INFORMATION SEEKING BY SURVIVORS OF SUICIDE:

WHAT DID THEY KNOW, WHEN DID THEY KNOW IT, HOW DID THEY FIND

IT, AND WAS IT HELPFUL?

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ABSTRACT

Survivors of suicide are individuals who have lost someone close to them by suicide. This study explored survivors' experiences in seeking and being given information about suicide both before and after their loss. The purpose was to examine the ways in which survivors came into contact with this information and whether it had been helpful in coping with their loss. The goal was to comment on ways to improve the quality and accessibility of this information. Twenty-three survivors were interviewed. Each participant completed the Ways of Coping questionnaire and a series of questions regarding their attitudes towards suicide before and after their loss as well as their experience of seeking information before and after the loss. Demographic information was obtained about both the participant and the individual who had died by suicide. Participants were also questioned about their knowledge of the individual's mental health treatment. Results suggested participants' attitudes towards suicide shifted after the suicide to understanding suicide as a result of mental illness rather than psychosocial stress or weakness and a decreased belief that suicide could be prevented. Most of the participants did not seek or report having been given information about suicide prior to their loss. This was a surprising finding given that all of the individuals who suicided had been in some form of mental health treatment and over half had made prior attempts. Participants had, however, sought or been given information about related subjects, including mental illness. Most participants did seek or were given information within a month of their loss. Their efforts were sometimes hampered since many referral and information sources were unfamiliar with the concept of "survivor of suicide." Participants stated the information, including having met with another survivor, was

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helpful in finding a shared experience, understanding mental illness, normalizing feelings after loss, and coping with guilt and stigma. Issues related to survivor research, suggestions for clinical practice and training, and areas for future research are discussed.

DEDICATION

I would trade this dissertation and my degree to have my friend Kim Barter back. Her perseverance and ability to find joy in the midst of despair inspired me to return to school and eventually led to this study.

This study would not have been possible without the help of others who have unfortunately also lost loved ones to suicide. My participants gave of themselves and took a huge risk that I would understand them. I hope I have lived up to that hope.

Without the support of my first dissertation chair, John Kalafat, this study would not have been proposed, much less completed. His untimely death was a great loss to his friends and family, to the field of suicidology, and to those of us who were privileged to have worked and studied with him.

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The "it takes a village to raise a child" idea is certainly applicable to raising a graduate student. My professors, supervisors, peers, friends and family have provided years (many years) of support and encouragement, without which I might be unsuccessfully seeking employment as a stand-up comedian, my second choice in the "what do I want to be now" decision that I faced after Kim died.

Kina Leitner, my advisor at New York University, never once hesitated in her support of my applying to graduate school, even though the odds were clearly against me given my age and inability to apply to schools outside of the New York/New Jersey area. The same can be said of my therapist, Aviva Rohde, who in the best self-psychological tradition, repeatedly stated that she looked forward to the day I would be a colleague.

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suggested by John as someone "interested in suicide," provided support, encouragement, and contributed significantly to the proposal. Lew Gantwerk graciously (under some duress from Lucy Takagi) stepped in as my new chair after John's death and managed to convince me that I could finish—and then saw to it that I did. Brenna Bry also joined the committee, offering a fresh perspective to the work as well as making helpful proofreading and editing suggestions.

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My peers (and peeps) at NYU, GSAPP, my practicum sites, Intensive Family Support Services, my internship site, and my current job are too numerous to mention by name. Arthur Copertino and Rich Poploff were "adult" students with me at NYU who rarely felt the need to act as adults. Lucy Takagi, Nancy Coba, and Martha Temple joined me in trying to act like adults since we were now the therapists, which proved hard to do since we regularly regressed in each other's company. Claudia Guevara, Mary Commisso, Jennifer Lefort, Jennifer Caruso, Jill Donelan (now Deary), and Rachel Duzant kept me going through internship and into my current position—thanks, peeps!

My family and my "adopted" family are relieved that I am writing this acknowledgement since that means I might finally be done with school and they can stop asking when they can call me doctor and when I am moving home. It has been, as of this writing, 15 years since Kim died. For their support during this time, I am grateful beyond words. Unfortunately, I now have to tell them how long it will take to get my license.

