use may be alienating or carry the shame-based stigma discussed above, interactions such as this can also be stigmatizing. It sends a message to the bereaved that they are not expressing their grief "normally." For those discussed in the sections above, coming forward about the death is challenging at times – to be told one is expressing their grief incorrectly can further compound this alienating process and increase a feeling of lack of social support. Third, Claire's resists enforcement of expressive norms that characterize stigma surrounding drug overdose death.

Other survivors describe feeling rules couched in temporal arguments of healing. In such accounts, they are ordered to find closure in their grieving process and "move on." Prior research on drug overdose deaths highlights that this type of loss does not align with the cultural narrative of "time healing all wounds" (Titlestad & Dyregrov 2022). Such stories are closely tied to the social construction of closure (Berns 2011). Kathleen, who experienced alienation from her mother following Tanners passing discussed above, reflected on how people told her the grief would subside after the first year:

> But you know, we're not supposed to mourn. You're supposed to get over it. You're supposed to get through that first year. And everybody tells you, you get through all those firsts, and then it's like, oh, okay, so if I get through all, I feel like the weight of the world has been lifted off my shoulders. Well, I can tell you, that second year was horrible. Horrible!

Expressive norms and feeling rules such as this can send a message to the bereaved that they are not grieving appropriately or healing in an appropriate amount of time, further otherizing the bereaved. Kathleen's experience reflects how there were expectations of closure presented to her, yet upon hitting the temporal milestones, she did not find relief. As Berns (2011:162) cogently explains, "The appeal of closure rests in large part on the hope that pain will lessen, and healing will come." Upon not experiencing closure or relief one year after her sons passing, Kathleen experienced greater levels of grief.

In some instances, these feeling rules of what the bereaved ought to feel, and when, acted as a barrier to support. Mary, discussed above, lost her son Chester and experienced alienation from her ex-husband and lack of social support following her loss. Mary describes how her husband – the stepfather of her deceased son – believes that she should move on faster than she has:

> Well, he looks at it like, he can understand how I feel because he lost both of his parents; he looks, he doesn't understand, he feels as though I should be better by now, it's been six months, I should be okay but, it's not the same, and it will never be the same. So…Right, I should be, I should be okay because, you know, he lost both of his parents, rendered it was seven years apart, but he lost both of his parents, and he's gotten over it, you know, it's also been four years since he lost his father, and you know, that is an expectation to lose your parent in their seventies. God forbid anything happened to my mom and dad, but if I lost them, I would get past that because they are in their late sixties and early seventies - you expect it. You don't expect to lose your child, especially at the age of thirty.

Mary highlights how her husband acted as an enforcer of feeling rules in telling her where she ought to be in her mourning process. Experiences such as this further stigmatize the bereaved through "normative" grief scripts. Because of the experiences with her husband (and stigmatizing experiences with her ex-husband described earlier), Mary feels that the only support she has in her grief is her son's fiancé. Like Kathleen, she experienced stigmatization through culturally held beliefs of "closure" and the feeling rules ascribed to this social construct.[5]

Survivors describe how the way that others discussed the death or the support they tried to provide was rather unhelpful, given the nature of their loss. Recall how Rose, the woman who lost her fiancé Mel, asked others for help and support. However, because she is a counselor, those closest to her placed expectations on her to overcome the grief on her own. This made expressing her grief even more stigmatizing. Rose was told that she had to "pull it all together" for her children:

> I was trying to explain to people, listen, I am not okay. It felt as if I was thrown from a boat and I'm in the water, everybody is on the boat, and the boat's circling me and they're looking at me, and I'm like trying to

---

[5] Berns (2011:4) provides a detailed account of how closure is a social construct:

> From the social constructionist study of social problems, I use the idea that the way we name and describe experiences has consequences. 'Closure' is not some naturally occurring emotion that we can simply 'find' with the right advice. Rather, closure is a made-up concept: a frame used to explain how we should respond to loss. The term 'frame' has been adopted from the sociologist Erving Goffman to describe how people identify, interpret, understand, and label their experiences and to explain social problems. We make something like closure 'real' through social interactions. Any understanding we have of closure comes from how people have defined it through stories, arguments, court cases, and so on. This does not mean that the pain from loss is just imaginary, but how we interpret and respond to the loss is shaped by our social world, such as popular culture, life history, social norms, friends, and family.

> tell people how to help me, and then I'm getting judged because I'm the counselor, so I'm supposed to figure it all out, and I'm supposed to be the mom and be the one to put it all together and just go back to work? I could not get over the amount of people who were so apathetic or the stuff they would say to me, like, "you have kids; you have to get up."

Stigmatizing feeling rules in this exchange signifies that Rose ought to overcome her grief to be a good mother and employee. Thus, survivors felt stigmatization in expressing their grief when it did not align with the feeling's rules in place. Rose counters some of the sentiments she received by stating:

> Just the stuff that people would say, I felt like the cockroaches just came out. I cannot explain to you the alone - yes, people die, and yes, if anyone ever says to me ever, "It's part of life," that's bullshit. Death is death. It is not a part of life. It is death. It is the craziest thing you could ever experience. We can't deal with it. We don't know how to deal with it.

Rose highlights that the experiences of the bereaved often do not align with normative feeling rules. In this, when the experiences of individuals do not align with the normative expectations established by dominant cultural feeling rules, it can lead to another stigmatizing experience.

Similar to Rose's statement of there not being a script for navigating this unique form of loss, other survivors also described feeling trapped in anomic state. Notably, survivors expressed that they did not know how to express their feelings or, at times, even *what* to feel surrounding the loss. Some studies have described tensions that are unique to those bereaved by a drug overdose death. Specifically, survivor's express feelings of both a sense of relief and grief. Yet little is known about how this sense of normlessness is experienced by the drug overdose death bereaved. After losing his brother, Terry recalls not being sure how to grieve. In interacting with his family immediately after they received the news of his brother Gavin's passing, Terry

expressed how he and his parents were unsure of what to do or talk about: “What do you talk about? There was no precedent that had been set before for us on this. Everybody was trying to figure out how to keep on keeping on just in the moment.” Terry highlights how the experience of losing a loved one to a drug overdose death does not neatly fit into the cultural feeling rules surrounding death, leaving the bereaved in an anomic state.

Sally describes uncertainty on the “appropriate” expressive norms surrounding the expression her grief. Sally had been in a relationship with Morgan while both were attempting to get sober. Morgan passed away shortly after he and Sally broke up. Sally described the trauma of discovering his body; a memory that was still greatly impacting her at the time of our interview. In dating again, Sally voiced that she was unsure what the expressive norms are regarding her loss, highlighting an ambiguity in feeling rules:

> It feels like a betrayal by not putting that post up on Facebook. It feels like a betrayal by not mentioning a memory that I have when someone’s talking about a certain place or a certain thing that me and him have done because the new boyfriends there. I don’t know if it’s out of respect or out of fear. I don’t want to diminish the love that I had for Morgan any less just because I’m with someone else, but then I don’t know, you know? It’s like I want to move on, but I don’t want to not honor his memory somehow, so it’s hard.

The ambiguous nature of these feeling rules can propel the bereaved into a state of anomie. Sally’s sentiments highlight that she was in a state of normlessness being in a new relationship while still grieving the loss of her former partner. Entering this state may serve as another sign of stigmatization, for the bereaved may feel “different” or otherized in their expressions of grief.

Feeling rules and expressive norms can create another layer of stigma for the bereaved. In not aligning with these cultural scripts, the bereaved receive messages that a) they are grieving inappropriately and b) the nature of their loss does not align with normative scripts. Otherization is created by the normative feeling rules, and expressive norms further categorize the "us" versus "them" system. Specifically, those who grieve in the appropriately sanctioned ways and for the appropriate amount of time are accepted as insiders into the sentimental normativity. Adversely, those who are told by agents of stigmatization that their grief is expressed inappropriately or has not been overcome in an acceptable manner or timeframe may have an outsider experience in this grief. As discussed above, this otherization and alienation is a product of stigma. The larger cultural narrative of feeling rules and expressive norms becomes further convoluted following the unique grief experienced from a drug overdose death, creating another arena of stigmatization for the bereaved in the expression and internalization of their grief. The responses above highlight how these feeling rules and expressive norms were enforced and the ambiguous state that this creates.

4.6 Choice Narrative: "Chester's dad is a piece of work. He's said, 'He did it to himself, I guess he got what was coming for him.'" – Ingrid, Fiancé

The cultural stigma surrounding substance use often rests on the belief that users choose to continue their active use and, therefore, may stop at any time. Prior research shows how blame is often placed on those with addiction as responsible for their condition, and in turn, deserving of social ostracization (Lloyd 2013). Others have also observed the impact such sentiments have on the bereaved experiencing

stigmatization (Dyregrov and Selseng 2021). Prevalent views such as this signal that the deceased could have stopped their use and, therefore, were complicit in their death. As Valentine et al. (2016:286) describe:

> The experiences of those who are grieving so-called self-inflicted deaths can be obscured by commonly held assumptions and stereotypes… along with the life of the deceased, the grief of those left behind was also devalued due to their being considered in some way complicit in the death.

Survivors in this study describe interactions rooted in the stereotypical imagery of substance use. As Valentine points out, this further serves as a moment of stigmatization in which the grief of the bereaved becomes devalued.

One survivor reflects on the way she has heard responses rooted in stigmatization. In reflecting on her friend and coworker Erica's death, Maggie's account evokes the cultural narrative of addiction as a sign of personal weakness:

> I just feel like when people talk about heroin addicts in such a derogatory fashion I wanna say, "Do you have any idea what you're talking about? 'Cause for me, you look really dumb! You have no idea what you're talking about." And it bothers me that people think it's a weakness.

This statement highlights both the "derogatory" ways that those with substance use are commonly discussed and how such statements focus on the ideas of individual choice. Similar to studies on suicide and other studies on drug overdose deaths, such statements often leave the bereaved feeling that their grief is devalued (Doka 1989, Dyregrov and Selseng 2021; Feigelman et al. 2008, 2009a, 2009c, 2012, 2020).

Some statements are more hostile. Specifically, the stigma surrounding substance use may take on a more violent form: The message is not that those struggling with drug addiction chose to die but that they *deserve* to die. Fran, who lost

her brother and has a son who has substance use, is actively engaged in a wide range of advocacy efforts, including seeking to implement Naloxone training in communities to combat overdoses (see Chapter 5). Fran highlights some of the derogatory statements she is confronted with when engaging in these harm-reduction efforts:

> *My anger flares when people feel like addicts deserve death, that's what gets me*. It's okay if they don't understand [addiction], but when they flat out say they deserve to die or something like that, I can't take it. I get angry.

Experiences such as this serve as a stigmatizing process through which the decedent's death is viewed as just, leaving the grief of the bereaved to be devalued. Devaluation of the grief further demonstrates stigmatization.

The majority of survivors in our study viewed substance use as a disease. Substance use has continued to undergo a process of medicalization in recent years (Anderson et al. 2010). Regardless of the survivor's relationship to the deceased, the prevailing view was that their loved one died from the disease of addiction. Internalization of this belief system shows an active process of destigmatization for the bereaved in which they frame their loved ones' drug use and death as the result of an illness rather than a failing. This reframing is clear in Jennifer's account:

> He was a victim of a disease. I look on Facebook, and people say, "Why do junkies get free Narcan" and, you know. "People with diabetes don't get free insulin." That's their attitude, like, "Oh, you're giving the junkie something; they don't deserve it." And as many things as I post, you know, "It's a disease." Unless it happens to them, unless it touches them, they're ignorant about it. They don't care to change their attitude. Their [view is], "They're junkies, they chose their life. They steal. They hurt people." And it's true, but that's a symptom of the disease. They're a good [people] with a bad disease. And they need to be treated like it's a disease, not like they're criminals.

Being confronted by derogatory terminologies, such as “junkie” and stigmatizing choice arguments, further highlights the stigmatization that the bereaved experience surrounding their loss. In these interactions and exchanges, the bereaved are left defending their loved ones rather than receiving support in their grief.

4.7 Countering Stigma Stereotypes: “Luke never had another overdose. He had one overdose, and it killed him.” – Jan, Mother

The pervasive nature of the stigma experienced by the bereaved can be seen in the ways that many survivors sought to demonstrate that their loved one was different from the negative images and stereotypes commonly associated with substance use. These stereotypes often include that substance users are dangerous, hopeless, reckless, crazy (Nieweglowski et al. 2019), dirty (Lindesmith 1968), and criminal (Taylor 2008). Survivors focused primarily on two ways of countering stereotypical imagery of their loved ones: noting that they were not using needles and that their loved one was not an active user. Further, families sought to counteract courtesy stigma by expressing that addiction did not happen in families like theirs.

Intravenous drug use is often associated with stereotypical imagery of “the dirty addict.” However, most heroin users begin by snorting heroin (Casriel, Rockwell and Stepherson 1988). Survivors counteracted the stereotypical imagery through statements such as, “Anyway, she tried one more time. She tried to sniff, and it killed her.” (Chuck, Fiancé), and “Does he think I handed him a straw (he never IV’d [used a needle]) and stuck it up his nose?” (Audrey, Wife). The quote by Audrey is telling, for, during her train of thought regarding the way her father-in-law blames her for her husband’s passing, she paused to clarify that Wyatt never used intravenously. In doing so, survivors sought to destigmatize their loved one’s use.

These attempts to destigmatize can also be seen in the ways survivors sought to clarify that their loved one was not a long-time user or that their death resulted from a relapse following a period of sobriety. Claire demonstrates this by highlighting how her roommate's death resulted from a fatal relapse. Claire states, "I don't think there's anything we could've done to prevent it. It was her f... - she had been sober for almost 18 months. It was the first time that she got high." Others sought to emphasize that their loved one's use had never resulted in an overdose before. Nancy and Clyde lost their son Noah, who had been sober for many years prior to a sudden and fatal relapse. Noah worked in the treatment industry, and having been sober for nearly a decade, left many shocked by his passing. Nancy and Clyde sought to highlight that he was not a habitual user, like the sentiments of Patrick above:

> Nancy: We were just in our kind of little zone there. I mean, he had – he's never OD'd or anything like that.
>
> Clyde: No, he never overdosed before.
>
> Nancy: Never any of that stuff going on.

A narrative such as this signals that the deceased was not the "typical addict," serving as a phenomenological buffer against stigmatization. In the same way Patrick and Penelope chose to disclose the nature of their son's passing to alert people that their son was not a "street addict," Nancy and Clyde felt the need to highlight that Noah was not a habitual user.

Another way that survivors sought to destigmatize their loved ones' use and passing was by clarifying that addiction did not happen in "families like theirs." This approach relies on stereotypical imagery of addiction. Notably, survivors who shared this view were often upper-middle or upper-class survivors. Trinity, the sister of Ryan,

who was discussed earlier regarding difficulty accessing treatment, explains the importance of informing others that it could happen in other communities:

> I think talking about it so that there isn't as big of a stigma involved is helpful for people to know that there are other people who are experiencing this, good people. It's not like a poor people problem, it's not like a certain location in the city. This is a problem that good people are facing.

Trinity signposts the stereotypical imagery of substance use being a product of lower-income communities. Further, the cultural narrative of substance users being "bad people" can be seen in her need to clarify that some users are also "good people." Similarly, when asked why they chose to participate in the study, one survivor, Grace, says that she chose to participate to show that drug addiction could happen in 'families like hers.' Grace lost her cousin to an overdose death five and a half years ago. Grace described having a healthy family environment, highlighting stigmatizing the belief that those with substance use come from troubled homes. Grace states: "I think it's kind of like… it's kind of weird because sometimes you're like… they're shocked because they think that people that have a drug addiction they come from broken homes and all this and like that's not the case at all with my family."

However, families and friends often experience stigmatization rooted in these sentiments. Rather than attempting to destigmatize their courtesy stigma, some survivors focused on combating stigmatizing cultural narratives rooted in this imagery. Nancy - mentioned above, who lost her son Noah - describes how she experienced stigma by someone expressing shock that it happened in a "family like theirs":

> You know, just after you leave a school the rumor mill starts by all these people who really don't know you, they make all these proclamations that aren't true. The most recent one that hit me was on Easter Sunday. Someone who had not even known our story said to me, "Oh my god! I didn't think that things like that happened to you, to

> people like us." I said, "Well, they do." And she immediately tried to backtrack, but her filter was gone, and it wasn't malicious. I don't have hard feelings with her. But I do think that some people still do wonder. *At this point, I don't really care what they think, it's not my problem. We did what we did out of love, and we tried really hard with this kid.*

Nancy's statement reflects how she experienced the stigma associated with stereotypical imagery and prejudice surrounding substance use in this exchange. Nancy's experience of stigma is rooted in gossip and feeling judged by people she perceives as lacking credibility. Her ability to do so may also be linked to involvement in advocacy work described in more detail below.

4.8 Stigmatized Bereavement Process

Feigelman et al. (2012:65) argue that disenfranchised grief, as currently conceptualized, lacks attention to "active processes of social stigmatization." Indeed, a sociological approach to the study of stigma focuses on how the "elements of labeling, stereotyping, separation, status loss, and discrimination *occur together in a power situation*" (Link & Phelan 2001:377). Yet, current studies of stigmatized bereavement either explicitly or implicitly focus on stigma at the individual level. The objective of this research then is incorporate expectations from Link and Phelan's important synthesis of the sociology of stigma with expectations from the bereavement literature–namely, how stigma intersects with the four categories of loss (e.g., anticipatory, sudden, ambiguous, and symbolic) (see Introductory Chapter). The findings from the analysis presented here demonstrate how various forms of stigma surrounding substance use contribute to recent debates on stigma in the experiences of the drug overdose death bereaved.

Stigma is experienced in different ways across various relational contexts (e.g., parents and child) and subsequent harmful interactions with family members. That is

to say, experiences of stigmatized grief do not exist as static events. Conversely, survivors' accounts illuminate a more experiential process of *compounding* degrees of stigmatized grief. What is meant by compounding degrees is that each stigmatizing interaction builds upon previous stigmatizing experiences and survivors' own internalized beliefs, intensifying the negative aspects of stigmatized bereavement. Thus, more stigmatizing interactions lead to greater levels of stigmatized bereavement experienced by survivors. Rather than thinking of these stigmatizing interactions in isolation, these findings highlight how experiences in various interactions and settings compound the stigma of the bereaved similar to what Prescosolido and Martin (2015:101) describe as a "stigma complex":

> A stigma complex requires a systems approach to understand the complicated nature and effects of stigma. We define the stigma complex as the set of interrelated, heterogeneous system structures, from the individual to the society, and processes, from the molecular to the geographic and historical, that constructs, labels, and translates difference into marks. In turn, reactions from the internal to individual to those by even remote association, to a cultural bundle of prejudice (i.e., values, beliefs, attitudes, intentions) and discrimination (from other individuals, organizations, and institutions) are produced. This cultural bundle both shapes and is shaped by larger contexts that attempt to reduce them and subject them to larger, often unacknowledged, feedback loops, as well as intended and unintended consequences.

Extending the stigma complex to the process of stigmatized bereavement is presented in Figure 2. This visual is designed to show how social relations and subsequent degrees of stigmatization are experienced by the bereaved.

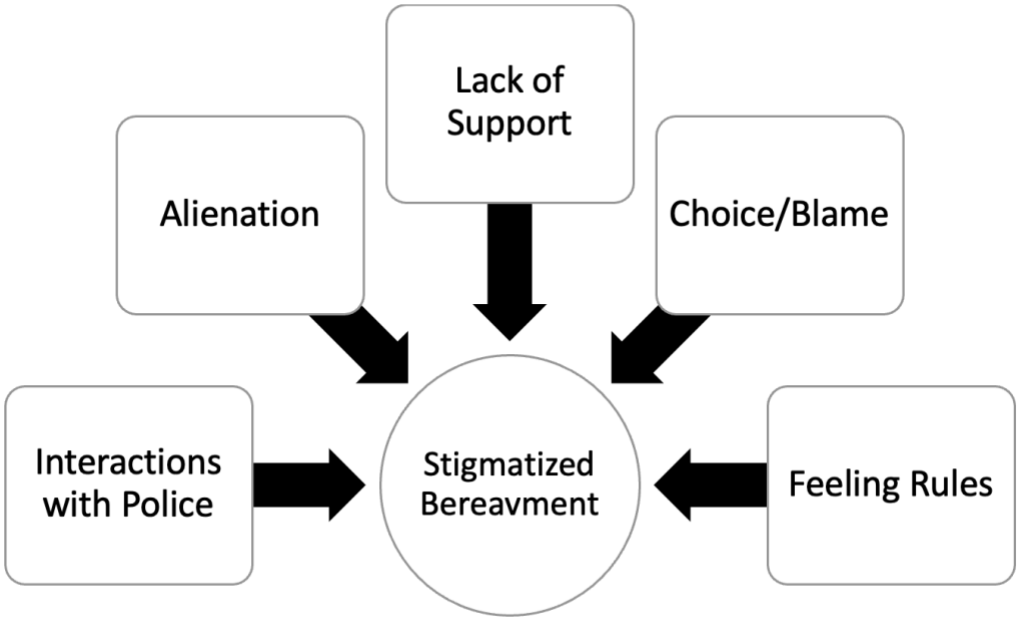

Figure 2: *Stigmatized* Bereavement Process

It is important to reiterate that the process of stigmatized bereavement is not linear, as survivors often experienced stigma *both* before and after their loved one's passing. Figure 2 illustrates this process of stigmatized bereavement. As presented at the beginning of the chapter, it is important to understand how stigmatizing experiences involving barriers to treatment *prior* to death may carry over into bereavement process. Many survivors describe feeling a lack of support as their loved ones are denied treatment. This can be seen in the accounts of parents who had to send their loved ones to recovery facilities out of state. Attempts to maintain caring and supportive relationships are perceived as cut off and contributing to the deterioration of their loved one's health and eventual drug overdose death. Experiences of

stigmatized bereavement are not separate from the broader cultural stigma of drug addiction as the actions of irresponsible individuals. Indeed, it is clear from many survivors that narratives of the deceased as "having done this to themselves" and are thus "undeserving of help/support" are salient in their accounts. Such experiences occurring before the drug overdose death is described as a persistent label of unworthiness that impacts the grieving process. Indeed, survivor's accounts are replete with expressions of guilt and self-blame for their loved one's death.