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CHAPTER 1

INTRODUCTION

But where does one find help? Is it through friends, through counseling, through God? Can a support group help? Is it helpful to speak with other survivors, allowing them to give hope by their very existence? Can I find answers in books as to why this happened? Is there research in libraries which will help me? Can a minister or rabbi even begin to comprehend my agony? What about my family? Are they in so much personal pain that they are unable to help me with mine? What is my responsibility to help myself? The search feels endless. It is not.

Iris Bolton, Our Son Mitch, In Suicide and its Aftermath, 1987

A survivor of suicide is, like the mother speaking about the loss of her son in the quote above, someone who has lost a loved one to suicide. It has been suggested that another term should be used to avoid confusing those left behind with those who have survived suicide attempts (Seager, 2004). The counter-argument is that only another individual can "survive" the suicide (Andriessen, 2004). Since the term has been in use for over 30 years, this study will continue to use it.

This study seeks to explore survivors' experiences in seeking information about suicide both before and after their loss. The purpose of this research is to examine the ways in which individuals who have lost a family member or friend to suicide came into contact with information about suicide and whether that information has been helpful. The goal is to help improve the quality and accessibility of this information. Given the extensive research and knowledge about suicide and the people who attempt and complete suicide, it is somewhat surprising to discover that relatively little is known about the effects of those suicides on family and friends outside of anecdotal and first-person accounts. The field is still somewhat dominated by works written by survivors that often include some historical or religious explanations of why suicide has been shunned as a segue to why survivors often experience difficulty in being open about their experiences. (Colt, 1991; Robinson, 1989; Stimming & Stimming, 1999; Wertheimer, 1991).

The first major academic work on the subject, edited by Cain, *Survivors of Suicide*, was published in 1972. The next major work, edited by Dunne, McIntosh, and Dunne-Maxim, *Suicide and its Aftermath: Understanding and Counseling the Survivors*, was not published until 1987. McIntosh (1996) has published two bibliographies on survivors of suicide; in the more recent, covering the years 1986-1995, he stated that "the primary outcomes of the present literature on survivors of suicide have been to raise awareness of this often ignored suicidological issue and assist in the establishment and proliferation of therapy and support groups" (p. 148). What both sets of literature—the academic and the general—have in common is a consistent refrain that there is a great need for further research in this area.

Survivor issues are beginning to get the attention they deserve, mostly at the urging of survivors. A conference was held in May of 2003 on survivor issues, sponsored by the National Institute for Mental Health (NIMH), the National Institute of Health Office of Rare Diseases (NIH), and the American Foundation for Suicide Prevention (AFSP). The goal of the conference was to present current understanding of survivors and their issues and to discuss what research needs to be done. With an estimated 30,000 suicides per year in the United States, a number that has varied only slightly over the past 50 years (Liu, 2009) and with estimates ranging from 6 to 28 survivors for each suicide, the survivor population is significant enough to warrant such attention. The AFSP and NIMH released a brief summary of the findings and proposed a research agenda that included six main areas that need further study: defining and identifying survivors of suicide; individual vulnerability to distress after suicide; impact of suicide on family functioning and suicide risk; interventions for survivors of suicide; special populations, and research strategies (AFSP, 2004).

The lack of research on the survivor population is in some ways particularly odd since it has long been clinical lore and is now a well-established fact that the survivor population is at higher risk for suicidal ideation, suicide attempts, and completed suicides, for multiple and over-determined reasons, including a potential genetic predisposition to illnesses such as depression and the modeling of suicidal behaviors among the family (Cain, 1972; Jamison, 1999; Lizardi et al., 2009). This fact prompted Shneidman to call for "postvention," defined as "working with survivor victims of a committed suicide to help them with their anguish, guilt, anger, shame and perplexity" (1969, as quoted in Cain, 1972, p. ix). Much of the research on the survivor population has focused on an area of postvention, such as assessing problems related to grieving (including issues of stigma and lack of social support) or highlighting issues specific to a particular relationship (e.g., parent-child). The concept of "active postvention" has been promulgated by Campbell, among others, in an attempt to reach out to survivors at the time of their loss rather than waiting for them to seek services on their own (Campbell, 1997; Campbell, Cataldie, McIntosh, & Millet, 2004; Cerel & Campbell, 2008). Kaslow, Ivey, Berry-Mitchell, and Franklin (2009) developed a "culturally informed postvention model" for the African American community, a particularly underserved survivor group due not only to intense stigma but lower overall rates of suicide compared to Whites (p. 165). The underlying assumption—that all survivors need and will benefit from intervention—appears to have brought the field full circle, from ignoring survivor needs to assuming a global need for mental health services. What is often subsumed under such topics is the need to educate survivors about suicide itself, both to increase their understanding of what happened and to help them cope with the possibility that they themselves will someday experience suicidal ideation.

As in other under-researched areas, opinions and available information on subtopics are often conflicting depending on the source from which they are taken. A prime example in the survivor literature is whether or not the grief experienced by survivors is different and perhaps more complicated than the grief experienced in other types of loss. Bailey, Kral, and Dunham (1999) and Kneiper (1999) argue that there is a difference; Jordan (2001) and Ellenbogen and Gratton (2001) question whether the differences have been adequately demonstrated in the studies provided. Sveen and Walby (2007) in a review of studies on this topic found no differences between survivors and other bereaved individuals on mental health variables but did find differences in areas specific to grief around suicide loss, including levels of "rejection, shame, stigma, concealing the cause of death, and blaming" (p. 25). Mitchell, Kim, Prigerson, and Mortimer (2005) assessed for a complicated grief reaction among survivors. Complicated grief is a construct found to be related to higher levels of suicidality among bereaved individuals. Survivors have been compared to persons losing a loved one unexpectedly, such as in a car accident, to account for the suddenness of the death, and have also been compared to trauma victims, particularly if the survivor was the individual who found the person who completed suicide; neither of these comparisons adequately seems to account for the social stigma associated with suicide. The many variables of survivorship—demographics, relationship to person who committed suicide, time of interview following the loss—have not been adequately studied or accounted for in much of the literature. The self-selecting nature of most samples is another contributing factor in the skepticism some researchers display in accepting that survivor grief is of a qualitatively different kind, yet all acknowledge that the stigmatizing nature of suicide has the potential to complicate this process in ways not yet fully understood.

The conflict between information collected by those who are survivors or who work with survivors as opposed to independent researchers is another complicating issue. Although those who publish in academic journals appear to freely disclose their survivor status, if applicable, and acknowledge the potential bias in their work, the underlying bias—that survivors are different—is often taken at face value, making the search for in what ways they might be different more problematic. A further area of conflict comes from the nature of the support groups that have formed around the country—as in many of the 12-step programs, the idea that only another survivor will understand one's difficulties in grieving is often cited. While the need to meet with and talk to other survivors must surely have great healing value, this idea may confound surveys of those in such groups since they may not be representative of the population as a whole. Further stigmatizing survivors is research supporting the fact that many of those who complete suicide were mentally ill at the time of their death; the confound of conflicted family relationships over this issue may also complicate the grieving process, not just the manner in which the person died (Dorpat, Resnick in Cain, 1972; Hauser in Dunne et al., 1987; Jamison, 1999). Some survivor families have been shown to have had higher levels of distress even before the suicide; the effect of poor functioning before the tragedy on the grieving process may prove to be a difficult subject within the survivor community. The nature of that mental illness is another variable not well studied in the survivor population: how might the struggles of coping with a loved one's mental illness prior to the suicide complicate the grieving process? What effect might there be for those who come to the realization after the loss that their loved one was ill? Some of these variables are discussed in the clinical and anecdotal works, and there are even suggestions for interventions based for differing presentations (Dunne, 1992; Jordan, 2008), but no longitudinal or outcome studies have been done.

McMenamy, Jordan, and Mitchell (2008) assessed what survivors themselves say they need, confirming much of what had been written by survivors and found results similar to those of this study. Although not asking directly what information survivors sought related to suicide, McMenamy, Jordan, and Mitchell found that survivors reported varying levels of difficulty accessing support after their loss and a need to provide more education about survivor resources.

There are many issues that make survivor research difficult. First, the nature of suicide itself, still one of the most taboo subjects, may make researchers and participants alike reluctant to engage in conversations about events leading to the suicide. The low

base rate of suicide makes recruitment difficult, a fact compounded by the still prevalent tendency to deny the cause of death. However, given that survivors may have been closer to their loved ones than any mental health or medical professional at the time of the suicide, it would appear an appalling oversight not to include survivors in the process of finding better ways to help disseminate useful information about suicide and resources, both to help survivors understand the complexity of this problem and to allow for their loss to contribute in a positive way.