Another salient moment for understanding stigmatization in social relations involving the bereaved occurs in the immediate aftermath of their loved one's death. This is also seen in interactions with law enforcement. Survivors' views of law enforcements' perception of addiction are rooted in moral judgment as opposed to a more sympathetic medical understanding, which is empirically supported in recent studies of police attitudes (Murphy and Russell 2020). The criminalization paradigm of the "war on drugs" is, moreover, seen in the police's emphasis on drug addiction as dangerous and threatening to the broader community (Kruis et al. 2020). Interactions with the bereaved created stigmatizing exchanges in which those in mourning felt members of law enforcement were indifferent or callous to their grief.

Alienation was another dominant theme in survivors' accounts of experiences both before and after the death. While social stigma for those in active addiction is well documented, the accounts of the bereaved demonstrated a spillover effect, or courtesy stigma. Although the majority of survivors do not report a personal history of drug addiction, experiences of alienation are clearly expressed in their accounts. This is compounded when a loved one dies, and the mourning process is made far more difficult (Burke and Neimeyer 2013). This analysis highlights the particular forms

(e.g., isolation) in which alienating stigmatization was experienced by the bereaved. A lack of an adequate social support system is evident in survivors' feelings of blame and shame. That is to say, "the survivors' network essentially disavowed the survivor's right to receive solace and support" (Feigelman et al. 2012:65). The qualitative responses show how a lack of support leads survivors to hide the nature of their loved one's death. They are unable to discuss their loss in grief support groups involving parents who have lost children to more "socially acceptable" causes of death.

Lastly, survivors in this study experienced stigmatization through the enforcement of feeling rules and expressive norms. Notably, interactions consisted of individuals telling the bereaved how they should grieve, for how long, and what were appropriate ways to express this grief. Interactions such as these created another moment where the bereaved felt a lack of social support. Stigma was incorporated into these experiences in two ways: first, feeling rules and expressive norms surrounding deaths that are socially contentious carry a message that mourning sentiments should be lesser due to the perceived culpability of the deceased; second, in experiencing stigmatization in the ways outlined above, the bereaved further felt a lack of support in their expressions of grief being judged.

These experiences and interactions compounded the degrees of stigmatization experienced by the bereaved. Notably, in understanding the stigmatization that they were experiencing, survivors sought to engage in agentic efforts of mutual aid to challenge stigma. While the stigmatization bereavement process above demonstrates the ways in which stigmatization was experienced, the following chapter explores the ways survivors in this study sought to address this stigmatizing experience.

4.9 Summary of Chapter 4

These findings highlight the complex interconnectivity of stigmatizing relationships and interactions. These qualitative accounts reveal the enduring perception of substance use as a choice, discriminatory structural practices by law enforcement, and interpersonal exchanges of judgment and blame. These negative experiences are compounded by survivors' own internalized beliefs. From this, it can be observed that the grief following a drug overdose death is experienced in a unique way not adequately captured by preexisting frameworks of bereavement and stigma that lack attention to the salience of relational and broader social contexts. Alternatively, the findings presented here show how experiences can best be understood as part of a Process of Stigmatized Bereavement (see Figure 2 above) that emphasizes the importance of stigmatizing interactions that profoundly disrupt the bereavement process and social support systems provided to those in mourning.

Chapter 5

EMPIRICAL FINDINGS: NEGOTIATING STIGMATIZED IDENTITY AS AN AGENTIC PROCESS

Research on death, dying, and bereavement, including the experiences of the drug death bereaved (see Chapter 2) has long been studied by psychologists. This research provides an understanding of stigmatized experiences of loss and mourning written almost exclusively for clinical psychologists and counselors who specialize in grief support. The current dissertation uses a sociological approach to study stigmatized bereavement with attention to the broader social structures, institutions, and cultures that shape how individuals express feelings, conceptualize these experiences, and respond to them (Barbalet 2002; Brabant 2008; Frost and Hoggett 2008). As Durkheim ([1895] 1982) famously contended, society comes *before* the individual. That is to say, the individual experiences occur within a social context of preexisting norms, beliefs, and values. In the context of Goffman's seminal sociological work on stigma, this means focusing on the broader social "scripts" that shape the interactions of stigmatized individuals. Applying Goffman's theory to the study of stigmatized bereavement begins with the following observation: In the U.S. and other Western cultures, there is a very strong culture of individual responsibility. As we saw in the previous chapter, this belief system is critical to understanding how bereavement is stigmatized. For those who have lost a loved one to a drug overdose death, the experience is one of *interactional stigmatization*. More specifically, the loved ones of the deceased are disrespected and alienated because of their relationship

to the deceased as. For example, a parent is attacked as irresponsible or an intimate partner as a possible criminal by the police. At the same time, the well-established stereotype of substance misuse as the individual choice of "addicts" is also activated (see Chapter 2). Yet the bereaved as powerless victims of interactional stigma is, as Nancy and others illustrated, not the end of the story. Rather, the survivors in this study find, to varying degrees, ways of engaging in negotiating their stigmatized identity through help-seeking behaviors.

Employing the sociological understanding of Goffman highlights the importance of understanding stigma in interactional contexts. Link and Phelan (2001) expand on such an approach by highlighting different power systems that allow for this stigmatization to occur - e.g., it takes power to stigmatize and reproduce systems of stigmatization. Parker and Aggleton (2003) highlight that stigma functions to create categories of difference rooted in cultural systems of power and operates in service of this power differential. Chapter 2 highlights the cultural nature of the stigma and the power it holds in notions of difference. Some have argued that stigma, when conceptualized in this way, is better understood through linking Foucault and Goffman - that "stigma plays a key role in producing and reproducing relations of power and control." (Parker and Aggleton 2003:16). Carrasco et al. (2017) use this approach to demonstrate how HIV positive sex workers employ social cohesion and mobilization to resist stigmatizing norms, thus actively challenging the power structures that allow for cultures of difference to exist. Survivors in this study engage in similar efforts of mobilization to alter the existing power structure of stigma surrounding drug overdose death.

Prior studies in the psychology of grief focus on stigma management with an emphasis on how practitioners can more effectively support the bereaved in their grief. Alternatively, this dissertation focuses on grief as damaging to social bonds (Seale 1999). While most of the research does not focus on grief in the context of drug overdose death (see Chapter 2), it provides a relevant analytical framework for the current study. Specifically, the sociology of grief highlights how interactions shape *self-concepts*: "Conversation, taken as a social institution in which participants may draw upon a variety of available cultural scripts, serves as a micro-ritual for the sustenance and renewal of a secure narrative of self-identity" (Seale, 1999:193). As discussed in the previous chapter, most of the interactions reported by survivors were rooted in highly individualized cultural narratives that negatively impacted the mourning experiences of the bereaved. Having experienced stigmatization in this way, survivors' narratives are, to varying degrees, characterized by a far less secure - or to use Goffman's phrase - stories of "spoiled identity." As the multilevel Stigmatization Bereavement Process highlights (see Chapter 4), stigma shapes and influences interactions on both interpersonal and institutional levels, which is not separate from widely shared cultural beliefs about substance use related deaths (Perscosolido and Martin 2015). These cultural beliefs are rooted in cultural difference of power and notions of difference (Parker Aggleton 2003). This is not a linear process but one more akin to Goffman's conception of stigma management as negotiation involving the revealing or concealing of stigmatized identities, coupled with Link and Phelan's (2001) analysis of stigma being rooted in power structure. A recent analysis of stigma management in the UK by Walter et al. (2015) and Walter and Ford (2018) sheds important light on how individuals bereaved by a drug or alcohol-related death engage

in the more agentic process of stigma management. Specifically, this research shows how survivors manage stigmatized bereavement through advocacy work (Walter and Ford 2018; Valentine et al. 2016). Likewise, recent research shows how the specific experience of courtesy stigma may also lead survivors to other help-seeking behaviors. While this research is focused largely on informing clinical grief practitioners, one study does make the connection between stigma management as "grounds for resistance and exercising one's agency." (Valentine et al. 2016:14). Further, these processes can be seen as building social cohesion to challenge stigma collectively (Carrasco et al. 2017).

The current dissertation builds on the important insights of this prior research. Indeed, an overwhelming majority (77.14%) of survivors in this study had attended some form of a support group at the time of their interview. Figure 3 below highlights the frequency of attendance among survivors:

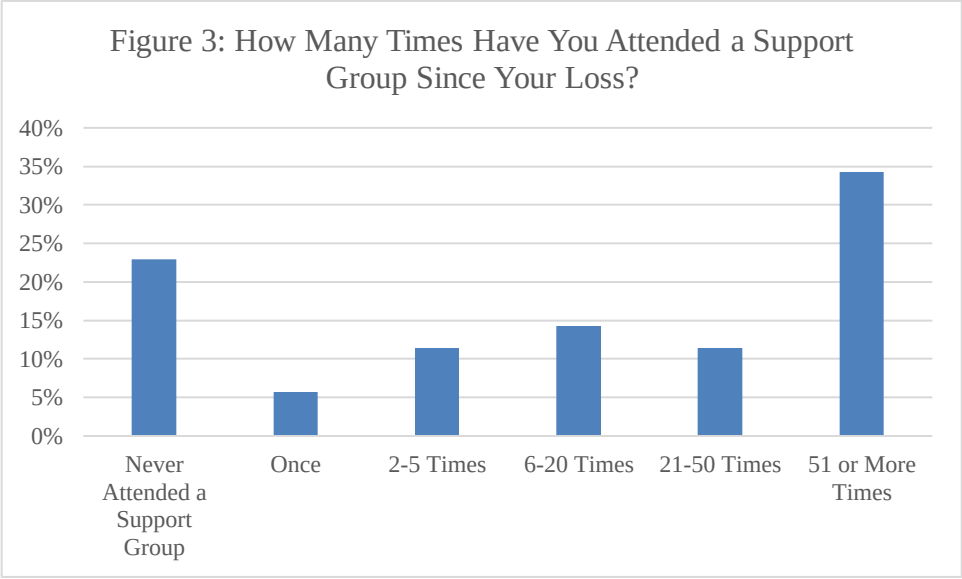

Figure 3: How Many Times Have You Attended a Support Group Since Your Loss?

Drawing on Feigelman et al. (2008, 2012) important research on stigma management and help-seeking after loss of a loved one to suicide, the following sections explore how survivors engaged in various forms of help-seeking. Specifically, these findings show how survivors seek support, find purpose, and negotiate stigma. Goffman's seminal insight shows how stigmatized individuals may seek groups who share their status (the own) and those who are sympathetic to the stigma (the wise):

> The first set of sympathetic others is of course those who share his stigma. Knowing from their own experience what it is like to have the particular stigma, some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person (1963:20)...The second set are the "wise," namely, persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan. Wise persons are the marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other. (1963:28)

However, Goffman does not attend explicitly to the various ways supportive communities can deepen acceptance and belonging.

Goffman explored the ways in which those with a stigmatized identity seek to resist such labeling and discrimination (1963). However, the majority of research that has stemmed from this has focused on approaching these efforts from a sociocognitive perspective, exploring individual management strategies of the stigmatized persons. When the term management is employed, it holds the connotation of maintaining a stigmatized identity, placed in the binary of concealing, or revealing ones "stigmatizing marks" in different groups. Alternatively, survivors in this study negotiate individual stigma by resisting broader stigmatizing narratives of substance

use and overdose as the responsibility of the deceased and those who label them as enablers. Resistance is grounded in collective action involving recovery advocacy organizations and other less formal communities of resistance. As Carrasco et al. (2017) observe "community or collective empowerment develops when individuals work together to achieve a larger impact than they could have on their own." It is important to clarify what is meant by "empowerment."

For Rowlands (1997) empowerment includes power within (such as stigma management), power with others (working collectively with others to destigmatize), and power to (exercising power to create change). This framework incorporates the Goffmanian framework of stigma management with a Foucauldian understanding of stigma rooted in culture and power and suggests various agentic practices employed to challenge these marginalizing systems. That is to say, empowerment can be understood as internal destigmatization, collective work with others, and seeking to create social change. Through these efforts of managing stigma and engaging in collective action, survivors "re-organise and re-construct the self, putting into practice a positive narrative, which replace[s] the negative narrative imposed by society…" (Carrasco et al, 2017:552). Survivors in this study engaged in agentic empowerment that allowed them to "embody new [destigmatized] narratives through repetition and practice" (Carrasco et al 2017:554). Prior research focused on those bereaved by a drug related death shows that support groups play a central role in negotiating stigma (Walter and Ford 2018). The present study also finds that help-seeking plays a central role. However, this study finds that involvement in help-seeking varies among survivors. As Figure 3 shows, approximately 1 in 5 or 20% of survivors did not

engage in *any* help-seeking behaviors[6]. This level of variation allows me to provide some in depth comparisons of survivors' help-seeking activities, stigma management, and challenging cultures of difference that arises from the stigmatization surrounding addiction (e.g., advocacy, support groups, 12-Step Fellowships, religion, and counseling). Further, many survivors were engaged in multiple help-seeking efforts, allowing for comparisons to be parsed out further. Appendix D provides information on survivors' help-seeking.

5.1 Advocacy

Survivors who reported the highest levels of support group attendance were frequently engaged in recovery advocacy. Such efforts also served as a bridge between individual mourning sentiments and collective mourning. Specifically, advocacy transformed stigmatized bereavement into opportunities for meaningful individual change and strengthened social bonds. Further, this can be seen as empowerment. Rather than concealing or rejecting the stigmatizing label, many in our study saw embracing the label and their experience as a way to facilitate social change. Indeed, many survivors reoriented their bereavement *and* self-identity towards collective advocacy and activism efforts. This finding is consistent with Simos's (1979:2) observation that "any loss has in it the potential for damage to self-esteem" and restored "self-esteem can be sought by identification with a social movement or cause from which one derives reflected power and glory." Support groups help individuals to

[6] 22.9% said they never attended a support group, however, in answer to the support specific questions below, 14.3% (5 respondents) selected "never attended" as their answer.

grieve and redefine their concept of self and manage emotions surrounding a situation (Francis 1997). The findings in this study indicate that involvement in advocacy organizations can create a similar socializing effect. However, even if grief does become socialized, there are few established norms for bereavement, especially in the wake of an overdose death (Valentine et al. 2016).

Finding themselves lost in the ambiguity of grief, the bereaved often turn to activism work, like victim-activists, such as Mothers Against Drunk Driving (MADD). Another example is the organization Fed Up! Following MADD's model, this organization was formed to respond to family members feeling "patronized and dismissed as unreasoned by grief" to combat the overprescribing of opiates in the early 2000s (McGreal 2018:153). The mission statement of Fed Up! makes it clear that these bereaved members do not view themselves as individuals who are bereaved by their loved one's choices but rather as victims of systemic failures within the public health system to address and treat substance use and find themselves victims of greed and corruption of big pharmaceutical companies - this is evidenced in the Fed Up! mission statement:

> Who Are We? We are families who have been ripped apart by opioids. We have lost loved ones to death or addiction. We are medical experts and advocates who understand that the root cause of the problem is overprescribing. This is a grassroots coalition, all seeking action from the federal government to bring this public health crisis to an end...We accept no money from pharmaceutical companies or their affiliates and 100% of the donations we receive are directly applied to managing the costs of holding our Fed Up! Rallies and coordinating our advocacy efforts. We are beholden to no one – except our lost loved ones, or our family members struggling with addiction. We have come together to save lives.

Other groups have continued to form and flourish over the past decade that shares this message, demonstrating that they too take the role of the bereaved victim advocate in utilizing their grief to create social change.

Activism is one avenue of managing and navigating grief (Maxwell 1995; Nowak 2015). Furthermore, groups of this nature place the bereaved into both contact and action with sympathetic others, providing a structure of peer support that may help them in their grief work. Given the hundreds, if not thousands, of advocacy groups of this nature that have emerged nationwide in response to the opioid epidemic, most of which are founded by someone who has lost a loved one, it is surprising that little research has been done on these groups (for full history see White 2007). This study highlights how these groups help the bereaved navigate their spoiled identity and, in turn, make their grieving process less alienating and stigmatized. Through storytelling of the deceased, survivors can reconstruct their loss (Kleinman 1988; Neimeyer 2002). Stigmatizing narratives are challenged both through individual empowerment and through creating networks of mutual aid.

5.1.1 Mid-Atlantic Advocacy (MAA)

Survivor's report being actively involved in, or having previously worked with, a group that we will call Mid-Atlantic Advocacy (MAA). The mission statement of this group explicitly highlights efforts to destigmatize addiction by bringing awareness through education, changing and drafting legislative policy, and providing support to those who have a loved one actively struggling with addiction (although they do further state that they are not a support group). It is important to highlight that their explicit goal is to destigmatize addiction. MAA can be seen as a social cohesion movement, geared towards challenging cultures of difference.

This group was founded by a handful of individuals who lost a loved one to a drug related death. Titlestad et al. (2017:8) states, “In making sense of the loss, the bereaved described that helping others or being politically active were examples of how they tried to prevent others from having to experience the same situation themselves.” Engagement in the various forms of advocacy discussed above allow the bereaved to practice negotiating their stigmatized identity in the aftermath of a drug related death. Survivor support groups and other forms of help-seeking are far more than an opportunity to reveal stigmatized bereavement. Prior research has highlighted that constructing meaning around traumatic loss is a vital part of the healing process (Bonanno 2013). In this way, mutual aid creates possibilities for “destigmatizing narratives that redefined their identity” (Carrasco et al. 2017:554).

Those in this study who were primarily engaged in advocacy were parents who had lost a child. Survivors frequently point to their engagement in such efforts as having helped them make sense of their grief and simultaneously use the efforts to destigmatize substance use. Notably, survivors used their spoiled identity from their stigmatized marginalization to speak on substance use. This can be seen as embracing their marginalized status to seek ways to help others with stigmatized identity – precisely, those who shared the same stigma as the lamented.

Nancy and Clyde, who lost their son Noah, were actively involved in the MAA at the time of their interview. As described previously, Noah had been in long term recovery prior to his death. Nancy and Clyde sought to bring attention to how Noah was not a long-term user and did not fit stereotypical imagery of an “addict” by emphasizing that he did not have a history of overdoses (see 4.7 above). They had lost their son nine months before the interview and found their involvement in the group to

be an avenue to share their sons' story. Engaged in "conversational remembering" (Walter 1996), a form of memorialization where the bereaved discuss the departed with loved ones as an important mourning ritual (Valentine 2008), Clyde describes why participating in MAA was meaningful to his family:

> I think bringing the topic of substance abuse and addiction and the danger of overdose out in the open so that people are willing to talk and learn about it is very helpful. It was helpful for me in dealing with my own grief and also helpful in ways that my motivation to do something to pay forward the message of our son's life is beginning to come into focus.

For Clyde, sharing the narrative of his son's life and passing could help serve to counter stigmatizing messages and imagery about *who* a substance user is. By creating an environment where he could make the loss more meaningful, he feels free to share his son's biography. As Clyde described, "paying forward" to help others is essential to his grieving process.

Kelsey and Nicholas had faced multiple barriers in seeking treatment for their son Ryan (see 4.1 above) and sought to create structural change so that other families would not be met with such barriers. Nicholas and Kelsey were involved in creating MAA in hopes of doing so, as well as combating the stigma surrounding substance use. They describe how years of advocacy work is deeply therapeutic for managing their own grief:

> Nicholas: We have a passion now to do things in these recovery and supporting roles which provides us with…
>
> Emily: A purpose.
>
> Nicholas: A purpose as we go forward…It has really provided us with support, new friends were made, and other [MAA] activities we get involved with. Yeah, I think it's really acting as a need for us to become involved. Sometimes I wonder how other people, who don't

> become involved in trying to help others or try to break down the stigma, find comfort.

Both of these examples highlight two key points. First, groups like MAA foster both therapeutic and de-stigmatizing social cohesion. Nicholas sees MAA as directly involved in challenging the stigma of substance use and bereavement, as well as creating structural change to help those with addiction. He finds these efforts rewarding and wonders what others do for healing if they are not involved in helping others. Second, in countering the alienation and anomie (see Chapter 2), groups like MAA promote what Durkheim ([1893]1984, [1897]1952) describes as a *social integration* - a process of collective action that depends on attachment and regulation that promotes healthy grieving, negotiation of stigmatized identity, and solidarity focused on the destigmatization of addiction. Both sets of parents above discussed how their involvement in these efforts allowed them to feel like a part of something more, and in turn, that the loss of their loved one could mean something more by facilitating social change.