This study begins exploration of a research question that crosses both the work on survivors of suicide and suicide prevention-what, when, and how did those who have survived the loss of a loved one to suicide learn about the potential hazards of suicide? Was it before or after their loss? Had they any contact with mental health resources or providers and if so, were they given any information? If they were, was it helpful in any way? This question is not meant to ask what survivors would have done differently to prevent the suicide. Rather, it attempts to determine survivor's perceptions of how helpful such information was or might have been and to look at potential differences in information seeking between different groups, based on demographic and event-related variables, such as whether the individual who took his/her life was or had been in any treatment for mental illness. It is hypothesized that this group had more access to information about suicide since there would have been contact with mental health professionals, however, a second hypothesis is that this information, if available, was not disseminated to family members even though it has been suggested that including families in the treatment of a suicidal individual is crucial, not only for assessment but for ongoing support (Rudd, Joiner, & Rajab, 2001). Other variables, such as relationship to

the deceased, level of education, and history of prior attempts, may prove to have influence on the behavior of survivors related to information seeking.

CHAPTER II

METHOD

This chapter discusses the rationale behind the development of the interview, selection of the coping instrument, the selection criteria for participants, and the method of recruiting participants.

Development of the Interview

Given that the purpose of the interview was to discover what information about suicide survivors sought before and after their loss, consideration was given to what variables might influence an individual's decision to rely on information-seeking as a means of coping. Two significant variables appeared relevant: first, the individual's attitudes towards suicide and second, the individual's predisposition to a given coping style.

Attitudes towards suicide have been assessed by researchers seeking to gain an understanding of cultural and personal norms regarding suicide, often in an attempt to correlate such attitudes with suicide rates. One of the earliest attempts by Domino, Moore, Westlake, and Gibson (1982) resulted in the Suicide Opinion Questionnaire (SOQ), which became the benchmark for future instrument development. This first attempt was a 100-item questionnaire that resulted in 15 factors. Subsequent attempts at refinement of this instrument found eight clinical scales that the authors recommend as more meaningful (Domino, MacGregor, & Hannah, 1988; Domino, personal communication). The clinical scales include: suicide as mental illness, suicide threats as "not real", the right to die, importance of religion, impulsivity, suicide is normal, suicide reflects aggression/anger, and suicide is morally bad.

Salander Renberg and Jacobsson (2003) describe the development of the Attitudes Towards Suicide scale (ATTS) and its administration to a random population sample in Sweden in 1985/87 and again in 1996. Of interest to this study are comments by Salander Renberg and Jacobbsson (2003) about the self-reported suicidal behaviors of the sample and their suggestion that those who did not respond perhaps had less experience of suicide. Salander Renberg (2001) discusses the self-reported suicidal behaviors of the sample but did not appear to ask any questions about whether the participants had any experience of others expressing suicidal ideation, making attempts, or completing suicide. The permissive attitude they note among some participants is perhaps in need of further research to assess any differences between survivors and non-survivors. For this research, the work of Salander Renberg and Jacobsson (2003) was helpful in determining a shorter number of questions that might be usefully added to the interview. Ten factors were obtained during the 1996 study after incorporating the analysis of the earlier study. The top four factors included attitudes towards suicide as a right; the incomprehensibility of suicide; that suicide happens without warning; and whether suicide is preventable. These results as well as the work of Domino led to the selection of four probes that followed the open-ended question regarding participants' attitudes and beliefs about suicide:

Under what circumstances did you think someone might take his/her own life?

Did you think there was any particular kind of person who might take his/her own life?

Did you think there was anything someone else could do to prevent an individual from taking his/her life?

Did you believe that individuals had the right to take their own lives? Participants were asked to answer these questions retrospectively, both before their loss and after, to assess whether there had been any changes in their beliefs. Additionally, participants were asked whether they knew that their loved one was at risk for suicide before the suicide occurred.

In addition to the question of the participant's attitudes towards suicide, other variables that might have influenced an individual's decision to seek information were incorporated into the demographic section of the interview. Thus, the demographic questions were asked not only to be able to describe the participants and their experiences but also to begin to determine if variables such as prior attempts or a history of mental health treatment were influential. The interview is attached in the Appendix.

The questions related to information seeking both prior to and following the suicide were developed by the interviewer with the goal of assessing not only what information survivors sought and found but also how useful it was and how easily accessed. Additional questions related to information provided by others and to the timing of receiving and finding information. Finally, participants were asked how this process might have been made easier for them and asked for any comments they wished to include.

Selection of the Coping Instrument

The Ways of Coping Questionnaire (Folkman & Lazarus, 1988) "is designed to identify the thoughts and actions an individual has used to cope with a specific stressful encounter. It measures coping processes, not styles" (p. 1). The authors note that to assess coping styles the instrument would need to be administered across a range of situations rather than a single event. Although this research study does not focus on assessing coping processes survivors have used, the administration of this instrument will help to determine whether there is a correlation between coping process and informationseeking behaviors.

The Ways of Coping Questionnaire (Folkman & Lazarus, 1988) measures eight processes based on a participant's responses to how they have coped with a specific stressful event: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal. Participants were asked to complete this questionnaire with regard to how they have coped with the loss of their loved one.

Although the Ways of Coping Questionnaire has been used to assess coping processes in many populations, including caregivers attempting to help suicidal individuals (Mishara, Houle, & Lavoie, 2005), a search in PsychInfo and Medline did not produce any studies of the survivor population. This is not particularly surprising since little formal research has been done with this population and much of what has been done focused on the grieving process.

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Participants

Participants were survivors of suicide, defined as individuals who lost a family member or friend to suicide. Participants must have been adults (18 years of age or older) at the time of the suicide. The individual who completed suicide must have been an adult (18 years of age or older) at the time of death. The loss must have occurred within approximately the past five years to allow for exposure to recent changes in information technology. There were no other selection criteria, such as gender, ethnicity, or relationship to deceased. The initial proposal estimated that approximately 20 to 25 participants would be interviewed; 23 participants completed the interview.

Participants had the purpose of the interview explained to them by the researcher prior to or at the time of the interview. Participants were given an informed consent form prior to or at the time of the interview by the researcher. Participants were offered the opportunity to be informed of the final results. Participants were assured that all identifying information and any quoted material would be disguised within the body of the final work.

Subjects were recruited through two of the main suicide organizations—the American Foundation for Suicide Prevention (AFSP) and the Suicide Prevention and Action Network (SPAN). These groups agreed to disseminate researcher's name and phone number to potential participants after IRB approval was received and after any internal review process on their part. In an attempt to avoid the potential bias of a sample drawn solely from such groups, the researcher attempted to recruit through other individuals who come into contact with survivors; however, this attempt did not produce any participants. Additionally, support group leaders local to the researcher's internship site in Connecticut were contacted and asked to provide the researcher's contact information to any group member who might be willing to discuss or participate in the research.

Approval for this project was obtained from the Rutgers University IRB before data collection began. In order to protect participants from potential emotional harm, participants were informed that they might stop the interview at any time, either for a respite period or to end their participation. The researcher is a master's level clinician who was able to refer them for services if needed as well as to counsel them on available supports.

Researcher

The researcher made known her own survivor status, having lost a close friend to suicide in 1994, when asked by any participant or any individual who was helping to recruit participants. Additionally, during the course of the interviews, if participants asked to discuss the researcher's experiences and how they led to the research, this request was honored. This additional conversation usually prolonged the interviews beyond the expected 90 minutes.

Recruitment

Interested individuals were asked to contact the researcher by phone or email. The purpose and scope of the interview was explained by phone or by email prior to the interview. Interviews were held in person at a location convenient for the participant, including the participant's home if the participant were willing to have the interview conducted there. If participants preferred not to meet in person or if they were not located in the states of New Jersey or Connecticut where researcher's graduate school and internship were located, respectively, telephone interviews were conducted. The interview was expected to take approximately 90 minutes; the assessment instrument approximately 10 to 20 minutes. If telephone interviews were conducted, participants were offered the option of having the Ways of Coping Questionnaire mailed in advance, either to be returned by mail or for use in answering by telephone. Informed consent forms were mailed in advance to all participants who chose to have a telephone interview with return envelopes enclosed; the signed forms had to be received by the researcher before the interview was held. Notes were taken during all interviews.

Analysis

Data were analyzed using qualitative research methods, notably looking for common themes among participants' answers. Strauss and Corbin (1998) suggest methods for improving the interview as the interviews take place; however, given the need to have IRB approval as well as the approval of the AFSP and SPAN, no changes were made during the course of these interviews, but suggestions for further research are included in the discussion section that became clearer as some themes appeared to need more detailed exploration, a common experience in initial research.