Other parents sought to use their experience and stigmatized bereavement to create pointed changes. Recall Chloe, a mother who continued to meet barriers when trying to get her daughter into treatment, who described herself as blamed by others for her daughter's death (see Chapter 4). As an alternative to MMA's focus on cultural stigma, Chloe engages in advocacy work occupied in challenging structural stigma created by failed systems of treatment. Chloe describes how this work makes her feel: "It makes me feel like I'm letting her live on through what I'm doing, because I promised her that somehow that I would make Delaware open a long-time treatment program." Chloe displays agency by focusing on solving the concrete but challenging problem of improving systems of care. By centering her daughter's experience as her

primary motivation, she embraced the most stigmatizing interactions that labeled her as a failed mother. These efforts enable her to negotiate stigmatized bereavement as motivation to broader social change. Chloe's motivation emerged from experiencing barriers to treatment, similar to Nicholas and Kelsey.

5.1.2 Other Advocacy Efforts

Some parents sought other forms of activism in negotiating their grief. Recall Kathleen, a mother alienated by her mother following her son Tanner's death. Embracing this experience, Kathleen drew strength from her Christian faith to create her own advocacy:

> I actually started a ministry for the homeless called *A Hug From Tanner*. Blue was his favorite color, so we have blue backpacks with that name on them. I stuff them with socks and toiletries and hats and gloves and hand warmers and blankets in the winter, and I go down to the city. A lot of people that Tanner knew were homeless because they were kicked out of their homes, families didn't want anything to do with them. I found that the homeless community down there are the most incredible people. It's just taking the time to treat them like human beings and talk to them.

Kathleen's efforts show a sense of meaning making shaped by her experiences of stigmatized bereavement. In having felt members of their family alienated her son, Kathleen reclaims her identity through building social bonds and a sense of community with the homeless. Her focus on the homeless is not random. Because Tanner was homeless and befriended others in that community, Kathleen dedicates her life to serving them.

Fran lost her brother and is actively involved in various forms of advocacy. Her son is in recovery, and she actively works in these efforts alongside him. As discussed above (Chapter 4), Fran often felt others not only lacked understanding but

believed that those with addiction deserved to die. Fran combatted this stigma by seeking to distribute the live saving overdose reversal drug Naloxone (Narcan) into communities. She describes her advocacy as helping her grieve. Specifically, Fran describes supporting those struggling with substance misuse as therapeutic and promotes self-forgiveness:

> My son started an organization, so I volunteer more for him now than the Mid-Atlantic Advocacy Group. We just did a Narcan training and free Narcan giveaway. My son is traveling a lot to do outreach, and I help organize his trips. *So that is therapeutic for me to help other people* and to partner with my son is just a bonus. Like, where he came from in deep addiction to heroin, and now he's helping others into treatment and doing all these good things - it's a good connection for me *'cause I couldn't help my brother, but maybe I can help someone else.*

Fran describes therapeutic benefits of her advocacy as deeply meaningful. In working with her son's organization, she is able to rebuild the maternal bond. By contrasting the past characterized by struggle and regret with a hopeful and active present, she is able to find meaning in her life. Indeed, in addition to repairing her relationship with her son, she describes this work as meaningful to her brother's memory. She sees her present advocacy as a way to negotiate her own stigmatized bereavement and find what she describes as "good connection" with others in need of treatment.

5.2 Support Groups

Many survivors' help-seeking involved support groups. Specifically, a full 80% attended a support group at least once. Of that group, 42.9% found their involvement very helpful (Figure 4). Support groups create a comforting and supportive environment for many bereaved by a drug overdose death (Ford et al., 2018) and can serve as an arena for managing stigma by immersing the bereaved with

those who share their same experience (Walter and Ford 2018). Further, such groups "provid[e] safe collective spaces to develop, repeat and perform new narratives, which ultimately are new configurations of power" (Carrasco et al. 2017:554).

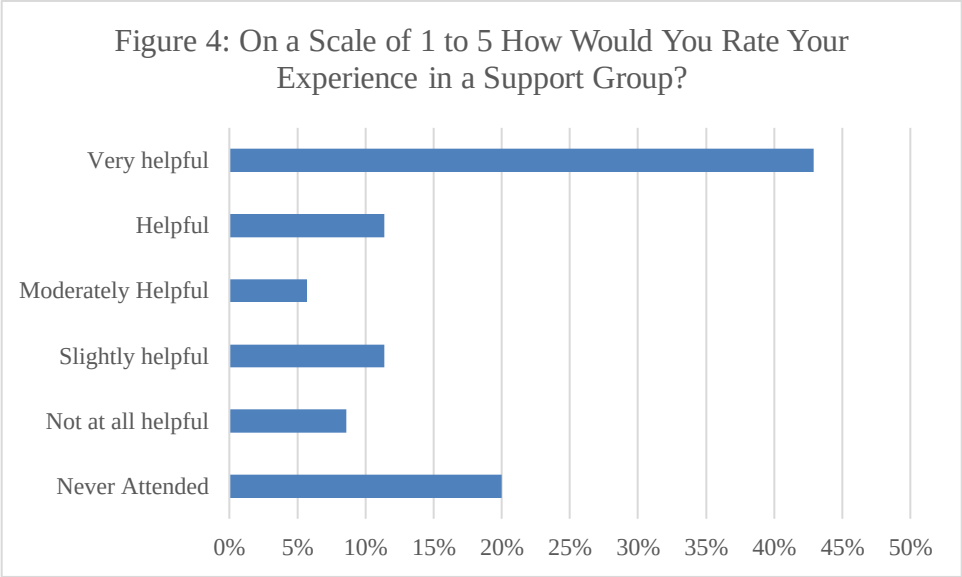

Figure 4: On a Scale of 1 to 5 How Would You Rate Your Experience in a Support Group?

When completing the survey for this study, survivors who had attended support groups were asked the following question: People attending support groups mention various benefits from participation. Please rate the importance of each of the benefits below in terms of their importance in helping you with your grief (Feigelman et al. 2012). Survivors were asked to identify various benefits commonly found in support groups on a 1-5 Likert scale ranging from "Not Important" to "Most Important":

Table 3: Importance of Support Group Benefits

People attending support groups mention various benefits from participation. Please rate the importance of each of the benefits below in terms of their importance in helping you with your grief.	*Not Important*	*Slightly Important*	*Important*	*Very Important*	*Most Important*
Friendship – support	6.67%	3.33%	23.33%	43.33%	23.33%
Sharing information and support	0.00%	10.00%	13.33%	36.67%	40.00%
Having a sounding board to develop new skills	10.00%	3.33%	26.67%	33.33%	23.33%
A place for discussing tabooed subjects	6.67%	10.00%	30.00%	23.33%	30.00%
Being among people like myself	0.00%	0.00%	23.33%	26.67%	50.00%
Helping myself to deal better with my loss	0.00%	6.67%	16.67%	36.67%	40.00%
Helping others to deal better with their losses	0.00%	3.33%	20.00%	33.33%	43.33%
Spiritual beliefs	3.33%	23.33%	16.67%	20.00%	36.67%
Banding together with others to promote positive mental health	3.33%	0.00%	20.00%	26.67%	50.00%
Getting help from the group facilitator	6.67%	20.00%	30.00%	20.00%	23.33%

This summary data suggests various ways help-seeking was meaningful to survivors. Support groups provided space to discuss stigmatized topics ("Most Important" = 30%), be among others who shared their same identity and experience ("Most Important" = 50%) and created an environment for them to both help others ("Most Important" = 43.33%) and be helped by others ("Most Important" = 40%) in navigating their stigmatized bereavement. The qualitative analysis provides crucial insight into understanding why these support group functions are "important."

In *Devastating Losses*, Feigelman et al. (2012:183) found that peer-facilitated support groups often provided an environment that "help[ed] survivors advance their healing after a suicide loss." From this analysis, the authors articulate "10 principles" for how support groups are meaningful to survivors. It is useful to discuss some of the

most salient principles to the current study. In the *"all-in-the-same boat" phenomenon*, survivors learned that others shared the same problems that they had. This seemingly obvious principle is in fact important for the expectations it provides. How survivors learn that they are not alone is clear in the analysis of the qualitative accounts that follow. Likewise, the emergence of a *universal perspective* is also important to consider. Allowing survivors to see their loss as something not just occurring in their own personal life, but within the broader social context deepens agency. Specifically, as we will see, such understanding can lead survivors to commit their lives to destigmatization efforts. Lastly, Feigelman et al posit a *strength-in-numbers phenomenon*. The importance of group support cannot be overstated. As we will see, survivors experience this phenomenon to various degrees. For some, the group becomes a surrogate family that goes well beyond attending to matters of grief and stigma alone. One other important caveat from Feigelman et al. (2012) that this study also found relevant is that not every help-seeker has positive experiences in support groups. Many others found support through multiple help-seeking efforts.

Kathleen, who created *A Hug From Tanner*, is engaged in support groups and advocacy work (see Appendix D). Kathleen describes a supportive and welcoming support group. For her, this support meant a much greater sense of agency as she negotiated stigmatized grief. She describes her feeling of isolation as liberated by deepened social bonds and newly established friendships:

> It's very isolating after you lose a child. And the people in my support group actually have become my friends. *We call each other on bad days; we support each other*; we'll get together for dinners. I actually had everybody over to my house a week before Christmas to just have a potluck dinner, and it was, it was nice. People were able to talk about our kids without feeling guilty for bringing anyone down, and we could

> cry about them and tell stories, and *you didn't feel like you had to hide your grief.*

Providing a supportive community served as an environment for both stigma management and understanding for Kathleen. Her support groups allowed survivors to talk about their loved ones without judgment and alienation, and gave her somewhere to express her feelings free of judgment and the anxiety of being judged. Beyond the group, Kathleen formed deep and trusting friendships with other bereaved individuals. This new peer group supports one another far beyond the formal meeting alone. She describes a kind of deeply trusting and close surrogate family that spends holidays together. Chloe succinctly describes how her support group is important to her: "I don't know how, but you actually have people there that can relate to you." Both Kathleen and Chloe provide context for how support groups create opportunities for negotiating stigmatized bereavement.

At the same time, not all survivors described support groups as positive. Recall in Chapter 4 how some survivors described feeling ashamed by grief support groups open to all parents who lost a child. Brittany and Sean sought to hide the nature of their sons passing from others (see 4.4 above). Indeed, Brittany describes how vital it was for her to find a group specifically focused on individuals bereaved by a drug overdose:

> So, I sought a grief group only for drugs overdoses, because I didn't wanna go to a regular bereavement group. I knew there were all sorts of losses there, *and I felt like we would be judged in that group and kind of shunned.* So, thank God I found one on the internet. I feel like it's invaluable, because *I don't know if we would have survived this first year without having a place to share.*

Brittany navigates her stigmatized bereavement by first avoiding non-specialized grief support groups. Her avoidance is focused on the fear of being otherized by parents

who lost a child to a non-drug overdose death. Brittany demonstrated stigmatization above by seeking to keep the circumstances of her son's death secret, but she actively sought a setting where she could openly discuss the nature of her sons passing. Brittany's account calls attention to the enormous importance of specialized grief support in the year after her son's overdose death. Rather than succumb to isolation, Brittany is proactive in her family's need for grief support. Thus, the internet becomes an extraordinarily important tool for connecting with a group that fits this vital need.

For other survivors, finding the right support group is more difficult. Jan is involved in multiple help-seeking groups (Appendix D). Following the loss of her son, Jan sought to keep the cause of her son's death on a "need to know" basis, and only told immediate family. Jan recalls that after the death of her son Earl, finding the right group was a more involved process:

> The first group helped me to understand the disease of addiction. I didn't have my other son here to talk about it and I just wanted to learn as much as I could…But the second group is definitely better 'cause everyone there has either lost a child or a sibling or a spouse [to a drug overdose death]. And I'm at the point now where I can give some support and not just get the support. I mean, first group meeting I went to, I couldn't even talk.

Jan describes her first group experience as a mixed bag. She learns more about the science of addiction but does not feel comfortable enough to speak. Further, as discussed above in Chapter 4, Jan initially felt that she could not openly disclose how her son died, signifying the stigma surrounding her loss. In finding the right group, Jan describes a feeling of satisfaction in her ability to both give and receive support. Indeed, she is now the leader and primary facilitator of the group she belonged to at the time of her interview. Although she began her support journey unable to speak with others who had experienced the drug overdose death of a loved one, Jan not only

finds needed comfort to share, but she also describes herself in a leadership role in supporting others. Although few survivors describe themselves as group facilitators, a full 43.3% of survivors found that being able to help others in these groups through their experience was *most* important.

Ruby lost her daughter Jasmine. Jasmine and Ruby had a strained relationship while Jasmine was actively using, leading to Ruby having to call the cops on Jasmine after Jasmine had robbed her house. Following her arrest, Jasmine's relationship with her mother greatly improved during the year and a half that she was sober. Ruby was shocked when Jasmine relapsed and fatally overdosed. Ruby described initial hesitation to join a support group or what she recalled as a pressure to "join your club":

> In the beginning, I didn't want that because I can barely deal with myself, you know what I mean? Like even someone I didn't really know–a friend of a friend–tried to reach out to me, and I was like, "No, I don't want to be part of your club!" Even after you're in that club, you don't want to be part of it, so you don't even want to acknowledge it. So, I kind of pushed those people away until recently, probably within the last probably six months. But then I found it helpful. I wasn't ready for it right away.

Ruby's account is a clear demonstration of the tension between concealing and disclosing one's spoiled identity. By contrast to Kathleen's account, Ruby found it difficult to be a part of group brought together because of stigmatized grief. Ruby also found great support in 12-Step Fellowships (discussed in more detail below). The supportive community leads to a sense of purpose and belonging that is at first challenging for Ruby. In this way, her account is important and may be more typical of others in her situation. By comparing individuals with varying levels of participation in help-seeking, it is clear that the process of negotiating stigmatized

grief is complex. A spoiled identity due to stigmatized bereavement requires parents like Ruby to effectively manage stigma *and* feel comfortable enough to be supported. While it has only been six months since Ruby rejoined her support group, she describes feeling supported by the group and less beholden to an exclusive club.

5.3 12-Step Fellowships

Stigma management and agentic actions that deepened belonging and self-efficacy can be fostered in 12-Step Fellowship groups. Prior research has highlighted that these programs serve as "identity transformation organizations" (Greil and Rudy 1984). Some survivors in the present study describe involvement with Nar-Anon, Al-Anon, Alcoholics Anonymous (AA), and Narcotics Anonymous (NA). Both Nar-Anon and Al-Anon have long served as support groups for family members and friends who have a loved one currently in active addiction. Many were involved in these groups prior to their loved one's death, which provided an invaluable arena of support after drug overdose death. All of these groups provided access to a group of understanding peers who either shared their same struggles after losing a loved on to an overdose and the stigmatization that surrounds this form of loss, or were informed about the stigma enough to provide support even if they had not directly experienced the loss. Goffman (1963) would categorize this as "the own" and "the wise." Survivors who attended Al-Anon and Nar-Anon meetings felt supported by members with loved ones in active recovery. The same was true for those in AA and NA. Beyond a diffuse sense of support, these survivors describe these groups as empowering in ways that resist stigma by helping others. Notably, in this study, most parents attended Al-Anon and Nar-Anon. Meanwhile, spouses, friends, and significant others were members of

AA and NA. The foregoing analysis explores survivors involved in 12-Step groups with different relationships to the deceased.

5.3.1 Nar-Anon/Al-Anon

Survivors in Nar-Anon and Al-Anon emphasize experiences of solidarity and support. More specifically, 12-Step Fellowships fill the void caused by estrangement from family. Recall that Jennifer had been alienated by her family both during her son's use and after his death (see 4.3 above). She describes involvement in Nar-Anon as empowering her following Eugene's death:

> Eugene died on that same day my Nar-Anon group meets. I stayed at home, and *the only people that came to my home were all my Nar-Anon*. They shut the meeting early, went out, bought all this food and stuff, and came to my house and sat with me. *They were there for me*. My mother didn't come. My sister didn't come. My cousins didn't come. And the whole week before the funeral only Nar-Anon people kept coming to be with me. My family was never there for me.

In addition to support at the time of Eugene's death, Jennifer describes how Nar-Anon provided a space for managing the ongoing stigma surrounding her son's substance use. Although others "look down" on her, she described Nar-Anon as providing an unconditional community of support:

> I was embarrassed; I didn't want to tell anybody because I figured they would look down on me. And they would! And they still do! *But now I don't care because I'm with a Nar-Anon group, we're all in the same boat, we all understand* that if people don't want to take the time to understand and have some sympathy and empathy, then I don't need to be with those people anyway.

Jennifer's account highlights that while stigma remains present, it no longer alienates her. Her story is one of finding a group of those who shared her courtesy stigma as a family member of someone who is addicted to substances. Further, others in her group

had lost their loved one as well. Having a supportive and understanding group that Jennifer could relate to counteracted the stigmatized bereavement she experienced through being alienated by her family.

Other participants in this study echoed similar sentiments of finding a group of "the own" to provide a destigmatizing space. Sarah, who lost her son Marshal and experienced stigmatizing interactions with the police (see 4.2 above), describes how Nar-Anon has provided her a space to discuss topics that she would not discuss elsewhere and disclose parts of herself that she would otherwise conceal:

> You're surrounded by people with the same story. You go in there, and there's no judgment. It's like wow, you're not alone they're going through the same thing as you. You think everybody has this wonderful life, and they don't. And you keep it hidden. You don't tell people it's going on, but in those rooms, you can tell anybody anything you want. There were times in that room that I said that I hated my son, and wished he died. That's a horrible thing. But you could say that in those rooms. I didn't mean that, and they knew it. And they didn't judge. So, you just automatically became part of another family that was living your life…

For Sarah these groups create a space for her to share her story without judgment and feel that she is not alone. She can share taboo feelings and not be judged as a failed mother. The destigmatization in these settings allows for embodiment of destigmatized narratives, such as "a sense of a valuable self" (Carrasco et al. 2017, p. 552). Specifically, Sarah's story highlights how she could share feelings of animosity towards her son without feeling judged as a bad parent, but instead, be provided understanding, support and a sense of togetherness by those with a shared knowledge of her feelings and experience. Nar-Anon is a family that forges its bond through shared suffering. It is this experience that illuminates negotiating stigmatized identity as collective action that fosters healing and identity repair.

For many survivors who found support in their stigmatized bereavement through 12-Step Fellowships, their involvement in the organization preceded their loss. Family members with a loved one struggling with addiction often experience stigma and shame (see Chapter 2 and 4). Stigma management is underway prior to the devastating loss. The survivor is provided support as an almost seamless continuation of active participation while their loved one was alive. Previous participations allowed survivors to have an existing support system when their loved one passed. Ruby, who lost her daughter, established a foundation in Nar-Anon during the tumultuous experience of Jasmine's active substance use. Ruby recalls how having this foundation helped her in her bereavement:

> I already had a strong foundation in Nar-Anon. That was something I had been doing since she first went into her first rehab in February of 2015, so I already had that support when everything happened. I wasn't even there at the house yet [where her daughter's body was found], and I was texting my people, you know what I mean? I had that foundation.

The foundation of support Ruby describes is strong long before her daughter's drug overdose death. She has developed a level of support that she can depend on as soon as the tragedy occurred. That is to say, she finds belonging in those who understand her experience for immediate support.

Sarah, who felt the familial ties to Nar-Anon as discussed above, credits her involvement in Nar-Anon with helping her have many positive experiences with her son in the year leading up to his passing. These positive experiences helped Sarah in navigating her grief:

> The last year of his life was my best year because of Nar-Anon. Actually, the last two years of his life were my best years, because I learned how to love him more and not be so angry all the time because of Nar-Anon and the people that I surrounded myself with.

Involvement in these groups provided a meaningful community for survivors. For Sarah, this is a profound experience of deepening her identity as a mother capable of unconditional love in the last 2 years of her son's life. Beyond support she credits Nar-Anon as fostering this profound transformation. Likewise, Ruby's experience in her Nar-Anon group helped her to navigate her daughter's addiction.

12-Step groups also provide survivors with a sense of purpose similar to what is described by those who are active in advocacy groups. Notably, in the 12-Step program of both Nar-Anon and Al-Anon, the 12th step focuses on service to others. The primary text of these programs highlights that the 12th step is, "[h]aving had a spiritual awakening as the result of these Steps, we tried to carry this message to others, and to practice these principles in all our affairs." (Al-Anon Family Groups 1995). The survivors involved in these programs commonly seek to help others going through the similar trials and tribulations that they experienced. Jennifer explains her decision to participate in this study as rooted in the spirit of service found in Nar-Anon:

> Part of Nar-Anon is giving back. You receive so much help and support. And to me, this study is kind of like another way of giving back. If it's going to help anybody, you know, with their grieving process or if it's going to help people, then that's well worth doing it.

Jennifer participates because of her own experience of support. She seeks to honor those who helped her by sharing her story. Any chance to help others in a similar situation signifies another way in which involvement in 12-Step programs empower survivors.

As mentioned above, those in this sample who were active in Nar-Anon and Al-Anon were primarily parents. Their experience in this form of help-seeking and stigma management highlights that they experienced support in their loss through

involvement both before and after the drug overdose death of their child. Such groups create a non-judgmental environment that allows for a deepened sense of agency and empowerment.