CHAPTER III

RESULTS

This chapter presents the main findings of the research and is divided into the following sections: a description of the participants and of the individuals lost to suicide; a discussion of coping styles as assessed from participants' responses to the Ways of Coping instrument; participants' attitudes towards suicide both prior to and following the suicide; information seeking by participants prior to the suicide, information seeking by participants following the suicide, and finally, a discussion of the researcher's experience of suicide and of being the researcher.

The Participants

A total of 23 participants completed the interview. Nineteen other individuals expressed interest or were referred to the researcher; of these, nine did not meet criteria due to the age of the individual lost (under 18) or to the length of time since the loss; nine did not respond to initial calls or did not respond to follow-up calls to schedule; and one individual whose loss was very recent was contacted after a waiting period and was no longer interested. These 23 participants lost a total of 20 individuals to suicide; three pairs of participants were interviewed regarding their loss of the same individual. The suicides occurred between 2001 and 2007. The interviews took place between November 2006 and June 2007; the suicides occurred between 5 months to 6 years prior to the interviews.

Four interviews were conducted by phone due to distance (the participant resided outside of New Jersey or Connecticut, the states in which the researcher was able to conduct in-person interviews) and one because the participant chose to be interviewed by phone. Thirteen in-person interviews were conducted in New Jersey; six in Connecticut. Three interviews were conducted in a public setting chosen by the participant and/or researcher; the rest were conducted in the participants' homes.

Twenty of the participants were female; three were male. The participants' ages ranged from 26 to 65 at the time of the interviews. Twenty-two participants identified themselves as either Caucasian and/or of European heritage, with three also identifying as Jewish; one identified as African-American. The questions related to race and ethnicity were difficult for many participants to answer; the researcher often had to clarify that the participant identified as Caucasian or had to question what countries participants' ancestors came from. This issue has been addressed in the multi-cultural literature related to "white privilege" and is not an area of interest to this work; however, as will continue to become clear, this sample is not representative of the population.

Participant were asked their relationship to the deceased: Mother (5); Father (1); Stepmother (1); Wife (1); Husband (1); Partner/Fiancée (3); Daughter (5); Sister (3); Aunt (1); Uncle (1); Cousin (1).

Participants reported income levels according to four categories: under \$25,000 (1); \$25,000 to \$50,000 (4); \$50,000 to \$75,000 (3); and above \$75,000 (15). Participants reported education levels in response to the question what was the highest year completed in school: High School (2), some college (7), college graduate (5), some graduate school (2), graduate degree (7).

Participants were asked about their residence and whether they had moved since the suicide occurred. This question was meant to accurately locate where the individuals would have sought information and/or services. Four participants reported having moved since the time of the loss; two had moved within their state; one moved to a neighboring state; one moved to a distant state.

Participants were asked if they knew whether the individual lost to suicide had made any attempts prior to the suicide and whether they had this information prior to the suicide. Seventeen participants reporting on sixteen individuals stated that the individual had made prior attempts; of those seventeen, twelve reported knowing about the attempts prior to the suicide. Three participants stated that there had been no prior attempts. Three participants did not know or were not sure if there had been prior attempts.

Participants were asked if the individual lost to suicide was the only person known to them who had either attempted or completed suicide. Eleven participants reported knowing other individuals who attempted suicide. Fourteen reported knowing other individuals who completed suicide. Within those groups, eight participants reported a family history of suicide attempts or completions and four participants reported a personal history of suicide attempts.

The Individuals Lost to Suicide

All information about the individuals lost to suicide comes from the participants, who acknowledged that they could not be certain of the accuracy of some of their responses, including past attempts and treatment history. Of the 20 individuals lost to suicide, 17 were male and 3 were female. Their ages at the time of death ranged from 20 to 68. Two were identified as of mixed race; eighteen were identified as Caucasian with further identification as being of European and/or Jewish background. Methods of suicide included: overdosing/ingesting/inhaling toxic substances (7); gunshot (5); hanging (4); stepping in front of a vehicle (1); drowning (1); and fire (1). One participant chose not to disclose the manner of death. As noted above, 16 of these individuals were known or believed to have made attempts prior to the suicide.

According to the participants, all of the individuals who suicided had received some type of mental health treatment. Participants reported that 13 of these individuals had diagnoses known to the participants: depression (8); bipolar disorder (4); substance abuse problems (2); anxiety (2); attention deficit disorder (1) and possibly schizophrenia (1). Additionally, participants who were not sure if the individual had been diagnosed believed that five of those individuals may have had: depression (2); bipolar disorder (2), and substance abuse problems (1). Eighteen individuals were known or believed to have taken medications; one had possibly taken medication. Eight individuals were believed to be taking medication at the time of death. Participants reported knowing or believing that the individuals utilized the following types of treatment: hospitalization (11); day treatment programs (3); outpatient services (7); substance abuse treatment or rehabilitation programs (6); psychiatrists (7); primary care physicians (2), and therapy (13).

When asked if they knew prior to the suicide that the individual was at risk, ten participants reported knowing that the individual was at risk; seven reported not knowing the individual was at risk, and six reported feeling unsure of what they knew or felt at the time. However, from the responses given, it appears likely that some participants may have been worried about the individual but not acutely aware of the possibility of another suicide attempt. In other instances, participants may have answered positively based on the individual's past history. Below are some paraphrased responses that demonstrate the difficulties faced not only by the wording of the question but the ongoing struggles the participants faced in coping with their loved one's often long-term mental health issues:

I always knew he would attempt, didn't think he'd succeed.

In the back of my mind, knew, not willing to accept it.

I'm not sure I knew what "at risk" was. I didn't know what was going on.

Yes, I got concerned a few days before; he went out, I thought something happened, I almost had him screened.

I knew that if he didn't make a change, there would be a tragic ending.

Don't know if I ever considered him at risk? He had struggled to feel good and steady. At the time, new job, engaged—looked good.

Had absolutely no idea—didn't think she was close.

Yes, at some point in the future. Still had up and down periods, rapid cycling.

No, living in (another state), only saw him twice a year.

False sense of security—he was in NA, saw a counselor—but it was in the back of my mind.

Yes, but I didn't take it seriously enough. Worried for a long time.

No, he was doing better. Saw him right before—he was doing good.

The difficulties presented by the concept of "at risk" will be addressed further in

the discussion section, particularly the apparent lack of general knowledge that one

suicide attempt increases the likelihood that the individual will attempt again; however,

given the treatment history of the individuals and the number of previous attempts, it should be noted that this was an at risk population by clinical definition.

Coping Styles

All participants completed the Ways of Coping (Lazarus and Folkman, 1988). This instrument assesses coping methods used during a specific time period and for a specific event, which is usually left to the participant to select; however, for this research, participants were asked to respond how they had coped with the suicide of their loved one. This meant that the time period was the time since the loss, a period much longer than the instrument has been designed for; however, this limitation cannot be resolved until an instrument is designed for this population or until an effort is made to assess coping styles in this population closer to the time of loss.

As described by Lazarus and Folkman (1988), the relative scores method developed by Vitaliano et al. (1987) was used to determine participants results. This method allows for the fact that some styles have more items within the questionnaire, and without weighting, may result in higher raw scores that do not accurately reflect participant styles. Results are in the form of percentages of the total score.

Folkman and Lazarus (1999) describe the scales in the Ways of Coping manual:

<u>Confrontive Coping</u> describes aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking.

<u>Distancing</u> describes cognitive efforts to detach oneself and to minimize the significance of the situation.

<u>Self-Controlling</u> describes efforts to regulate one's feelings and emotions.

Seeking Social Support describes efforts to seek informational support, tangible support, and emotional support.

<u>Accepting Responsibility</u> acknowledges one's own role in the problem with a concomitant theme of trying to put things right.

<u>Escape-Avoidance</u> describes wishful thinking and behavioral efforts to escape or avoid the problem. Items on this scale contrast with those on the Distancing scale, which suggest detachment.

<u>Planful Problem Solving</u> describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem.

<u>Positive Reappraisal</u> describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension. (p. 7)

Participants commented or noted while completing the survey that many of the questions did not seem relevant to the experience of losing a loved one to suicide. One participant who submitted the survey by mail wrote "The survey just didn't work for me. Suicide is in the past tense—beyond fixing. This would have worked after first attempt. But I answered best I could." Participants were encouraged to answer all questions and had the option of choosing "does not apply or not used."