5.3.2 AA/NA

Other survivors in this study were actively involved in the 12-Step Fellowships of AA and NA. These were primarily partners, siblings, and friends of the deceased. While parents describe a sense of community and a destigmatized environment being the primary benefits of their involvement, those in AA and NA expressed different forms of beneficial stigma negotiation. Will and his brother Seth had begun using together, gone through the throes of addiction together, and eventually got sober together. After multiple years of sobriety, Seth relapsed, leading to his death a few months later. Will expressed that he was still actively involved in AA. Notably, he emphatically states the importance of his involvement in AA:

> Will: I mean, I have faith, a program, and I believe in a God I just don't know.
>
> Dr. Fleury-Steiner: Does that continue to help you?
>
> Will: Yeah, *it's the only thing I have*.

For Will, his involvement in AA became his primary support following the loss of his brother. Those involved in AA or NA describe its importance in their bereavement process. Like the parents in Nar-Anon and Al-Anon, survivors describe a strong sense of community. Jeremy, who lost his girlfriend Hailey (see 4.2 above), voiced during his interview that he felt he would have been unable to navigate his grief without the support of his peers in AA:

> Honestly, people in AA, I wouldn't be here without them either. So, it's a blessing. They're like the true friendships in there. It's not like the friends I had in high school; none of them were there for me. None of them asked me if they could come and support me with Hailey.

Some, like Jeremy above, expressed in their interviews that they felt they may not have been able to cope with their loss without using substances if it were not for their involvement in AA or NA. Jeremy's account demonstrates the communal support he found from participation in 12-Step Fellowships. He describes how group members provide guidance for negotiating his grief.

Other survivors involved in AA or NA expressed that their involvement allowed them not only a supportive community in their grief but also guidance on how to navigate their bereavement process. Notably, the guidance that they often received was based on the 12th step of service discussed above: "Having had a spiritual awakening as the result of these Steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs." (Wilson 1939). Chuck, who lost his fiancé (see 4.3 above), describes this:

> I immediately got into that [helping others] because that's what the [basic text of alcoholics anonymous] tells me to do. The [basic text of alcoholics anonymous] has been the honest to God truth, from the beginning until now… it is not a lie to me. That's for sure. *So, when it tells me to jump in and help other people, that's what I did. I went through that and was working with my sponsees* [individuals he sponsors], *taking them through the steps, I was doing what was suggested of me to get through those things. That's what we do. We're in service even harder.* You know? And that's what I did. And it worked. And it still works.

Chuck attributes the principles he learned through AA as helping him navigate his loss. Specifically, helping others struggling with addiction gives him a sense of purpose. Chuck's account, moreover, highlights that his involvement in AA prior to

his loss helped him navigate his grief by giving him an environment where he could be of service to others.

Carter lost five family members to substance use and was actively involved in AA. Reflecting on his own experience of recovery and sobriety, and taking others through the 12-Steps helped him understand, navigate, and destigmatize his grief, he describes the centrality of helping others:

> *I've been able to help people*. And I never used it as a sympathy card for my own losses. I was always taught you should never do that, and I feel it would lessen what my family members meant to me. Luckily for me AA reconnects me with my family. I talk to my living sister who never struggled with addiction and that has helped me grieve. I've been able to open up about it, and I've surrounded myself with a lot of good people. And that's what we talk about in AA: you always have a place to go.

Carter voices that the personal work he has done for his recovery in AA has placed him in a position of repairing social bonds with his sister, which he describes as helping him with his own grief process. AA has provided him with a space to open up and talk to others. Carter reconstructs his own tragic losses as a strength for helping others. Other survivors involved in AA or NA also used their experience to help others in settings other than 12-Step meetings. Claire, who lost her roommate and close friend Erica (discussed above in Chapter 4), works in the treatment industry. As discussed above, Claire experienced stigma from coworkers by the way they enforced feeling rules and expressive norms. However, Claire displays a great degree of agency by using her experience of losing Erica and the stigma this loss presented to help her clients. She emphasizes how this job is crucial to her own grieving process:

> It gives me the opportunity to use that loss to help other people too., What else am I going to do? If I'm not using it to be helpful, it's just going to eat me alive if I don't talk about it. I have to spin it in a way to be a positive thing, or it's going to kill me.

The accounts of those in AA and NA show the importance of helping others bereaved by a drug overdose death. These individuals found a supportive community and guidance in their grief through their 12-Step Fellowships. Involvement in 12-Step Fellowships served as an environment for survivors to be agentic in a way that led to a healthier grieving process. Parents involved in Nar-Anon and Al-Anon also describe a supportive, understanding support network. Their experiences of acceptance empowers them against stigmatization. Those involved in AA or NA found an environment where they could help others by incorporating program principles and tools used in their own recovery to their own grieving process.

5.4 Religion

Religious services provided another arena of empowerment for survivors in this study. For some, worship was the primary form of help-seeking. Sociologists have long observed that religion fosters social solidarity (Durkheim [1912] 2001) and provides theodicies for approaching death and suffering (Ellwood 1913). Audrey, who lost her husband to a drug overdose death and experienced stigma through facing multiple barriers to treatment (see 4.1 above), describes her grief process as transformed through participation in a church support group:

> I attended a Christian-based program for those who have lost a loved one. It's kind of like a recovery group but only for those who have lost people. Our group had about 8 or 10 people. It is a Bible-based program. We have what's called small groups, and you can join whatever you want, and the people you join the groups with become your best friends. Our pastor always says that "alone time is good," but if you don't want to be alone, make sure you have a group of people whom you can be with. If you don't have anybody to fall back on, that's when you really get lonely. *So that's good advice: Be with people, you can't do it alone, or you'll end up sitting in front of the TV with a bottle of bourbon (laughs).*

Audrey's church provided her a group who may not have the same bereavement experience, or shared courtesy stigma, but accepted her as a Christian and provided a sympathetic and supportive community for her to navigate her grief. Beyond deepening her religious identity, she describes this group in ways that are similar to survivors in 12-Step programs. The members of her group became her close friends. This experience helped her to understand her own needs more clearly. Specifically, she needed a supportive community. Rather than evangelize, Audrey sees her experience as commonsense advice on the need for social support during grieving. Further, in experiencing the benefits of her involvement in this church-based group, she sought to reach out to others who had lost a loved one to an overdose and invite them to the group.

Ruby, who found support in Nar-Anon (Appendix D) also described the importance of her church in navigating the grief of her daughter Jasmine. It's not clear if Nar-Anon encouraged her participation, but her deepened faith began after she lost her daughter:

> I just started going to church. The pastor is just an amazing person. So, I don't know what the plan is, but I know there has to be one. And I must believe that, or I wouldn't be able to get out of bed every day. Because how come I'm still sitting here? How can I function? God's holding me up. If that wasn't true, I don't even know where I would be. So, there must be something stronger; there is something greater than I am. And I believe that. That's how I survive, so that's how I make it, you know. And that's a blessing.

Ruby's account shows how the shame associated with stigmatized bereavement can be neutralized through the support of clergy and the church. For Ruby, theodicies deepen acceptance of her past and destigmatize the loss of her daughter. She describes her devout faith as allowing her to embrace the present without having to understand the

devastating losses she experienced in the past. In this way, Ruby's story is one of redemption in which McAdams (2006) describes as culminating in expressions of "future growth."

Stories of redemption are also common among survivors who lost an intimate partner. Chuck describes his own recovery in the context of a deep religious faith. After his fiancé's death, he frames his account as one of overcoming expectations that he too would soon die of an overdose:

> People are like, "How did you do that, Chuck?" People who know me call me up man, and I'm like, "God, man, God made that possible for me." I didn't want to lose that connection that I had with him. My connection with God helped me feel and communicate with her [fiancé]. I knew that allowed me to do that, so of course, I want to do his work. I spend most of my life in service. It's not like a church thing or nothing like that. It's a service to God: Whatever God tells me to do wherever I'm at. If I'm walking down the street or if I'm at work or church, whatever I'm doing, I try to help other people. And that's all through what happened. I got a lot of that through because of what happened.

Chuck's account is an even more definitive redemption story than Ruby's story of a deepened faith that began through participation in a formal church support group. Chuck's story is a devotional one. He even makes a point that his redemption is not based on work through the church. Rather he is able to see the loss of his fiancé now as a kind of spiritual awakening. Beyond stigma management, Chuck is able to transform his grief into an asset or invitation to a fuller life of gratitude and selfless service. While Chuck is unique among the survivors interviewed in this study, his story clearly shows how the belief in a higher power may have profound transformative effects on the identity of someone who is both in recovery and has lost a loved one to a drug overdose death.

Another example of a similar transformative experience was seen in Audrey. While Audrey attends some support groups, the primary support that she has found for her grief has been through her church (discussed above). While Chuck story highlights how experiencing loss drove him closer to his higher power, Audrey expressed gratitude in her loss clearing the way for her to deepen her relationship with her higher power. Audrey explains how her husband's addiction stood in the way of the need to deepen her religious faith:

> I was not doing what I should have been doing. I was spending way too much time worrying about someone else and not doing for me, what I needed to do for me. Through my faith, and through my counseling, and through my Church groups and everything I think I've come to realize that *Wyatt was standing in the way of my faith*.

Audrey had a spiritual awakening similar to Chuck's as a result of her multiple forms of help-seeking. Through her faith, Audrey began to prioritize herself, and in turn, her bereavement process, further challenging the stigma surrounding Wyatt's death by voicing that it was, in some respects, a blessing, for it allowed her to deepen her faith.

Religious principles have often served as a way for individuals to understand complex issues in the human experience, including death (Ellwood 1913). These religious tenants provided survivors with an approach to destigmatize their loss by understanding their loved one's death as part of a divine plan. In doing so, the death no longer fit the stigmatizing framework of moral failing or choice discussed above, but rather was a predestined fate. Further, religious bodies served as an understanding community of support and social solidarity for survivors. Although those within the religious communities may not have shared the same stigmatizing experience as survivors, many survivors in our study found empathy and understanding in these communities. Religious experiences also helped survivors find meaning in their loss,

which in turn, allowed some like Chuck and Audrey to experience gratitude in how their loss had deepened their faith and changed their identity in ways that they viewed as positive, actively countering the stigma surrounding their bereavement.

5.5 Counseling

Counseling was also an emergent theme in exploring the help-seeking behavior of survivors. However, experiences were varied. Some participants noted that their experience with a therapist or psychiatrist was beneficial or served as a springboard for them to be referred to other support groups and services (Jennifer, discussed above, initially was referred to Nar-Anon by her therapist). On the other hand, some survivors experienced interactions with counselors that were not supportive, or their therapist did not have the lived experience necessary to provide support.

Jan continued counseling since her son's passing: "I have been in counseling since a few weeks after he died. I'm still in counseling; I go every other week at this point." Jan did not initially find an environment in support groups where she felt comfortable disclosing how her son died, (see Chapter 4) but was more readily able to discuss her loss in therapy. Jan eventually became more comfortable discussing her loss through these efforts, leading her to be able to share more openly in support groups. As a result, she now facilitates support groups (see discussion above). Jan, and others, found counseling to provide a supportive environment for discussing their loss without facing stigmatizing narratives. Therapy served as a setting where survivors could share their feelings to an understanding person, free of judgement and stigma, similar to the experiences of those in support groups, advocacy efforts, religion, and 12-Step Fellowships discussed above.

Walter and Ford (2018) highlight how therapists can aid in destimatization by creating an empathetic and understanding environment for the unique experiences of survivors. As discussed above, some survivors experienced interactions where they were blamed for their loved one's passing or felt that they were viewed as responsible for their loved one's use. Samuel expressed that counseling helped him counter feelings of guilt and shame that stemmed from this by helping him learn that others who lost a loved on to an overdose experienced these feelings as well: "A lot of guilt, which I have talked about in therapy, it is apparently very common." Notably, Samuel wrestled with feelings of guilt surrounding his stepdaughter's passing, for he grieved her death while simultaneously finding relief in her passing due to the emotional turmoil he experienced while she was actively using drugs. For example, Samuel's daughter Laura had left syringes used and uncapped in the house while an infant was present, creating an unsafe living environment. Further, Laura was continuously in and out of specialized treatment for her dual diagnosis (see 4.1 above), which cost Samuel and his wife Karen a lot of money. Once Laura passed, Samuel was conflicted by feelings of relief that the turmoil was over while simultaneously grieving the loss of his stepdaughter. Samuel's experiences with Laura's death led to a PTSD diagnosis. Therapy provided an environment for Samuel where he could unpack these contradictory feelings and experiences safely. He also describes the importance of not feeling alone in having these feelings.

By demonstrating that what survivors are going through in their grief process is expected, such interactions can help to destigmatize bereavement. Grace, who lost her cousin, highlights that she sought counseling after experiencing difficulty grieving: "I was seeing a counselor for a while probably because we realized I don't deal with

grief." While survivors like Chuck, Nicholas, Kelsey, Kathleen, Jan, and others discussed above found meaning in their loss, Grace did not have a similar experience. Grace felt disenfranchised in her grief because she was a cousin to Tim, and therefore, that she could not attend grief support groups like those closer to the lamented (e.g., parents, spouses, siblings). In feeling her loss was not "credible" enough for attendance in these groups, Grace initially coped with her grief through drinking heavily, but eventually saw that a healthier avenue to address her grief could be found through counseling. Therapy provided her with the supportive space to address her grief.

Fran describes developing a close relationship with her therapist. Fran did not find understanding from her husband when it came to the loss of her brother. While he tried to be supportive, Fran voiced that it was nice to have a someone with a more in-depth understanding of addiction to whom she could relate:

> My therapist and I are best buds now. he'll call me before my appointments and say do you want anything for lunch (laughs). I've been seeing her for almost two years! Sometimes my husband who doesn't come from a family [of] addicts, tries to understand it but really doesn't understand it. Although I have a lot of friends, I can talk to about it, [I can talk to] the therapist and I can go in there, and she's not gonna say you know Fran you're crazy (laughs).

Fran further highlights that while she does feel she can talk to her friends, she still experiences judgment at times – a judgment that she does not experience with her therapist. This highlights how therapy served as an avenue for destigmatized interactions for the bereaved, helping to counter their stigmatized bereavement by providing an understanding and sympathetic person with which the bereaved could discuss their loss. Fran found therapy to be an avenue where she could discuss addiction without experiencing stigmatizing labels such as "crazy."

However, not all interactions with therapists served as an arena for challenging stigma or finding positive support. For some, interactions with therapists served as a moment of feeling alone and isolated in their grief and experience, in turn, furthered their stigmatization. As discussed earlier, stigma towards substance use is often a barrier to accessing prosocial services, including mental health services. Ruby, whose primary forms of support were found through Nar-Anon and religion, recalls an interaction with a therapist that was negative:

> I did try to go to a counselor right afterward, and she was a wacko. She was a really weird little lady. [It] could have been me, but part of it was definitely her. I literally cried the whole time; I'm like, "What good is this doing me if I sit here and just cry for an hour? Pay you 60 dollars for it?" I know that's wrong, but there was no connection. She had lost a child through addiction as well. She was just a weird little lady. I don't think she ever asked me my daughter's name, but I know what her daughter's name was. That's all I remember about the whole thing, you know. So that's not my thing.

Ruby went to a therapist to discuss her loss and hoped to find shared support and connection through the fact that her therapist had also lost a child to substance use. However, Ruby did not find relief or comfort, for her therapist did not provide her the space to openly discuss her loss. Instead, the therapist monopolized their time together talking about her own loss, leaving Ruby feeling that she was unsupported and wasting money. This experience contributed to Ruby seeking other services, eventually placing her into contact with the support group at her church discussed above. Her experience highlights that more than a shared stigma was needed for individuals to feel support. Specifically, mutual aid may promote agentic practices that promote empathy, support, and compassion.

Mary, who lost her fiancé Chester and currently has not sought additional forms of support, continues to attend therapy but feels that her therapist does not understand what she is going through:

> I go see a counselor, but that doesn't help much…People don't really understand. My counselor is the same way. I have seen him every other week for the past two months, and he just can't comprehend that I'm allowed to feel guilty. And *I don't want to hide how I feel.* I just want him to show me things to make it not be in my mind constantly because I picture him. I tried to figure out where he was in the hotel room, how he was sitting, what he was doing, what led up to it, and what he did in that time that I didn't talk to him. t's something [that] constantly runs through your mind. I constantly think about it, it doesn't go away. You try to like to push it in the back, but it just doesn't work that way.

Mary felt that her counselor could not relate to her experience or provide understanding for her feeling. While Samuel found support through his counselor telling him that guilt was a common emotion to experience after a traumatic loss, Mary felt she could not discuss her guilt with her therapist and had to hide her emotions. These interactions with her therapist echoed the stigma she felt through her interactions with others - i.e., a lack of empathy and understanding. In seeking to voice her feelings, she felt as if she was met with stigmatizing feeling rules by her therapist. For Mary, this and her relationship with her partners mother were her only avenues of support. Mary's account demonstrates the importance in having a space where she can safely discuss the details of her fiancés death and not be ignored or dismissed. Notably, in her account, she is grappling with feelings of guilt surrounding her fiancés passing and trying to understand the nature of his death. On the day her fiancé Chester died, Mary had refused to pick him up from the treatment center that he was completing. Chester ended up taking a bus to meet with his dealer, and shortly died thereafter in a hotel room. In her interview, she actively voiced things she felt she may

have done to prevent his passing, such as picking him up from treatment, while simultaneously noting how it was important for her to maintain boundaries with him while he was using. Such introspection demonstrates an agentic process of destigmatization through seeking to make sense of the loss. Destigmatizing arenas would provide her with space to engage in such processes. Unfortunately, Mary did not find this support, empathy, or understanding in therapy. She describes an experience of suppressing her emotions. In contrast, destigmatizing environments allow for the creation of spaces where feelings are reconceptualized under new narratives of "courage, strength, resilience and agency" (Carrasco et al. 2017: 551).

Negative interactions such as those experienced by Ruby and Mary led to referrals to other support groups and outlets. As presented above, Jennifer, who lost her son Eugene, was connected to Nar-Anon through a therapist:

> Through one of my psychiatrists. I had gone to [many different ones] – I went to [a therapy service] first, and that didn't work out because I kept talking about Eugene, Eugene, Eugene, and he said, "You're not here to talk about Eugene. You're here to talk about you." I said, "But my problems are all with Eugene. I need to talk about Eugene." And I didn't get it, and he didn't get it, so that wasn't a good fit. Then I went to another psychiatrist at [a hospital], and I didn't have a good mix with her. We'd just sit there and cry. And she'd say, "Well, you know, don't you – you have a sister, can't you, you know, talk to your sister [INAUDIBLE]." I said, "She's busy; I don't see her." But the only good thing she did do was she looked up and said, "You know, there's - maybe Nar-Anon will help you." So, she suggested Nar-Anon and got a listing of where they were.

Jennifer initially did not find support in meeting with her counselor. She describes her therapist as keenly identifying her lack of family social support and recommending Nar-Anon.

5.6 Negotiating Stigmatized Identity as an Agentic Process

Prior research on those bereaved by a drug overdose death has highlighted that the bereaved engage in the stigma management techniques of concealing or disclosing their spoiled identity (Walter and Ford 2018). Studies have emphasized that bereavement and stigma respectively can shape individual's self-concept (Feigelman et al. 2012; Francis 1997; Handsley 2001; Toller 2008). As presented in the previous chapter, survivors describe a stigmatized bereavement process. Such an understanding highlights the compounding effects of stigmatizing interactions that problematize the bereavement process. Yet experiencing stigma is not fatalistic. Indeed, one of the limitations of previous research on stigma is the assumption of "helpless victims" (Link and Phelan 2001:378). Clearly, the survivors in this study challenge such assumptions. While Walter and Ford (2018) provide important insight into how the bereaved engage in stigma management, survivor's accounts in this analysis show how different life experiences and contexts of help-seeking shape agency in both similar and different ways. A more agentic conceptualization of unspoiling identity is important for understanding why help-seeking is meaningful. Carrasco et al. (2017) provide additional insight in this respect. Survivors in their study challenged stigma by redefining it through spaces of destigmatization and support. Specifically, help-seeking behaviors can insulate survivors from stigmatized bereavement.

Many of the survivors in this study dedicated their lives to advocacy and help-seeking behaviors. Expanding beyond Goffman's seminal work of concealing or revealing one's spoiled identity or finding non-stigmatizing spaces among "the own" or "the wise," these findings demonstrate an agentic process of negotiating stigmatized identity that move beyond a "spoiled identity" to a process of "unspoiling" identity. It is important to clarify that my use of the term "unspoiling" does not mean that stigma,

or the process of experiencing stigmatized bereavement, comes to a static end point. Rather, many survivors in this study demonstrated agency in how they redefined their grief, challenged stigma, fostered a sense of belonging, and found purpose in the wake of their loved one's passing. Many survivors dedicate their lives to helping others through practices that move beyond expectations of continuing bonds or memorialization theories alone. Figure 5 presents a visual representation of an alternative model that highlights an agentic process of unspoiling identity:

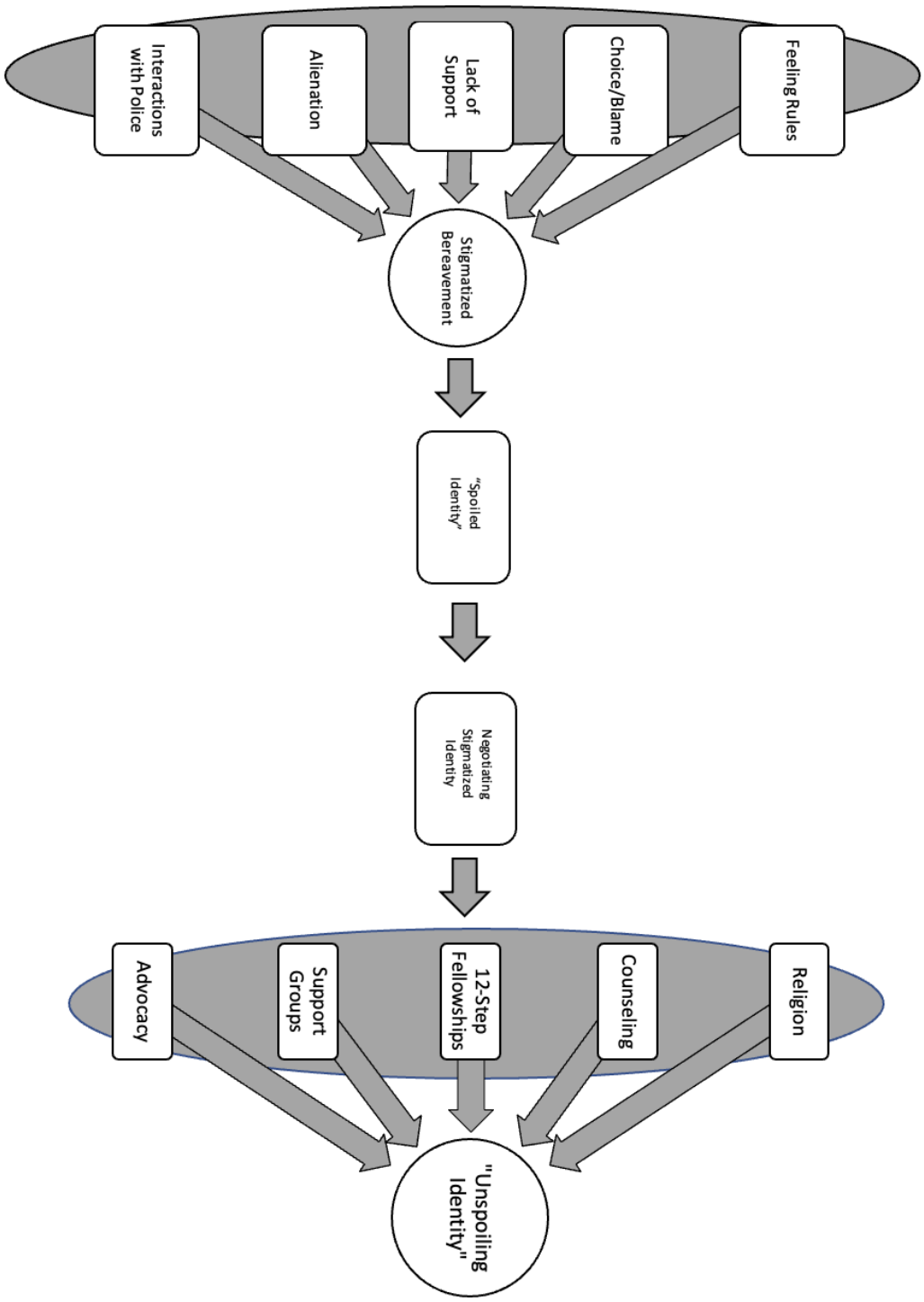

Figure 5: Negotiating Stigmatized Identity as an Agentic Process

Help-seeking behaviors became the primary avenues for this process to occur. In this way, three emergent themes result from survivors' engagement in various forms of social support: community, understanding, and service. Through involvement in advocacy groups, support groups, counseling, 12-Step Fellowships, and religion, survivors were able to find a community of both "the own" and "the wise." These communities helped the bereaved counteract alienation and lack of social support experienced in their stigmatized bereavement. Further, survivors found non-stigmatizing, understanding communities where they felt they could openly express their grief, the nature of their loved ones passing, and counteract cultural narratives on individual failing. Through these efforts, survivors actively sought to educate the public about addiction, create and implement policies to combat the opioid epidemic, and help those with substance use.

It should be noted that these endeavors were not mutually exclusive. The bereaved engaged in a host of interlapping efforts. Through engaging in these forms of help-seeking, survivors challenged the stigma, countering notions of "discredited" and "discreditable" identity. Many framed their discussion in the medicalized disease model above, which, as mentioned, has been a powerful narrative in counteracting the choice/failing arguments of substance use. A striking majority of survivors described these various efforts as leading to profound sense purpose. Indeed, survivors are involved in multiple advocacy groups, support networks, and activism in neighborhoods and communities most impacted by the opioid epidemic.

Some grief scholars have referred to these various help-seeking behaviors as a way of continuing bonds with the lamented. Klass (1996) describes various activities the bereaved may engage in to maintain a sense of connection similar to what Berns

describes as “continuing bonds” that involve “ways to keep someone’s life meaningful after he or she is dead [and] may lead people to create a diversity of memorials or to dedicate their lives in new directions in honor of a loved one (2011:169).”
While the efforts above can be seen as a process of continuing bonds, these findings highlight an agentic process that goes beyond. Survivors engaged in advocacy efforts may initially do so as a way of continuing bonds to honor their loved ones, but the findings from this study show that there are more agentic motives as well. Alternatively, some survivors sought to create communities of social bonding, create social change, and embark on efforts to prevent others from experiencing the same pains that they had.

As Link and Phelan (2001:377) highlight, one of the critical elements of stigma from a sociological perspective is the way “labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them.” This study sought to challenge the power systems that support stigmatized bereavement. Challenges were presented to barriers to treatment through advocacy groups founded by our survivors. Negative interactions and stereotypes by police officers were challenged by some survivors who provide Narcan training to police officers in Delaware. Alienation and lack of support were challenged by seeking support groups and creating them if the right groups were not found. Narratives of choice and blame were challenged by educating the public on the disease concept of addiction and, for some, embracing religious theodicies. Feeling rules were challenged through therapeutic efforts. These demonstrate a challenge to the existing power structures that propagate the culture of stigma surrounding drug overdose deaths. As Link and Phelan eloquently state: “We can see that people in stigmatized groups

actively use available resources to resist stigmatizing tendencies of the more powerful group and that, to the extent that they do, it is inappropriate to portray them as passive recipients of stigma" (2001:378).

5.7 Summary of Chapter 5

These findings demonstrate the various way survivors resist or counteract stigmatization. Demonstrating a system of mutual aid that served to reconstruct their identity from one viewed as "spoiled" to an agentic identity of helping others, survivors find purpose and meaning in their loss through communities of support, empathy, and empowerment. These findings highlight the ways in which negotiate stigmatized bereavement through a process of unspoiling identity (see Figure 5 above).

Chapter 6

CONCLUSION

Throughout the past twenty years of the opioid epidemic, the loss of life across the American landscape has been striking. Efforts by scholars to address, understand and examine this social phenomenon and its implications have been robust. However, commonly missing from this discussion has been the impact such a vast loss of life has on the survivors left behind. This study sought to understand how the pervasive cultural stigma of addiction impacted the bereaved. This concluding chapter will discuss how this research contributes to scholarly and policy debates and discuss directions for future research.

6.1 Theoretical Contributions: Stigmatized Bereavement and Unspoiling Identity

This study is framed around two research questions. First, how does the stigma surrounding addiction uniquely impact those closest to individuals who died from an overdose death? Secondly, what ways does this stigma impact the mourning processes of the bereaved? To analyze these questions, qualitative interviews with 35 survivors who lost a loved one to a drug overdose death were conducted. These in-depth interviews revealed how the bereaved experienced stigma following their loved one's death and how this experience led to various help-seeking efforts.

6.1.1 The Stigmatized Bereavement Process

Survivor's interactions are shaped by what I have termed the *stigmatization bereavement process*. In contrast to static events (e.g., "hitting rock bottom"), stigma compounds experientially both before and after a drug related death. While the concept of disenfranchised grief (see Chapter 2) is important for a broader understanding of cultural constructions of worthy and unworthy deaths, the stigmatized bereavement process focuses on social interactions. Survivors in this study describe their experiences of losing a loved one to an overdose as stigmatized prior to bereavement. Being denied adequate treatment may lead to profound feelings of frustration, guilt, and self-blame. Because illicit drugs are criminalized in the U.S., overdose deaths invariably bring survivors into contact with law enforcement. Indeed, this study shows how those interactions are stigmatizing and often harmful to the bereavement process. Subsequent interactions with family members perceived as uncaring compound feelings of blame and alienation. Building on prior research of stigma as conditioned by unequal power relationships (Carrasco et al 2017), the stigmatized bereavement process is relevant to the study of other marginalized deaths (e.g., HIV/AIDS and suicide).

A second theoretical contribution of this study is a focus on the process of *unspoiling identity*. Moving beyond Goffman's stigma management, survivors describe an agentic process of identity repair. Understanding how individuals conceal or reveal a "spoiled identity" remains relevant, especially when considering interactions outside drug death bereavement advocacy and support contexts. However, *unspoiling identity* provides a more capacious understanding of survivors deepening experiences of belonging and empowerment than stigma management. Beyond the "reveal or conceal" binary, survivors describe help-seeking experiences as

destigmatizing. At the same time, this is not to suggest a terminal endpoint in which stigma is somehow eradicated. Alternatively, a focus on unspoiling identity calls attention to meaningful collective action as part of an ongoing bereavement process. Indeed, survivors in this study were actively engaged in advocacy work surrounding substance use (e.g., public education and legislation designed to provide support to housing insecure individuals struggling with addiction). Moreover, participation in12-Step Fellowships, counseling, and religious communities deepened a sense of belonging. In these inclusive settings, survivors not only receive but also create support for others. Attending to this process of unspoiling identity is provides understanding of how help-seeking *empowers* survivors.

6.2 Applied Contributions: Mutual Aid and Stigma Informed Practices

Support systems challenge stigmatized bereavement and foster opportunities for unspoiling identity. Beyond theoretical concepts, this means furthering policies that invest in mutual aid:

> Mutual aid is when everyday people get together to meet each other's needs, with the shared understanding that the systems we live in are not meeting our needs and that we can meet them together, right now, without having to pressure power structures to do the right thing. Mutual aid is an idea and practice that is based on the principles of direct action, cooperation, mutual understanding, and solidarity (Izlar 2021).

Survivors in this study demonstrate the importance of engaging in mutual aid to challenge stigma. Specifically, they actively sought inclusive opportunities for help-seeking. Some engaged in collaborative efforts to form coalitions that challenge the structural stigma of criminalization and a lack of effective and meaningful treatment.

Others focused on building communities of understanding and empathy where individuals could speak without fear of judgment and experience solidarity.

The stigmatization bereavement process provides a roadmap that informs how mutual aid systems can more productively challenge stigma. Community coalitions of mutual aid focused on destigmatization are a relatively new development (Stout and Fleury-Steiner forthcoming). In demonstrating the help-seeking experiences of the bereaved, this study provides practical knowledge for how to support survivors more productively.

While prior research brings attention to the unique forms of loss experienced by those bereaved by a drug related death, the findings in this study demonstrate that counseling and therapy alone are often not enough to address stigmatized bereavement. This study demonstrates the need to expand community resources that can support and empower survivors. Systems of mutual aid can benefit by ensuring safe and accepting environments for the bereaved to grieve openly and memorialize the life of their loved ones.

The empirical findings show how a focus on stigmatized bereavement as a *process* of unspoiling identity can inform the development of more productive mutual aid. Community leaders' openness to multiple resources that meet needs of survivors is central to such efforts. Because needs may change, allegiances to one support group over the other is likely counterproductive. By understanding how individuals negotiate stigmatized bereavement (e.g., unspoiling identity) may lead to more empathic approaches to community support (Stout and Fleury-Steiner forthcoming).

6.3 Bringing Attention to Stigmatized Bereavement

This study contributes to emerging debates on drug related death bereavement. Indeed, a summary of findings from this dissertation will be published (Stout and Fleury-Steiner forthcoming) in *The Routledge International Handbook of Drug-Related Death Bereavement* (Stroebe et al forthcoming). In a word, the results from this study provide understanding through the words of people who have experienced the stigmatized bereavement process. A matter of particular interest to applied bereavement scholars is help-seeking. While this study contributes to such debates, one obvious implication is the need to expand mutual aid to marginalized areas where opioid overdose deaths are disproportionately high.

While this study was conducted in a state severely impacted by the opioid epidemic, survivors are affluent and reside in communities with high population density near metropolitan areas. That is to say, the survivors in this study have greater access to help-seeking and opportunities for unspoiling identity. By contrast, West Virginia, the state with the highest number of overdose deaths in the United States, is characterized by more rural and economically disadvantage areas. Indeed, these communities have been impacted the most by the ongoing opioid epidemic. The current study calls attention to the need to invest in mutual aid for the drug death related bereaved residing in such marginalized communities.

The experiences of economically marginalized and racially aggrieved survivors are not captured in this study. These groups have historically been denied access to a myriad of social supports that quite likely further complicate the stigmatized bereavement process. While the findings presented in this study has policy implications for all communities, future research in marginalized communities is needed.

6.4 Policing and Cultural Change

Survivors in this study describe negative interactions with law enforcement. The war on drugs has dramatically shaped the view of those who suffer from addiction as dangerous criminals. As demonstrated in this study, such an approach negatively impacted bereaved survivors when they are most venerable and in need of support. Two implications emerge from this finding. First, sensitivity training for officers could lead to positive interactions with survivors. Yet the ongoing war on drugs remains largely at odds with any such sweeping law enforcement reforms. Accordingly, advocacy groups that challenge stigma and advance public understanding of the disease model of substance use disorder remain essential in efforts to decriminalize drugs and destigmatize addiction.

6.5 Methodological Contributions

The limitations in Chapter 2 described by Titlestad et al. (2019) primarily focus on definitional parameters and sample size. This study begins to address those limitations. Specifically, the sample focuses on exclusively on drug overdose deaths (see section 2.3.1). Templeton et al. (2017) highlight the importance of this distinction, showing that those who die from a drug overdose death display unique circumstances surrounding their death compared to deaths occurring from alcohol use or other drug use complications. Through exploring drug overdose deaths explicitly, this study examined how bereavement following a drug overdose death presents a unique experience for survivors.

6.6 Limitations of Current Study and Areas for Future Research

Although this study presents compelling contributions to the literature on stigma and bereavement, it is not without limitations. It is vital to address the current

limitations, for doing so can also highlight areas for future research (discussed in more detail below). While Delaware has one of the highest overdose death rates in the United States, these findings are limited regarding generalizability. Future research should explore the experience of the bereaved in other locations in the United States. Location may influence stigmatization experienced by the bereaved. Available resources, political climate and, indeed, the prevalence of overdose deaths varies between counties and municipalities.

Sampling for this study began by recruiting survivors from MAA. While this was the initial touchpoint of recruitment that led to a larger pool of survivors through snowball sampling, more research is needed on those not engaged in help-seeking behaviors such as advocacy. Specifically, future research should explore the effects that stigmatized bereavement has on individuals who are not engaged in help-seeking behaviors. While some survivors were not currently involved at the time of this study, further exploration is needed. New pilot studies can begin to provide a fuller understanding of processes of negotiating stigmatized identity and how particular practices are beneficial to survivors.

Those who participated in this study were not a socially representative sample. All survivors in this study were white and middle class. A focus on more socioeconomically diverse samples can add considerable knowledge to the study of stigmatized bereavement. Specifically, future studies should explore the stigmatized bereavement process with attention to intersecting race, sexuality, and gender identities may. While some survivors had a history of addiction and were actively engaged in recovery, future research should also focus on differences in the

stigmatized bereavement processes and help-seeking practices for survivors in substance use recovery.

The survivors in this study are middle class and had strong social networks. Unique barriers to help-seeking behaviors may exist for the bereaved with less economic resources, weaker social networks, and less access to community resource than what is explored in the present study. Gender differences may also be important for understanding the experiences of the bereaved but were beyond the scope of the current study. While prior research has explored gendered differences in bereavement processes (e.g., Doka and Martin 2014; Schwab, 1996), future research should explore how gendered roles and gendered feeling rules may impact the stigmatized bereavement process.

The stigmatized bereavement process complicates present understandings of mourning. Hochschilds' ([1983] 2012) seminal work shows the importance of feeling rules and understanding emotions in particular contexts. Future research should examine how emotions complicate stigmatized bereavement and unspoiling identity processes. A more explicit focus on feeling rules and emotions may lead to a greater depth of understanding of why individuals engage in help-seeking (e.g., anger as a catalyst for bereavement advocacy).

6.7 Closing Summary

When asked what the purpose of this study was during an interview, I had the following exchange with a father who had lost his son:

Patrick: So, you're looking more at the family?

Joshua: Yeah, looking more at the family…

Patrick: Survivors.

This study, above all else, looks at the experiences of *survivors* – those who have experienced a devastating loss. In experiencing such a loss, survivors faced stigmatization in their bereavement. However, their ability to negotiate such experiences through various help-seeking strategies deepens agency and can lead to remarkable transformations in the lives of some survivors. Perhaps this study inspires more informed—indeed, survivor-informed—conversations on the opioid epidemic in the United States.

REFERENCES

Ahmab, F.B., L.M. Rossen, and P. Sutton. 2020. *Provisional Death Overdose Death Counts*. National center for Health Statistics. Retrieved March 2, 2022 (https://www.cdc.gov/nchs/nvss/vsrr/drug-overdose-data.htm?source=email#nature_sources_of_data)

Al-Anon Family Groups. 1995. *How Al-Anon Works for Families and Friends of Alcoholics.* Virginia Beach, VA: Al-Anon Family Groups.

Alexander, Michelle. [2010] 2020. The New Jim Crow: Mass Incarceration in the Age of Colorblindness. New York, NY: The New Press.

Alexander, Victoria G. 1991. Words I Never Thought to Speak: Stories of Life in the Wake of Suicide. New York, NY: Lexington Books.

Anderson, Tammy L. 1993. "Types of Identity Transformation in Drug-Using Recovery Careers." *Sociological Focus* 26(2):133-45. doi: 10.1080/00380237.1993.10571002

Anderson, Tammy L., Holly Swan, and David C. Lane. 2010. "Institutional Fads and the Medicalization of Drug Addiction." *Sociology Compass* 4(7):476-94. doi: 10.1111/j.1751-9020.2010.00292.x

Aoun, Samar M., Orla Keegan, Amanda Roberts, and Lauren J. Breen. 2020. "The Impact of Bereavement Support on Wellbeing: A Comparative Study Between Australia and Ireland." *Palliative Care and Social Practice*. doi: 10.1177/2632352420935132

Atkinson, Paul and Martya Hammersley. 1994. "Ethnography and Participant Observation." Pp. 248-61 in *Handbook of Qualitative Research*, edited by N. K. Denzin and Y. S. Lincoln. Thousand Oaks, CA: Sage Publications, Inc.

Barbalet, Jack. 2002. "Introduction: Why Emotions are Crucial." *The Sociological Review* 50(2):1-9. doi: 10.1111/j.1467-954X.2002.tb03588.x

Barrett, Terence W., and Thomas B. Scott. 1990. "Suicide Bereavement and Recovery Patterns Compared with Nonsuicide Bereavement Patterns." *Suicide and Life-Threatening Behavior* 20(1):1-15.

Becker, Howard S. 1963. *Outsiders: Studies in the Sociology of Deviance*. New York, NY: Free Press.

Berns, Nancy. 2011. *Closure: The Rush to End Grief and What it Costs Us*. Philadelphia, PA: Temple University Press.

Biong, Stian, Eli J. Sveipe, and Edle Ravndal. 2015. "Alt verker og alt har satt seg fast": Om pårørendes erfaringer med overdosedødsfall ["I Hurt All Over and Feel All Tied Up in Knots.": Bereaved experiences with death by overdose]." *Tidsskrift for Psykisk Helsearbeid* 12(4):278-287. doi: 10.18261/ISSN1504-3010-2015-04-02

Biong, Stian, and Birgitte Thylstrup. 2016. "Verdan Vælter: Pårønedes Enfaringer med Narkotikarelatrede Dødsfald [The World Collapses: Relatives' Experiences with Drug Related Deaths]." *Klinik Sygepleje* 30(2):75-86. doi: 10.18261/issn.1903-2285-2016-02-0

Bonanno, George A. 2013. "Meaning Making, Adversity, and Regulatory Flexibility." *Memory* 21(1):150-56. doi: 10.1080/09658211.2012.745572

Booth, Martin. 1999. *Opium: A History.* New York, NY: St. Martin's Griffin.

Brabant, Sarah C. 2008. "Clinical Sociology and Bereavement." Pp. 97-114 in *International Clinical Sociology*, edited by J. M. Fritz. New York, NY: Springer. doi: 10.1007/978-0-387-73827-7_8

Bukten, Anne, Marianne R. Stavseth, Svetlana Skurtveit, Aage Tverdal, John Strang, and Thomas Clausen. 2017. "High Risk of Overdose Death Following Release from Prison: Variations in Mortality During a 15-year Observation Period." *Addiction* 112(8):1432-39. doi: 10.1111/add.13803

Burke, Laurie A., and Robert A. Neimeyer. 2013. "Prospective Risk Factors for Complicated Grief: A Review of the Empirical Literature." Pp. 145-61. in *Complicated Grief: Scientific Foundations for Health Care Professionals, edited by* M. Stroebe, H. Schut, and J. Van den Bout. London, England: Routledge/Taylor & Francis Group.

Cacciatore, Joanne, Kara Thieleman, Ruth Frettes, Lori B. Jackson. 2021. "What is Good Grief Support? Exploring the Actors and Actions in Social Support After Traumatic Grief." *PLoS ONE* 16(5): e0252324. doi: 10.1371/journal.pone.0252324

Carr, Wilfred. 2000. "Partisanship in Educational Research." *Oxford Review of Education* 26(3/4):437-49. doi: 10.1080/713688539

Carrasco, Maria A., Clare Barrington, Caitlin Kennedy, Martha Perez, Yeycy Donastorg, and Deanna Kerrigan. 2017. "We Talk, we do not Have Shame: Addressing Stigma by Reconstructing Identity Through Enhancing Social Cohesion Among Female Sex Workers Living with HIV in the Dominican Republic." *Culture, Health and Sexuality* 19(5):543-56. doi: 10.1080/13691058.2016.1242779

Casriel, Cathy, Russell Rockwell, and Bruce Stepherson. "Heroin Sniffers: Between Two Worlds." *Journal of Psychoactive Drugs* 20(4):437-40. doi: 10.1080/02791072.1988.10472513

Caulkins, Johnathan P., Anne Gould, Bryce Pardo, Peter Reuter, and Bradley D. Stein. 2020. "Opioids and the Criminal Justice System: New Challenges Posed by the Modern Opioid Epidemic." *Annual Review of Criminology* 4:353-75. doi: 10.1146/annurev-criminol-061020-125715

Center for Disease Control and Prevention. 2011. "Vital Signs: Overdose of Prescription Opioid Pain Relievers – United States, 1999-2008." *Morbidity and Mortality Weekly Report* 60(43):1487-92.

Center for Disease Control & National Center for Health Statistics. 2020a. "National Vital Statistics System, Mortality." Retrieved March 3, 2022 (https://www.cdc.gov/drugoverdose/deaths/2019.html).

Center for Disease Control and Prevention. 2020b. "Opioid Overdose: Opioid Data Analysis and Resources. Retrieved March 3, 2022 (https://www.cdc.gov/drugoverdose/data/analysis.html)

Chiricos, Ted. 1996. "Moral Panic as Ideology: Drugs, Violence, Race and Punishment in America." Pp. 19-48 in *Race and Prejudice: Race and Justice in America*, edited by M. J. Lynch and E. Britt Patterson. New York, NY: Harrow and Heston.

Christensen, Donna Hendrickson and Carla M. Dahl. 1997. "Rethinking Research Dichotomies." *Family and Consumer Sciences Research Journal* 25(3):269-85. doi: 10.1177/1077727X970253002

Ciccarone, Daniel. 2017. "Fentanyl in the US Heroin Supply: A Rapidly changing Risk Environment." *International Journal of Drug Policy* 46:107-11. doi: 10.1016/j.drugpo.2017.06.010

Ciccarone, Daniel. 2019. "The Triple Wave Epidemic: Supply and Demand Drivers of the US Opioid Overdose Crisis." *International Journal of Drug Policy* 71:183-8. doi: 10.1016/j.drugpo.2019.01.010

Clayton, Paula J., James A. Halikas, William L. Maurice, and Eli Robins. 1973. "Anticipatory Grief and Widowhood." *The British Journal of Psychiatry* 122(566):47-51. doi: 10.1192/bjp.122.1.47

Connock, M., A. Juarez-Garcia, S. Jowett, E. Frew, Z. Lui, R. J. Taylor, A. Fry-Smith, E. Day, N. Lintzeris, T. Roberts, A. Burls, and R. S. Taylor. 2007. "Methadone and Buprenorphine for the Management of Opioid Dependence: A Systematic Review and Economic Evaluation." *Health Technology Assessment* 11(9):1-171, iii-iv. doi: 10.3310/hta11090

Corrigan, Patrick, Georg Schomerus, David Smelson. 2017. "Are Some of the Stigmas of Addictions Culturally Sanctioned?" *The British Journal of Psychiatry* 210(3):180-1. doi: 10.1192/bjp.bp.116.185421

Courtwright, David T. 2009. *Dark Paradise: A History of Opiate Addiction in America*. Boston, MA: Harvard University Press.

Cunningham, John A., Linda C. Sobell, and Virginia M. Chow. 1993. "What's in a Label? The Effects of Substance Types and Labels on Treatment Considerations and Stigma." *Journal of Studies on Alcohol* 54(6):693-9. doi: 10.15288/jsa.1993.54.693

da Silva, Eroy A., Ana R. Noto, and Maria Lucia O.S. Formigoni. 2007. "Death by Drug Overdose: Impact on Families." *Journal of Psychoactive Drugs* 39(3), 301-306. doi: 10.1080/02791072.2007.10400618

Daley, Dennis C., Erin Smith, Daniel Balogh, and Jodi Toscaloni. 2018. "Forgotten but not Gone: The Impact of the Opioid Epidemic and Other Substance Use Disorders on Families and Children." *Commonwealth*, 20(2-3):93-121: doi: 10.15367/com.v20i2-3.189

Devine, Patricia G., E. Ashby Plant, and Kristen Harrison. 1999. "The Problem of "Us" Versus "Them" and AIDS Stigma." *American Behavioral Scientist* 42(7):1212-28. doi: 10.1177/00027649921954732

Doka, Kenneth J. 1989. *Disenfranchised Grief: Recognizing Hidden Sorrow*. Ann Arbor, MI: University of Michigan Press.

Doka, Kenneth J. 1999. "Disenfranchised Grief." Bereavement Care 18(3):37-9. doi: 10.1080/02682629908657467

Doka, Kenneth J., and Terry L. Martin. 2014. *Men Don't Cry, Women Do: Transcending Gender Stereotypes of Grief*. New York, NY: Routledge.

Downes, David. 1977. "The Drug Addict as a Folk Devil." Pp. 80-9 in *Drugs and Politics*, edited by P. E. Rock. New York, NY: Routledge.

Duncan, Catherine, and Joanne Cacciatore. 2015. "A Systematic Review of Peer-Reviewed Literature on Self-Blame, Guilt and Shame." *OMEGA – Journal of Death and Dying* 71(4):312-42. doi: 10.1177/0030222815572604

Durkheim, Émile. [1893]1984. *The Division of Labor in Society*. New York, NY: The Free Press.

Durkheim, Émile. [1895] 1982. *The Rules of Sociological Method and Selected Texts on Sociology and its Method*. New York, NY: The Free Press.

Durkheim, Émile. [1897]1952. *Suicide: A Study in Sociology*. New York, NY: The Free Press.

Durkheim, Émile. [1912] 2001. *The Elementary Forms of Religious Life*. Oxford, England: Oxford University Press.

Dyregrov, Kari. 2011. "What Do We Know About Needs for Help After Suicide in Different Parts of the World? A Phenomenological Perspective." *Crisis: The Journal of Crisis Intervention and Suicide Prevention* 32(6):310–18. doi: 10.1027/0227-5910/a000098

Dyregrov, Kari, Dag Nordanger, and Atle Dyregrov. 2003. "Predictors of Psychosocial Distress after Suicide, SIDS and Accidents." *Death Studies* 27(2):143-65. doi: 10.1080/07481180390136973

Dyregrov, Kari, and Lillian Bruland Selseng. 2021. "Nothing to Mourn, He was Just a Drug Addict – Stigma Towards People Bereaved by Drug-Related Death." *Addiction Research and Theory.* doi: 10.1080/16066359.2021.1912327

Earnshaw, Valerie A. and Stephenie R. Chaudoir. 2009. "From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures." *AIDS and Behavior* 13(6):1160-77. doi: 10.1007/s10461-009-9593-3

Ellwood, Charles A. 1913. "The Social Function of Religion." *The American Journal of Sociology* XIX(3):289-307.

The END Project (2017). “Drug Death Related Bereavement and Recovery (The END Project).” Accessed July 5, 2022. https://www.hvl.no/en/research/group/mental-health-and-substance-abuse/the-end-project/

Feigelman, William, Julie Cerel, John L. McIntosh, David Brent, and Nina Gutin. 2018. “Suicide Exposures and Bereavement Among American Adults: Evidence from the 2016 General Social Survey.” *Journal of Affective Disorders* 227:1-6. doi: 10.1016/j.jad.2017.09.056

Feigelman, William, Beverly Feigelman, and Lillian M. Range. 2020. “Grief and Healing Trajectories of Drug-Death-Bereaved Parents.” *OMEGA-Journal of Death and* Dying 80(4):629-47. doi: 10.1177/0030222818754669

Feigelman, William, Bernard S. Gorman, Karyl C. Beal, John R. Jordan. 2008. “Internet Support Groups for Suicide Survivors: A New Mode for Gaining Bereavement Assistance.” *OMEGA-Journal of Death and Dying* 57(3):217-43. doi: 10.2190/OM.57.3.a

Feigelman, William, Bernard S. Gorman, and John R. Jordan. 2009a. “Stigmatization and Suicide Bereavement.” *Death Studies* 33(7):591-608. doi: 10.1080/07481180902979973

Feigelman, William, John R. Jordan, and Bernard S. Gorman. 2009b. “How They Died, Time Since Loss, and Bereavement Outcomes.” *OMEGA-Journal of Death and Dying* 58(4):251-73. doi: 10.2190/om.58.4.a

Feigelman, William, John R. Jordan, and Bernard S. Gorman. 2009c. “Personal Growth After a Suicide Loss: Cross-sectional Findings Suggest Growth After Loss may be Associated with Better Mental Health Among Survivors.” *OMEGA-Journal of Death and Dying* 59(3):181-202. doi: 10.2190/OM.59.3.a

Feigelman, William, John R. Jordan, and Bernard S. Gorman. 2011. “Parental Grief After Child’s Drug Death Compared to Other Death Causes: Investigating a Greatly Neglected Bereavement Population.” *OMEGA – Journal of Death and Dying* 63(4):291-316. doi: 10.2190/OM.63.4.a

Feigelman, William, John R. Jordan, John L. McIntosh, and Beverly Feigelman. 2012. *Devastating Losses: How Parents Cope with the Death of a Child to Suicide or Drugs.* New York: Springer Publishing Company.

Finlay, Linda. 2009. “Exploring Lived Experience: Principles and Practice of Phenomenological Research.” *International Journal of Therapy and Rehabilitation* 16(9):474-481. doi: 10.12968/ijtr.2009.16.9.43765

Fogger, Susanne, and Teena M. McGuinness. 2015. “Adolescents at Risk: Pain Pills to Heroin: Part II.” *Journal of Psychosocial Nursing and Mental Health Services* 53(2):27-30. doi: 10.3928/02793695-20150106-01

Francis, Linda E. 1997. “Ideology and Interpersonal Emotion Management: Redefining Identity in Two Support Groups.” *Social Psychology Quarterly* 60(2):153-71. doi: 10.2307/2787102

Friedman, Stanford B., Paul Chodoff, John W. Mason, and David A. Hamburg. 1963. “Behavioral Observations on Parents Anticipating the Death of a Child.” *Pediatrics* 32(4):610 625. doi: 10.1542/peds.32.4.610

Frost, Liz, and Paul Hoggett. 2008. “Human Agency and Social Suffering.” *Critical Social Policy* 28(4):438-60. doi: 10.1177/0261018308095279

Geertz, Clifford. 1973. *The Interpretation of Cultures*. New York, NY: Basic Book.

Gibson, Margaret. 2008. *Objects of the Dead: Mourning and Memory in Everyday Life*. Melbourne, AU: Melbourne University Press.

Gladden, R. Matthew, Predor Martinez, and Puja Seth. 2016. “Fentanyl Law Enforcement Submissions and Increases in Synthetic Opioid-Involved Deaths – 27 States, 2013-2014.” *Morbidity and Mortality Weekly Report* 65(33):837-43. doi: 10.15585/mmwr.mm6533a2

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon & Schuster.

Goodman, Leo A. 1961. “Snowball Sampling.” *The Annals of Mathematical Statistics* 32(1), 148-170. doi: 10.1214/aoms/1177705148

Goodrum, Sarah. 2005. “The Interaction Between Thoughts and Emotions Following the News of a Loved One’s Murder.” *OMEGA - Journal of Death and Dying* 51(2):143-160. doi: 10.2190/A69T-3GLW-A9PR-5QTH

Goulah-Pabst, Dorothy. 2021. “Suicide: Years in the Making.” *Qualitative Inquiry* 27(3-4):315-24. doi: 10.1177/1077800420917404

Grace, Philippa. 2012. “On Track or Off the Rails? A Phenomenological Study of Children’s Experiences of Dealing with Parental Bereavement through Substance Misuse.” PhD dissertation, School of Education, University of Manchester.

Greil, Arthur L. and David Rudy. 1984. ”Social Cocoons: Encapsulation and Identity Transformation Organizations”. *Sociological Inquiry* 54(3):260–78. doi: 10.1111/j.1475-682X.1984.tb00060.x

Grix, Johnathan. 2019. *The Foundations of Research*. London, England: Red Globe Press.

Guy, Phillip. 2004. “Bereavement Through Drug Use: Messages from Research. *Practice* 16(1):43-54. doi: 10.1080/0950315042000254956

Guy, Phillip and Margaret Holloway. 2007. “Drug-related Deaths and the ‘Special Deaths’ of Late Modernity.” *Sociology* 41(1):83-96. doi: 10.1177/0038038507074717

Handsley, Stephen. 2001. “But What About Us? The Residual Effects of Sudden Death on Self-identity and Family Relationships.” *Mortality* 6(1):9-30. doi: 10.1080/13576270020028610

Hari, Johann. 2015. Chasing the Scream: The First and Last Days of the War on Drugs. London, England: Bloomsbury.

Hainer, Ray. 2019. “Polysubstance Use and Stimulants: A Dangerous Fourth Wave in the Opioid Crisis.” *Boston Medical Center*. Retrieved from https://www.bhchp.org/sites/default/files/Polysubstance%20Use_%20The%20Fourth%20Wave%20of%20the%20Opioid%20Crisis%20_%20HealthCity%20_%20BMC.pdf

Haley, Danielle F., and Richard Saitz. 2020. “The Opioid Epidemic During the COVID-19 Pandemic.” *Journal of the American Medical Association* 324(16):1615-17. doi: 10.1001/jama.2020.18543

Hochschild, Arlie R. [1983] 2012. *The Managed Heart: Commercialization of Human Feeling*. Berkley, CA: University of California Press.

Holmes, Andrew G. 2020. “Researcher Positionality – A Consideration of Its Influence and Place in Qualitative Research – A New Researcher Guide.” *Shanlax International Journal of Education* 8(4):1-10. doi: 10.34293/education.v8i4.3232

Homans, Peter. 2000. “Introduction.” Pp. 1-40 in *Symbolic Loss: The Ambiguity of Mourning and Memory at Century’s End*, edited by P. Homans. Charlottesville, VA: The University Press of Virginia.

Izlar, Joel. 2021. “What is Mutual Aid?” *University of Georgia School of Social Work Empower E-Newsletter*. Retrieved May 21, 2022 (https://ssw.uga.edu/news/article/what-is-mutual-aid-by-joel-izlar/)

Janoff-Bulman, Ronnie. 1992. *Shattered Assumptions: Towards a New Psychology of Trauma*. New York, NY: Simon and Schuster.

Jones, Christopher M., Joseph Logan, R. Matthew Gladden, and Michele K. Bohm. 2015. “Vital Signs: Demographic and Substance Use Trends Among Heroin Users—United States, 2002–2013.” *Morbidity and Mortality Weekly Report*, 64(26):719.

Jordan, John R. 2001. “Is Suicide Bereavement Different? A Reassessment of the Literature.” *Suicide and Life-Threatening Behavior* 31(1):91-102. doi: 10.1521/suli.31.1.91.21310

Keefe, Patrick R. 2021. *Empire of Pain: The Secret History of the Sackler Dynasty.* New York, NY: Penguin Random House, LLC.

Kleinman, Arthur. 1988. *Illness Narratives: Suffering, Healing and the Human Condition*. New York, NY: Basic Books.

Kolodny, Andrew. 2020. “How FDA Failures Contributed to the Opioid Crisis.” *AMA Journal of Ethics* 22(8):743-50. doi: 10.1001/amajethics.2020.743

Kruis, Nathan E., Jaeyong Choi, and Richard H. Donohue. 2020. “Police Officers, Stigma, and the Opioid Epidemic.” *Police Science and Management* 22(4):393-406. doi: 10.1177/1461355720962524

Leslie, Douglas L., Djibril M. Ba, Edeanya Agbese, Xueyi Xing, and Guodong Liu. 2019. “The Economic Burden of the Opioid Epidemic on States: The Case of Medicaid.” *American Journal of Managed Care* 25(13):S243-49.

Li, Jiong, Dorthe H. Precht, Preben B. Mortensen, and Jørn Olsen. 2003. “Mortality in Parents After Death of a Child in Denmark: A Nationwide Follow-up Study.” *The Lancet* 361(9355):363-67. doi: 10.1016/S0140-6736(03)12387-2

Lindemann, Erich. 1944. “Symptomatology and Management of Acute Grief.” *American Journal of Psychiatry* 101(2):141-48. doi: 10.1176/ajp.101.2.141

Lindesmith, Alfred R. 1968. *Addiction & Opiates*. New York, NY: Routledge.

Link, Bruce G., and Jo C. Phelan. 2001. "Conceptualizing Stigma." *Annual Review of Sociology* 27:363-85. doi: 10.1146/annurev.soc.27.1.363

Link, Bruce G., Elmer L. Struening, Michael Rahav, Jo C. Phelan, and Larry Nuttbrock. "On Stigma and Its Consequences: Evidence from a Longitudinal Study of Men with Dual Diagnosis of Mental Illness and Substance Abuse." *Journal of Health and Social Behavior* 38(2):177-90. doi: 10.2307/2955424

Lloyd, Charlie. 2013. "The Stigmatization of Problem Drug Users: A Narrative Literature Review." *Drugs: Education, Prevention and Policy* 20(2):85-95. doi: 10.3109/09687637.2012.743506

Malterud, Kristi. 2001. "Qualitative Research; Standards, Challenges and Guidelines." *The Lancet* 358(9280):483-8. doi: 10.1016/S0140-6736(01)05627-6

Maxwell, Carol J. C. 1995. "Coping with Bereavement Through Activism: Real Grief, Imagined Death, and Pseudo-Mourning among Pro-Life Direct Activists." Ethos 23(4):437-52.

McAdams, Dan P. 2006. "The Redemptive Self: Generativity and the Stories Americans Live By." *Research in Human Development* 3(2-3):81-100. doi: 10.1080/15427609.2006.9683363

McCann, Terence V., and Dan I. Lubman. 2017. "Stigma Experience of Families Supporting an Adult Member with Substance Misuse." *International Journal of Mental Health Nursing* 27(2):693-701. doi: 10.1111/inm.12355

McCann, Terence V., and Dan I. Lubman. 2018. "Stigma Experience of Families Supporting an Adult Member with Substance Misuse." *International Journal of Mental Health Nursing* 27(2):693-701. doi: 10.1111/inm.12355

McCann Pineo, Molly, and Rebecca M. Schwartz. 2020. "Commentary on the Coronavirus Pandemic: Anticipating a Fourth Wave in the Opioid Epidemic. *Psychological Trauma: Theory, Research, Practice, and Policy* 12(S1):S108-10. doi: 10.1037/tra0000622

McDonald, Rebecca, Nancy D. Campbell, and John Strang. 2017. "Twenty Years of Take-Home Naloxone for the Prevention of Overdose Deaths from Heroin and Other Opioids—Conception and Maturation." *Drug and Alcohol Dependence*, 178:176-87. doi: 10.1016/j.drugalcdep.2017.05.001

McGreal, Chris. 2018. *American Overdose: The Opioid Tragedy in Three Acts*. New York, NY: Public Affairs.

Meier, Barry. 2018. Pain Killer: An Empire of Deceit and the Origin of America's Opioid Epidemic. New York, NY: Random House Publishing Group.

Mercer, Justine. 2007. "The Challenges of Insider Research in Educational Institutions: Wielding a Double-edged Sword and Resolving Delicate Dilemmas." *Oxford Review of Education* 33(1):1-17. doi: 10.1080/03054980601094651

Merton, Robert K. 1972. "Insiders and Outsiders: A Chapter in the Sociology of Knowledge." *American Journal of Sociology* 78(1):9-47. doi: 10.1086/225294

Moggi, Franz, Anna Giovanoli, Werner Strik, Bernice S. Moos, and Rudolf H. Moos. 2007. "Substance Use Disorder Treatment Programs in Switzerland and the USA: Program Characteristics and 1-year Outcomes." *Drug and Alcohol Dependence* 86(1):75-83. doi: 10.1016/j.drugalcdep.2006.05.017

Mohammad, Robina. 2001. "Insiders and/or Outsiders: Positionality, Theory and Praxis." Pp. 101-17 in *Qualitative Methods for Geographers: Issues and Debates*, edited by M. Limb and C. Dwyer. Oxford, England: Oxford University Press.

Monico, Laura B., and Shannon G. Mitchell. 2018. "Patient Perspectives of Transitioning from Prescription Opioids to Heroin and the Role of Route of Administration." *Substance Abuse Treatment, Prevention, and Policy* 13(1):1-8. doi: 10.1186/s13011-017-0137-y

Morone, James A. 1997. "Enemies of the People: The Moral Dimension to Public Health." *Journal of Health Politics, Policy and Law* 22(4):993-1020. doi: 10.1215/03616878-22-4-993

Murji, Karim. 1998. "The Agony and the Ecstacy: Drugs, Media, and Morality." Pp. 69-85 in *The Control of Drugs and Drug Users: Reason or Reaction?* Edited by R. Coomber. London, England: Harwood Academic Publishers.

Murphey, Jennifer, and Brenda Russell. 2020. "Police Officers' Views of Naloxone and Drug Treatment: Does Greater Overdose Response Lead to More Negativity." *Journal of Drug Issues* 50(4):455-71. doi: 10.1177/0022042620921363

Musto, David F. 1999. *The American Disease: Origins of Narcotic Control*. Oxford, England: Oxford University Press.

Musto, David F. 2002. *One Hundred Years of Heroin*. Westport, CT: Praeger.

Nieweglowski, Katherine, Patrick W. Corrigan, Tri Tyas, Anastasia Tooley, Rachel Dubke, Juana Lara, Lorenzo Washington, Janis Sayer, and Lindsay Sheehan. 2018. "Exploring the Public Stigma of Substance Use Disorder Through Community-Based Participatory Research." *Addiction Research and Theory* 26(4):323-9. doi: 10.1080/16066359.2017.1409890

Neimeyer, Robert. 2002. *Death, Loss and Personal Reconstruction*. Newbury Park, CA: Sage Publications.

Neimeyer, Robert A., and Diana C. Sands. 2011. "Meaning Reconstruction in Bereavement: From Principles to Practice." Pp. 9-22 in *Series in Death, Dying and Bereavement. Grief and Bereavement in Contemporary Society: Bridging Research and Practice*, edited by R. A. Neimeyer, D. L. Harris, H. R. Winokuer, and G. F. Thornton. Francis Group. London, England: Taylor and Francis Group.

Nowak, Rosemary A. 2015. "Parents Bereaved by Drug Related Death: A Grounded Theory Study." PhD dissertation, Department of Human Services, Capella University.

O'Donnell, Julie K., Matthew Gladden, and Puja Seth. 2017. "Trends in Death Involving Heroin and Synthetic Opioids Excluding Methadone, and Law Enforcement Drug Product Reports, by Census Region – United States, 2006-2015. *Morbidity and Mortality Weekly Report* 66(34):897-903. doi: 10.15585/mmwr.mm6634a2

Oreo, Amanda, and Salih Ozgul. 2007. "Grief Experiences of Parents Coping with an Adult Child with Problem Substance Use." *Addiction Research and Theory*, 15(1):71-83. doi: 10.1080/16066350601036169

Parker, Richard, and Peter Aggleton. 2003. "HIV and AIDs-related Stigma and Discrimination: A Conceptual Framework and Implications for Action." *Social Science and Medicine* 57(1):13-24. doi: 10.1016/s0277-9536(02)00304-0

Pescosoldio, Bernice A., and Jack K. Martin. 2015. "The Stigma Complex." *Annual Review of Sociology* 41:87-116. doi: 10.1146/annurev-soc-071312-145702

Phillips, Rachel, and Cecilia Benoit. 2013. "Exploring Stigma by Association among Front-Line Care Providers Serving Sex Workers." *Healthcare Policy* 9(SP):139-51.

Prescott, Carol, and Kenneth Kendler. 2007. Genes, Environment, and Psychopathology: Understanding the Causes of Psychiatric and Substance Use Disorders. New York, NY: Guilford Press.

Prior, Lindsay. 1989. *The Social Organisation of Death: Medical Discourse and Social Practices in Belfast.* London, England: Macmillan Press.

Quinones, Sam. 2015. *Dreamland: The True Tale of America's Opiate Epidemic*. New York, NY: Bloomsbury Publishing USA.

Quinones, Sam. 2021. The Least of Us: True Tales of America and Hope in the Time of Fentanyl and Meth. New York, NY: Bloomsbury Publishing USA.

Rando, Therese A. 1983. "An Investigation of Grief and Adaptation in Parents Whose Children Have Died from Cancer." *Journal of Pediatric Psychology* 8(1):3-20. doi: 10.1093/jpepsy/8.1.3

Rando, Therese A. 1993. *Treatment of Complicated Mourning*. Champaign, IL: Research Press.

Reinarman, Craig, and Harry Levine. *Crack in America: Demon Drug and Social Justice*. Berkley, CA: University of California Press.

Riches, Gordon, and Pam Dawson. 1996. "Communities of Feeling: The Culture of Bereaved Parents." *Mortality* 1(2):143-161. doi: 10.1080/713685832

Ritsher, Jennifer B., Poorni G. Otilingam, and Monica Grajales. 2003. "Internalized Stigma of Mental Illness: Psychometric Properties of a New Measure." *Psychiatry Research* 121(1):31-49. doi: 10.1016/j.psychres.2003.08.008

Rothman, David J. 1971. *The Discovery of the Asylum: Social Order and Disorder in the New Republic.* New York, NY: Routledge.

Rowlands, Jo. 1997. *Questioning Empowerment: Working with Women in Honduras*. Dublin, Ireland: Oxfam.

Rudd, Rose A., Len J. Paulozzi, Michael J. Bauer, Richard W. Burleson, Rick E. Carlson, Dan Dao, James W. Davis, Jennifer Dudek, Beth Ann Eichler, Jessie C. Fernandes, Anna Fondario, Barbara Gabella, Beth Hume, Theron Huntamer, Mbabzi Kariisa, Thomas W. Largo, JoAnne Miles, Ashley Newmyer, Daniella Nitcheva, Beatriz E. Perez, Scott K. Proescholdbell, Jennifer C. Sabel, Jessica Skiba, Svettla Slavova, Kathy Stone, John M. Tharp, Tracy Wendling, Dagan Wright, and Anne M. Zehner. 2014. "Increases in Heroin Overdose Deaths – 28 States, 2010 to 2012." *Morbidity and Mortality Weekly Repor*t 63(39):849-54.

Sanghera, Gurchathen S., and Suruchi Thapar-Bjorkert. 2008. "Methodological Dilemmas: Gatekeepers and Positionality in Bradford." *Ethic and Racial Studies* 31(3):543-62. doi: 10.1080/01419870701491952

Sattler, Sebastian, Farzaneh Zolala, Mohammad R. Baneshi, Javad Ghasemi, and Saber A. Googhari. 2021. "Public Stigma Toward Female and Male Opium and Heroin Users. An Experimental Test of Attribution Theory and the Familiarity Hypothesis." *Frontiers in Public Health* 9(652876):1-13. doi: 10.3389/fpubh.2021.652876

Savin-Baden, Maggi and Claire Howell Major. 2013. *Qualitative Research: The Essential Guide to Theory and Practice*. London, England: Routledge.

Schomerus, Georg, and Matthias C. Angermeyer. 2008. "Stigma and its Impact on Help-Seeking for Mental Disorders: What do we Know*?"* *Epidemiologia e Psichiatria Sociale* 17(1):31-7. doi: 10.1017/S1121189X00002669

Schwab, Reiko. 1996. "Gender Differences in Parental Grief." *Death Studies* 20(2): 103-113. doi: 10.1080/07481189608252744

Seale, Clive. 1998. *Constructing Death: The sociology of Dying and Bereavement*. Cambridge, England: Cambridge University Press.

Seale, Clive and Sjaak Van der Geest. 2004. "Good and Bad Death: Introduction." *Social Science and Medicine* 58(5):883-5. doi: 10.1016/j.socscimed.2003.10.034

Simone, Caroline. 2010. "Walking the Walk: Memorialising the Suicide Victim." Pp. 178-94 in *The Matter of Death*, edited by In J. Hockey, C. Komaromy and K. Woodthorpe. London, England: Palgrave Macmillan.

Simos, Bertha G. 1979. *A Time to Grieve: Loss as a Universal Human Experience*. Families Intl.

Smyth, Nancy J., and Kathleen A. Kost. 1998. “Exploring the Nature of the Relationship Between Poverty and Substance Abuse: Knowns and Unknowns.” *Journal of Human Behavior in the Social Environment* 1(1):67-82. doi: 10.1300/J137v01n01_05

Stout, Joshua H., and Benjamin Fleury-Steiner. Forthcoming. “DRD-Bereavement Journeys: Lessons from the Overdose Bereavement Project (OBP).” In *The Routledge International Handbook of Drug-Related Death Bereavement*, edited by M. Stroebe, K. Dyregrov, and K. Titlestad. London, England: Routledge/Taylor & Francis Group.

Strauss, Anselm, and Juliet Corbin. 1994. “Grounded Theory Methodology: An Overview.” Pp. 273-85 in *Handbook of Qualitative Research*, edited by N. K. Denzin and Y. S. Lincoln. Thousand Oaks, CA: Sage Publications, Inc.

Stroebe, Margaret S., Kari Dyregrov, and Kristine B. Titlestad. Forthcoming. *The Routledge International Handbook of Drug-Related Death Bereavement*. London, England: Routledge/Taylor & Francis Group.

Stroebe, Margaret S., Henk Schut, and Wolfgang Stroebe. 2007. “Health Outcomes of Bereavement.” The Lancet 370(9603):1960-73. doi: 10.1016/S01406736(07)61816-9

Stroebe, Wolfgang, and Margaret S. Stroebe. 1987. *Bereavement and Health: The Psychological and Physical Consequences of Partner Loss*. Boston, MA: Cambridge University Press.

Tan, Gregory T. H., Shazana Shahwan, Chong Min Janrius Goh, Wei Jie Ong, Ker-Chiah Wei, Swapna Kamal Verma, Siow Ann Chong, and Mythily Subramaniam. 2020. “Mental Illness Stigma’s Reasons and Determinants (MISReaD) Among Singapore’s Lay Public – A Qualitative Inquiry.” *BMC Psychiatry* 20(422). doi: 10.1186/s12888-020-02823-6

Taylor, Stuart. 2008. “Outside the Outsiders: Media Representations of Drug Users.” *Probation Journal* 55(4):369-87. doi: 10.1177/0264550508096493

Templeton, Lorna, Christine Valentine, Jennifer McKell, Allison Ford, Richard Velleman, Tony Walter, Gordon Hay, Linda Bauld, and Joan Hollywood. 2017. “Bereavement Following a Fatal Overdose: The Experience of Adults in England and Scotland.” *Drugs: Education, Prevention and Policy* 24(1):58-66. doi: 10.3109/09687637.2015.1127328

Titlestad, Kristine B., and Kari Dyregrov. 2022. “Does ‘Time Heal all Wounds?’ The Prevalence and Predictors of Prolonged Grief Among Drug-Death Bereaved Family Members: A Cross-Sectional Study.” *OMEGA - Journal of Death and Dying*. doi: 10.1177/00302228221098584

Titlestad, Kristine B., Sari K. Lindeman, Hans Lund, and Kari Dyregrov. 2019. “How Do Family Members Experience Drug Death Bereavement? A Systematic Review of the Literature.” *Death Studies* 45(7):508-21. doi: 10.1080/07481187.2019.1649085

Titlestad, Kristine B., Sonja Mellingen, Margaret Stroebe, and Kari Dyregrov. 2020. “Sounds of Silence. The “Special Grief” of Drug-death Bereaved Parents: A Qualitative Study.” *Addiction Research and Theory* 29(2):155-65. doi: 10.1080/16066359.2020.1751827

Toller, Paige W. 2008. “Bereaved Parents’ Negotiation of Identity Following the Death of a Child.” *Communication Studies* 59(4):306-321. doi: 10.1080/10510970802467379

Valentine, Christine. 2008. *Bereavement Narratives: Continuing Bonds in the Twenty First Century*. London, England: Routledge.

Valentine, Christine, Linda Bauld, and Tony Walter. 2016. “Bereavement Following Substance Misuse: A Disenfranchised Grief.” *OMEGA – Journal of Death and Dying* 72(4):283-301. doi: 10.1177/0030222815625174

Veilleux, Jennifer C., Peter J. Colvin, Jennifer Anderson, Catherine York, and Adrienne J. Heinz. 2010. A Review of Opioid Dependence Treatment: Pharmacological and Psychosocial Interventions to Treat Opioid Addiction. *Clinical Psychology Review*, 30(2):155-166. doi: 10.1016/j.cpr.2009.10.006

Walter, Tony. 1996. A New Model of Grief: Bereavement and Biography. *Mortality* 1(1):7-25. doi: 10.1080/713685822

Walter, Tony and Allison Ford. 2018. “Managing Stigma.” Pp. 67-89 in *Families Bereaved by Alcohol or Drugs: Research on Experiences, Coping and Support*, edited by C. Valentine. New York, NY: Routledge.

Walter, Tony, Allison Ford, Lorna Templeton, Christine Valentine, and Richard Velleman. 2015. “Compassion or Stigma? How Adults Bereaved by Alcohol or Drugs Experience Services.” *Health and Social Care* 25(6):1714-21. doi: 10.1111/hsc.12273

Weed, Frank J. 1990. “The Victim-Activist Role in the Anti-Drunk Driving Movement.” *The Sociological Quarterly* 31(3):459-473. doi: 10.1111/j.1533-8525.1990.tb00339.x

Wertheimer, Alison. 2001. A Special Scar: The Experiences of People Bereaved by Suicide. New York, NY: Routledge.

White, William L. 2007. “The New Recovery Advocacy Movement in America.” *Addiction* 102(5):696-703. doi: 10.1111/j.1360-0443.2007.01808.x

Wilson, Bill. 1939. *Alcoholics Anonymous: The Story of How More Than One Hundred Men Have Recovered From Alcoholism*. Newark, NJ: Alcoholics Anonymous World Service.

Wodak, Alex, and Annie Cooney. 2005. “Effectiveness of Sterile Needle and Syringe Programs.” *International Journal of Drug Policy* 16(1):31-44. doi: 10.1016/j.drugpo.2005.02.004

Wogen, Jenifer, and Maria T. Restrepo. 2020. “Human Rights, Stigma, and Substance Use.” *Health and Human Rights Journal* 22(1):51-60.

Wright, Clare, and Adrian Coyle. 1996. “Experiences of AIDS-related Bereavement in Gay Men: Implications for Care.” *Morality* 1(3):267-282. doi: 10.1080/13576279609696248

Yang, Lawrence, Liang Y. Wong, Marguax M. Grivel, and Deborah S. Hasin. 2017. “Stigma and Substance Use Disorders: An International Phenomenon.” *Current Opinion in Psychiatry* 30(5):378-88. doi: 10.1097/YCO.0000000000000351

Young, Ilanit T., Alana Iglewicz, Danielle Glorioso, Nicole Lanouette, Kathryn Seay, Manjusha Ilapakurti, and Sidney Zisook. 2012. “Suicide Bereavement and Complicated Grief.” *Dialogues in Clinical Neuroscience* 14(2):177-86. doi: 10.31887/DCNS.2012.14.2/iyoung

Young, Jock. 1971. “The Role of the Police as Amplifiers of Deviance, Negotiators of Reality and Translators of Fantasy: Some Consequences of our Present Day System of Drug Control as seen in Notting Hill.” Pp. 27-61 in *Images of Deviance*, edited by S. Cohen. Middlesex, England: Pelican.

Appendix A

OVERDOSE BEREAVEMENT PROJECT (OBP): OPEN-ENDED INTERVIEW QUESTIONS

1. Tell me about [name]. What were they like?

2. How did you first become aware of [name] substance abuse?

3. Were you able to get them into treatment?

    a. If so, what challenges did [name] experience in treatment?
    b. If not, why did [name] not receive treatment?

Events leading up to death

4. Tell me in as much chronological detail as possible the events that occurred leading up to [name] overdose?

    a. Prior Year
    b. Prior Month
    c. Prior Week
    d. Day of the Overdose

These questions focus on how your were treated by the police and other emergency responders at the time of the overdose

5. Tell me about how you were you treated by the police and other emergency personnel (e.g., EMTs, Emergency Room Nurses, Emergency Room Doctors) at the time of the death? Specific examples?

6. Tell me about how you were treated by police during any subsequent investigation. Specific examples?

For these questions I will ask you to elaborate on some of your answers from the closed-ended questions.

7. Do you think could have been done to prevent [name] overdose? Specific Examples?

8. Talking about your loss with other people: Difficult or Easy? Specific Examples?

9. People's reactions when they learn that [name] passed away due to an overdose: Positive or Negative? Specific Examples?

Impacts of the loss on you

10. Tell me about your financial situation presently

11. Tell me about your physical and mental health presently

12. Tell me about your job or work situation presently

13. If applicable, tell me about your consumption of alcohol changed since your loss

14. If applicable, tell me about your consumption of drugs

These questions focus on support and healing

15. If applicable, tell me about your experiences with formal support groups

16. If applicable, tell me about your experiences with any other forms of support

Memorialization

17. If applicable, tell me about any services that were held to celebrate [name] life

18. Tell me about any memories of [name] that bring you a sense of peace or closure

19. If applicable, tell me somewhere that you visit, or something that you do, to feel close to [name]

20. If applicable, tell me about the significance of any of [name] belongings you held on to

21. If applicable, tell me about the significance of any other ways you memorialize [name], such as jewelry or body art

Advice to Others in a Similar Situation

22. While it may be hard to imagine, what has your loved one's death taught you that you can pass onto to others? What would you suggest be done to prevent other

families from experiencing such a loss? What do families like you need and how can local agencies help?

Final Questions

23. Finally, I'd like to get an idea about why you decided to participate in the study. What were the reasons that you agreed to take part in the study?

24. Thank you for answering all of these questions. Is there anything else you'd like to mention or talk about right now?

25. Do you have any questions for me?

Appendix B

OVERDOSE BEREAVEMENT PROJECT (OBP): SURVEY INSTRUMENT

University of Delaware
Center for Drug & Health Studies (CDHS)

Overdose Bereavement Project (OBP)

Survey Instrument

Date:_____

1. How are you related to your deceased loved one or friend?
(1) Parent
(2) Spouse
(3) Sibling
(4) Step Parent/Step Sibling
(5) Aunt/Uncle
(6) Cousin
(7) Fiancé
(8) Niece/Nephew
(9) Girlfriend/Boyfriend
(10) Close Friend
(11) Other

2. To which gender do you most identify?
(1) Male
(2) Female
(3) Transgender Female
(4) Transgender Male
(5) Gender Variant/Non-Conforming
(6) Not Listed: specify here:
(7) Prefer not to answer

3. How old are you now?
(1) 35 or younger
(2) 36-45 years old
(3) 46-55 years old
(4) 56-65 years old
(5) 66 or older

4. Present employment status?
(1) working full time
(2) working part time
(3) unemployed, laid off, looking for work
(4) retired
(5) in school
(6) keeping house
(7) Other: Specify other here:

5. What is (was) your principal occupation?

Specify here: _____

(1) Managerial/ professional worker
(2) Technical/ sales/ administrative support
(3) Clerical
(4) Craftsperson
(5) service or laborer
(6) Retired
(7) Other: Specify other here:

6. Amount of schooling completed?

(1) less than high school
(2) high school graduate or equivalent
(3) some college, community college grad or finished technical training program
(4) four year college degree holder
(5) Masters, Doctoral and/or professional school degree holder

7. Annual Household Income [Before Retirement]?

(1) Less than $20,000
(2) Between $20,001 and $40,000
(3) Between $40,001 and $60,000
(4) Between $60,001 and $90,000
(5) Between $90,001 and $120,000
(6) Over $120,001

8. What is your religious preference?

(1) Protestant: If Protestant, specify denomination here:
(2) Catholic
(3) Jewish
(4) Other: If other, specify religion here:

9. Frequency of your attendance at religious services or events during last 12 months?

(0) never
(1) about once or twice a year or less
(2) Several times a year
(3) about once a month
(4) 2-3 times a month
(5) every week
(6) several times a week

10. Marital Status
(1) Married
(2) Divorced
(3) Separated
(4) Never married
(5) Widowed (If Widowed, how many years since your spouse died? _____ years)

11. How would you describe your political attitudes?
(1) Very liberal
(2) Slightly liberal
(3) Moderate, middle of the road
(4) Slightly conservative
(5) Very conservative

12. Which political party do you usually support?
(1) Strong Republican
(2) Not very strong Republican
(3) Independent
(4) Not very strong Democratic
(5) Strong Democrat
(6) Other

13. How did you vote in the last US presidential election?
(1) Did not vote
(2) Voted for Trump
(3) Voted for Clinton
(4) Voted for Stein or other candidate

14. Number of times you moved in the last five years:
(0) None
(1) One
(2) Two
(3) Three
(4) Four or more

15. Were you born in the US.
(1) yes
(2) no
If you were born outside the US, which is your country of birth:

_____

***This is probably the hardest part of the survey: The loss of your loved one or close friend**

16. How old was he/she at the time of death? _____years old

17. To which gender did your loved one or friend most identify?
(1) Male
(2) Female
(3) Transgender Female
(4) Transgender Male
(5) Gender Variant/Non-Conforming
(6) Not Listed: specify here:
(7) Prefer not to answer

18. How long has it been since the death?

Number of years _____ Number of months _____

19. Did you witness the overdose before your loved one or friend died?
(1) yes
(2) no

20. Did you find the body or were you present when the body was discovered?
(1) yes
(2) no

21. Did you see the deceased's body before it was buried or cremated?
(1) yes
(2) no

22. Initially, how surprised were you at the death?
(1) Not at all surprised
(2) Only slightly surprised; I had been worried they might overdose
(3) Somewhat surprised
(4) Very surprised, though not entirely unexpected
(5) Extremely surprised; it could not have been more unexpected

23. Had your loved one or friend suffered an overdose before?
(1) no
(2) yes, once before
(3) yes, two times before
(4) more than two times before

24. How would you describe your relationship *immediately prior* to their death?

(1) extremely negative
(2) somewhat negative
(3) unclear or uncertain
(4) somewhat positive
(5) extremely positive

Survey Continues on Next Page

The following questions ask about difficult experiences you have had as result of the death DURING THE PAST SEVEN DAYS

		Not at all	A little bit	Moderately	Quite Often	Very Often
25.	Any reminder of the death brought back difficult feelings about it.	1	2	3	4	5
26.	I had trouble staying asleep.	1	2	3	4	5
27.	I felt irritable and angry.	1	2	3	4	5
28.	Got upset when I thought about or was reminded of the death.	1	2	3	4	5
29.	I thought about it when I didn't mean to.	1	2	3	4	5
30.	I felt as if it hadn't happened or wasn't real.	1	2	3	4	5
31.	I stayed away from reminders of it.	1	2	3	4	5
32.	Pictures about it popped into my mind.	1	2	3	4	5
33.	I was jumpy and easily startled.	1	2	3	4	5
34.	I tried not to think about it.	1	2	3	4	5
35.	I denied my feelings by distracting myself	1	2	3	4	5
36.	My feelings about it were kind of numb.	1	2	3	4	5
37.	I found myself acting or feeling like I was back at that time.	1	2	3	4	5
38.	I had trouble falling asleep.	1	2	3	4	5
39.	I had waves of strong feelings about it.	1	2	3	4	5
40.	I tried to remove it from my memory.	1	2	3	4	5
41.	I had trouble concentrating.	1	2	3	4	5

42.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	1	2	3	4	5
43.	I had dreams about it.	1	2	3	4	5
		Not at all	A little bit	Moderately	Quite Often	Very Often
44.	I felt watchful and on-guard.	1	2	3	4	5
45.	I tried not to talk about it	1	2	3	4	5

The following questions focus on your experiences with grief since the death OVER THE PAST MONTH

46. In the past month, how often have you felt yourself longing and yearning for your loved one or friend?
(1) Almost never (less than once a month)
(2) Rarely (2-6 times a month)
(3) Sometimes (more than 7 times a month, but not every day)
(4) Every day
(5) Several times every day

47. In the past month, has the yearning been distressing to your daily routine?
(1) Almost never (less than once a month)
(2) Rarely (2-6 times a month)
(3) Sometimes (more than 7 times a month, but not every day)
(4) Every day
(5) Several times every day

48. In the past month, to what extent have you had difficulty accepting the death?
(1) No difficulty accepting the death
(2) A slight sense of difficulty accepting the death
(3) Some difficulty accepting the death
(4) A marked sense of difficulty accepting the death
(5) Extreme difficulty accepting the death

49. In the past month, to what extent have you had difficulty trusting people?
(1) No difficulty trusting others
(2) A slight sense of difficulty trusting others
(3) Some difficulty trusting others
(4) A marked sense of difficulty trusting others
(5) Extreme difficulty trusting others

50. In the past month, to what extent have you felt bitter over your loved one's or friend's death?
(1) No sense of bitterness
(2) A slight sense of bitterness
(3) Some sense of bitterness
(4) A marked sense of bitterness
(5) An extreme sense of bitterness

51. Sometimes people who lose a loved one or someone close to them feel uneasy about moving on with their life. In the past month, to what extent do you feel that moving on (for example, making new friends, pursuing new interests) would be difficult for you?
(1) Moving on would not be difficult
(2) Moving on would be a little difficult
(3) Moving on would be somewhat difficult
(4) Moving on would be very difficult
(5) Moving on would be extremely difficult

52. In the past month, to what extent have you felt emotionally numb or had difficulty connecting with others?
(1) No sense of numbness
(2) A slight sense of numbness
(3) Some sense of numbness
(4) A marked sense of numbness
(5) An extreme sense of numbness

53. In the past month, to what extent do you feel that life is empty or meaningless without your loved one or friend?
(1) No sense of meaningless
(2) A slight sense of meaningless
(3) Some sense of emptiness
(4) A marked sense of emptiness
(5) An extreme sense of emptiness

54. In the past month, to what extent do you feel that the future holds no meaning or purpose without your loved one or friend?
(1) Not at all
(2) A slight sense that the future holds no purpose
(3) Some sense that the future holds no purpose
(4) A marked sense that the future holds no purpose
(5) An extreme sense that the future holds no purpose

55. In the past month, to what extent have you felt on edge, jumpy, or easily startled?
(1) No feelings of being on edge
(2) A slight sense of feeling on edge
(3) Some sense of feeling on edge
(4) A marked sense of feeling on edge
(5) An extreme sense of feeling on edge

56. Has your grief resulted in impairment in your social, occupational, or other areas of functioning? For instance, does your grief make it difficult for you to perform normal daily activities?
(1) No difficulty performing normal daily activities
(2) A slight sense of difficulty performing normal daily activities
(3) Some sense of difficulty performing normal daily activities
(4) Marked difficulty performing normal daily activities
(5) Extreme difficulty performing normal daily activities

57. How many of the above symptoms (questions 46-56) <u>have</u> you experienced that have lasted six months or more?
(0) None
(1) One symptom has lasted six months or more
(2) Two symptoms have lasted six months or more
(3) Three symptoms have lasted six months or more
(4) Four or more symptoms have lasted six months or more

Survey Continues on Next Page

The symptoms described in Questions 46-56 may indicate a difficult adjustment to the death of someone close. In some instances, a mental health professional may diagnose such difficulty as a mental health condition known as "Complicated Grief."

58. If you were diagnosed with "Complicated Grief "would you take that to mean you were going crazy?
(1) yes
(2) no
(3) unsure

59. Considering your current level of grief-related distress, would you feel better knowing you were diagnosed with a mental health condition?
(1) Not at all better knowing you were diagnosed with a mental health condition
(2) Only slightly better knowing you were diagnosed with a mental health condition
(3) Somewhat better knowing you were diagnosed with a mental health condition
(4) Better knowing you were diagnosed with a mental health condition
(5) Much better knowing you were diagnosed with a mental health condition

60. Considering your current level of grief-related distress, would you consider receiving talk therapy conducted by a mental health professional?
(1) Would not consider talk therapy conducted by a mental health professional
(2) Unlikely to consider talk therapy conducted by a mental health professional
(3) Would possibly consider talk therapy conducted by a mental health professional
(4) Would consider talk therapy conducted by a mental health professional
(5) Would strongly consider talk therapy conducted by a mental health professional

61. Considering your current level of grief-related distress, would you consider taking medications prescribed by a mental health professional?
(1) Would not consider taking medications prescribed by a mental health professional
(2) Unlikely to consider taking medications prescribed by a mental health professional
(3) Would possibly consider taking medications prescribed by a mental health professional
(4) Would consider taking medications prescribed by a mental health professional
(5) Would strongly consider taking medications prescribed by a mental health professional

62. If you were diagnosed with a mental health condition, would you be relieved to know you were not going crazy?

(1) Not at all relieved to know you were not going crazy
(2) Only slightly relieved to know you were not going crazy
(3) Slightly relieved to know you were not going crazy
(4) Relieved to know you were not going crazy
(5) Very relieved to know you were not going crazy

63. If you were diagnosed with a mental health condition, would you be relieved to know you had a recognizable problem?

(1) Not at all relieved to know you had a recognizable problem
(2) Only slightly relieved to know you had a recognizable problem
(3) Slightly relieved to know you had a recognizable problem
(4) Relieved to know you had a recognizable problem
(5) Very relieved to know you had a recognizable problem

The following questions ask about your experiences with family and friends. The first group of questions asks about how people have treated you in the past because of the death of your or friend one. The second group of questions asks about how you think people will treat you in the present because of the death of your loved one or friend. The final group of questions asks about how you think people will treat you in the future because of the death of your loved one or friend.

How often have people treated you this way in the <u>past</u> because of the death of your one or friend?

Please circle your response.

		Never	Not often	Somewhat often	Often	Very Often
64.	Family members/friends have thought that I cannot be trusted.	1	2	3	4	5
65.	Family members/friends have looked down on me.	1	2	3	4	5
66.	Family members/friends have treated me differently.	1	2	3	4	5
67.	Medical professionals have not listened to my concerns.	1	2	3	4	5
68.	Medical professionals have given me poor care.	1	2	3	4	5

How often have people treated you this way in the present because of the death of your loved one or friend?

Please circle your response.

		Never	Not often	Somewhat often	Often	Very Often
69.	Family members/friends have thought that I cannot be trusted.	1	2	3	4	5
70.	Family members/friends have looked down on me.	1	2	3	4	5
71.	Family members/friends have treated me differently.	1	2	3	4	5
72.	Medical professionals have not listened to my concerns.	1	2	3	4	5
73.	Medical professionals have given me poor care.	1	2	3	4	5

How often do you believe people will treat you this way in the future because of the death of your loved one or friend?

Please circle your response.

		Never	Not often	Somewhat often	Often	Very Often
74.	Family members/friends have thought that I cannot be trusted.	1	2	3	4	5
75.	Family members/friends have looked down on me.	1	2	3	4	5
76.	Family members/friends have treated me differently.	1	2	3	4	5
77.	Medical professionals have not listened to my concerns.	1	2	3	4	5
78.	Medical professionals have given me poor care.	1	2	3	4	5

Survey Continues on Next Page

The next questions ask you to consider your own alcohol and drug use, mental, and physical health

79. How many alcoholic beverages on average do you consume?
(1) never/do not drink
(2) a few times during the year
(3) about once a month or several times a month
(4) usually 1 or 2 days a week
(5) almost daily or 3 to 6 days a week
(6) daily

80. How many days do you have five or more drinks?
(1) never/do not drink
(2) a few times during the year
(3) about once a month or several times a month
(4) usually 1 or 2 days a week
(5) almost daily or 3 to 6 days a week
(6) daily

81. During the past year how many times did you get drunk or very high on alcohol?
(1) never/do not drink
(2) a few times during the year
(3) about once a month or several times a month
(4) usually 1 or 2 days a week
(5) almost daily or 3 to 6 days a week
(6) daily

82. During the past year how often did you take any drugs or medications in a way not prescribed by a doctor?
(1) never/do not take any drug or medications in a way not prescribed by a doctor
(2) a few times during the year
(3) about once a month or several times a month
(4) usually 1 or 2 days a week
(5) almost daily or 3 to 6 days a week
(6) daily

83. Since your loss has your consumption of alcohol increased?
(1) Do not drink
(2) No increase in alcohol consumption
(3) Increased alcohol consumption
(4) Extreme increase in alcohol consumption

If your alcohol consumption has increased, briefly describe how:

84. Since your loss have you misused drugs or medications in a way not prescribed by a doctor increased?

(1) Do not misuse drugs or medications
(2) No increase in misuse of drugs or medications
(3) Increased misuse of drugs or medications
(4) Extreme misuse of drugs or medications

If you misuse drugs or medications since your loss, briefly describe how:

85. Since your loss how has your mental health declined?

(1) No decline in my mental health
(2) Only slight decline in my mental health
(3) Moderate decline in my mental health
(4) Strong decline in my mental health

If your mental health has declined, briefly describe how:

86. Since your loss how has your physical health declined?

(1) No decline in my physical health
(2) Only slight decline in my physical health
(3) Moderate decline in my physical health
(4) Strong decline in my physical health

If your physical health has declined, briefly describe how:

The next questions focus on your financial status (e.g., debts, ability to pay hospital bills, etc.) and employment status since the loss of your loved one or friend

87. Has your loss negatively impacted your financial status?

(1) Not at all
(2) Only slight negative impact
(3) Somewhat negative impact
(4) Strong negative impact

If your financial status is negatively impacted, briefly describe how:

88. Has your loss negatively impacted your employment status?
(1) Not at all
(2) Only slight negative impact
(3) Somewhat negative impact
(4) Strong negative impact

If your employment status is negatively impacted, briefly describe how:

Survey Continues on Next Page

The next questions focus on ways you might remember your loved one or friend

89. Did you hold a formal service (funeral, celebration of life, memorial service)?
1) yes
2) no

90. Did the service(s) bring you a sense of peace or closure?
1) No sense of peace or closure
2) A slight sense of peace or closure
3) A moderate sense of peace or closure
4) A strong sense of peace or closure
5) No service was held

91. Does visiting your loved one's or friend's grave bring you a sense of peace or closure?
1) No sense of peace or closure
2) A slight sense of peace or closure
3) Some sense of peace or closure
4) A strong sense of peace or closure
5) No grave, the body was cremated

If the body of your loved one or friend was cremated was there a memorial, ceremony to disperse the ashes, etc.? Please briefly describe here:

92. Does visiting memorable places other than the cemetery bring you a sense of peace or closure?
1) No sense of peace or closure
2) A slight sense of peace or closure
3) Some sense of peace or closure
4) A strong sense of peace or closure

93. Do photos of your loved one or friend bring you a sense of peace or closure?
1) No sense of peace or closure
2) A slight sense of peace or closure
3) Some sense of peace or closure
4) A strong sense of peace or closure

94. Does your one's or friend's jewelry or other items (wristwatch, clothing, etc.) help bring you a sense of peace or closure?
1) No sense of peace or closure
2) A slight sense of peace or closure
3) Some sense of peace or closure

4) A strong sense of peace or closure

95. Are there other ways you bring yourself a sense of peace or closure?
1) yes
2) no

If so, briefly describe here:

In the next section we would like to know if any of the personality changes mentioned below apply to you. Considering the thoughts you might have had since your loved one or friend died, circle the numbers below for each statement that best describes the way you have been feeling DURING THE PAST TWO WEEKS INCLUDING TODAY

		Does not Describe me at all	Slightly describes me	Moderately describes me	Describes me	Strongly describes me
96.	I have learned to cope better with life.	1	2	3	4	5
97.	I feel as though I am a better person.	1	2	3	4	5
98.	I have a better outlook on life	1	2	3	4	5
99.	I have more compassion for others	1	2	3	4	5
100.	I care more deeply for others.	1	2	3	4	5
101.	I am stronger because of the grief I have experienced.	1	2	3	4	5
102.	I am a more forgiving person.	1	2	3	4	5

These questions focus on help you have sought for your grief

103. How many times have you attended a support group since your loss?
(0) Never attended a support group
(1) Once
(2) 2-5 times
(3) 6-20 times
(4) 21-50 times
(5) 51 or more times

104. On a scale of 1 to 5 how would you rate your experience in a support group?
(0) Never attended a support group
(1) Not at all helpful
(2) slightly helpful
(3) modestly helpful
(4) helpful
(5) Very Helpful

People attending support groups mention various benefits from participation. Please rate the importance of each of the benefits below in terms of their importance in helping you with your grief.

		Not Important	Slightly Important	Important	Very Important	Most Important	Never Attended
105.	Friendship	1	2	3	4	5	6
106.	Sharing information and experiences	1	2	3	4	5	6
107.	Having a sounding board to develop new skills	1	2	3	4	5	6
108.	A place for discussing tabooed topics	1	2	3	4	5	6
109.	Being among people like myself	1	2	3	4	5	6
110.	Helping myself to deal better with my loss	1	2	3	4	5	6
111.	Helping others to deal better with their losses	1	2	3	4	5	6
112.	Spiritual benefits	1	2	3	4	5	6
113.	Banding together with others to promote positive mental health	1	2	3	4	5	6
114.	Getting help from the group facilitator	1	2	3	4	5	6
115.	Other, specify:	1	2	3	4	5	6

Survey Continues on Next Page

People experiencing grief also describe other sources of help and support. Please rate the importance of each of these other sources of help and support in terms of their importance in helping you with your grief.

		Not Important	Slightly Important	Important	Very Important	Most Important
116.	Other members of your family	1	2	3	4	5
117.	Relatives (e.g., aunts, uncles, cousins)	1	2	3	4	5
118.	Non-Related Friends	1	2	3	4	5
119.	Members of the clergy	1	2	3	4	5
120.	Professional bereavement counselor	1	2	3	4	5
121.	Psychiatrist, psychologist, social worker or psychiatric nurse	1	2	3	4	5
122.	Spiritualist or Psychic	1	2	3	4	5
123.	Other, specify:	1	2	3	4	5

Thank You for Completing the Close-Ended Questions Portion of the Survey!

Appendix C

IRB APPROVAL

Institutional Review Board
210H Hullihen Hall
Newark, DE 19716
Phone: 302-831-2137
Fax: 302-831-2828

DATE:	May 9, 2022
TO:	Benjamin Fleury-Steiner, PhD
FROM:	University of Delaware IRB
STUDY TITLE:	[1222857-10] The Experiences of Drug Overdose-Death-Bereaved Parents in Delaware: A Pilot Study
SUBMISSION TYPE:	Continuing Review/Progress Report
ACTION:	APPROVED FOR DATA ANALYSIS ONLY
APPROVAL DATE:	May 9, 2022
EXPIRATION DATE:	May 3, 2023
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # *(6,7)*

Thank you for your Continuing Review/Progress Report submission to the University of Delaware Institutional Review Board (UD IRB). The UD IRB has reviewed and APPROVED the proposed research and submitted documents via Expedited Review in compliance with the pertinent federal regulations.

As the Principal Investigator for this study, you are responsible for and agree that:

- All research must be conducted in accordance with the protocol and all other study forms as approved in this submission. Any revisions to the approved study procedures or documents must be reviewed and approved by the IRB prior to their implementation. Please use the UD amendment form to request the review of any changes to approved study procedures or documents.
- Informed consent is a process that must allow prospective participants sufficient opportunity to discuss and consider whether to participate. IRB-approved and stamped consent documents must be used when enrolling participants and a written copy shall be given to the person signing the informed consent form.
- Unanticipated problems, serious adverse events involving risk to participants, and all non-compliance issues must be reported to this office in a timely fashion according with the UD requirements for reportable events. All sponsor reporting requirements must also be followed.

Oversight of this study by the UD IRB REQUIRES the submission of a CONTINUING REVIEW seeking the renewal of this IRB approval, which will expire on May 3, 2023. A continuing review/progress report form and up-to-date copies of the protocol form and all other approved study materials must be submitted to the UD IRB at least 45 days prior to the expiration date to allow for the required IRB review of that report.

If you have any questions, please contact the UD IRB Office at (302) 831-2137 or via email at hsrb-research@udel.edu. Please include the study title and reference number in all correspondence with this office.

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Appendix D

THOSE LEFT BEHIND AND THEIR LOVED ONE

Survivors Name	*Relationship to Loved One*	*Help-Seeking*					
		Counseling	*Advocacy*	*AA/NA*	*Nar/Al-Anon*	*Religion*	*Support Groups*
Nancy	Mother of Noah	-	1 - MAA*	-	-	-	-
Clyde	Father of Noah	-	1 - MAA	-	-	-	-
Will	Brother of Seth	-	2 - MAA	1	-	-	-
Kelsey	Mother of Ryan	-	1 - MAA	-	2	-	-
Nicholas	Father of Ryan	-	1 - MAA	-	2	-	-
Trinity	Sister of Ryan	-	2 - MAA	-	1	-	-
Claire	Roommate of Erica	2	-	1	-	-	-
Maggie	Coworker/Friend of Erica	-	-	-	-	-	-
Jeremy	Boyfriend of Hailey	-	-	1	-	-	-
Rose	Fiancé of Mel	-	-	-	-	-	-
Eric	Father of Gavin	-	1 - MMA	-	-	-	-
Susan	Stepmother of Gavin	-	1 - MMA	-	-	-	-
Terry	Brother of Gavin	1	-	-	-	-	-
Penelope	Mother of Nolan	-	2 - MMA	-	-	1	3
Patrick	Father of Nolan	-	2 - MMA	-	-	1	3
Jennifer	Mother of Eugene	2	-	1	-	-	-
Jan	Mother of Earl	3	2 - MAA	-	-	-	1
Carter	Nephew of Latisha	-	-	1	-	-	-
Chuck	Fiancé of Lexi	-	-	2	-	1	-
Ingrid	Fiancé of Chester	1	-	-	-	-	-
Mary	Mother of Chester	-	-	-	-	-	-
Audrey	Wife of Ryan	-	-	-	-	1	2
Sally	Girlfriend of Morgan	-	-	1	-	2	-
Grace	Cousin of Tim	1	-	-	-	-	-
Karen	Mother of Laura	-	1	-	-	-	-

Harry	Brother of Laura	-	-	-	-	-	-
Samuel	Stepfather of Laura	1	-	-	-	-	-
Sarah	Mother of Marshall	3	-	1	-	-	2
Amy	Grandmother of Marshall	-	-	-	-	-	-
Ruby	Mother of Jasmine	4	1	-	2	-	3
Kathleen	Mother of Tanner	-	1 - Hug From Tanner	-	-	-	2
Chloe	Mother of Eustice	3	2 - MAA	-	-	-	1
Fran	Sister of Doug	-	1 - Multiple	-	-	-	-
Brittany	Mother of Alex	-	-	-	2	-	1
Sean	Father of Alex	-	-	-	2	-	1

1 = Primary; 2 = Secondary; 3 = Tertiary; 4 = Quaternary
* = Mid-Atlantic Advocacy