Fifteen of the twenty-three participants scored highest on Seeking Social Support. Two participants had equal scores on Seeking Social Support and another scale; one on Positive Reappraisal and one Escape/Avoidance. Four participants scored highest on Positive Reappraisal, one on Planful Problem Solving, and one had equal scores on Planful Problem Solving and Escape Avoidance. Participants' highest scores are not necessarily reflective of their overall style, rather they may reflect the coping manner most used or most remembered. Second place scores were as follows: as noted above, three participants had ties for their top two scores. Of the remaining twenty, two participants scored second highest on Escape Avoidance, two on Confrontive, three on Seeking Social Support, ten on Positive Reappraisal, two had tied scores on Positive Reappraisal and Self-Controlling, and one had tied scores on Self-Controlling and Escape Avoidance.

The top two scores accounted for between 30% and 64% of the individual totals. In general, participant reported using a range of styles. Sixteen participants endorsed responses from all eight styles; five endorsed items from seven styles; and two endorsed items from six styles. This wide range of endorsements might reflect both the length of time the participants were instructed to consider in that they may have shifted from one style to another over time or may reflect the inherent difficulties in coping with suicide loss.

The initial purpose of assessing coping styles was to determine whether the sample had a tendency toward passive or avoidant coping styles that might result in information-seeking not being a chosen coping method. In total, twenty participants had Seeking Social Support as one of the top two styles. This is likely reflective of the sample having been gathered mainly through the support group network; however, this does not mean that the support groups were the main source of information for the participants or that the groups were helpful to them, as will be discussed in the sections on involvement with groups and on seeking information after suicide.

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Attitudes Towards Suicide Before the Loss

Participants were asked to recollect their beliefs about suicide held prior to the suicide loss. This set of questions was originally designed to help assess what effect those beliefs might have had upon participant's subsequent information seeking, with the understanding that, given the retrospective nature of the questions, participants might not accurately remember their attitudes. As described in the Participants section, a significant number of the participants had prior experiences of suicide or attempts, either from prior attempts by the lost individual, attempts by other individuals, or knowing other individuals who had completed suicide. In fact, only two participants denied a previous experience with suicide. These experiences informed some of the participants' initial responses, with seven participants specifically referencing other losses or attempts in their initial responses. Conversely, four participants' initial responses indicated that they could not recollect firm or strong opinions. Following the initial open-ended question, participants were asked a series of additional questions for further clarification if the original response did not already contain the answer. They were then asked if any of their beliefs had changed since their loss.

There were seven main themes in response to the initial, open-ended question (To the best of your recollection, what personal [religious, philosophical, political, etc.] beliefs or opinions about suicide did you have <u>before</u> your loved one died?). Some participants gave responses that included more than one theme. Four individuals expressed that they had some training or experience in a mental-health related field, leading to an understanding of suicide as resulting from mental illness. ("It was partly because he was depressed, a chemical imbalance.") Four additional participants stated

that mental illness played a role in suicide. ("After [the diagnosis of] bipolar, family life has little to do with disease progression.") Nine mentioned religious beliefs, with five participants endorsing the concept that suicide was not allowed or a sin and four endorsing that although they might have been raised to believe suicide was a sin, this was not part of their belief system. ("God gave us life—only one who can take it away." "Bible says [suicides] can't go to heaven—[I] know that God knows he was sick.") Five participants endorsed the belief that difficulties in childhood, including "poor upbringing" and possibly abuse, played a role. ("We didn't have a wonderful childhood.") Related to that theme, seven participants endorsed difficult life circumstances or personal struggles that led to despair. ("Not acceptable or unacceptable—people who suicide are ill and desperate.") Finally, six participants discussed suicide in terms of making a choice or decision, with two participants stating that suicide was not cowardly, one stating it was a "cop out," two stating it was a selfish choice, and one stating individuals had the right to suicide. Additionally, four participants, although providing additional responses, stated that they were not sure they had/could recollect previous beliefs.

Participants were then asked four additional questions if the answers had not already been indicated in the original response. The first question asked "Under what circumstances did you think someone might take his/her own life?" Five themes emerged, again with participants sometimes providing multiple responses. Six participants endorsed the circumstances of age/poor health/physical illness/chronic pain—concepts commonly related to the term assisted suicide, although only one participant spontaneously used that term. Seven spoke of mental illness, with one of that number and another participant also mentioning substance abuse. Without naming a particular circumstance, four endorsed tragedy or otherwise unendurable duress. Seven endorsed ideas related to the broad category of relationship issues, including marital problems, childhood difficulties, loss of a loved one, and rejection by family. Seven endorsed personal psychology or individual reactions to stressful events, including embarrassment, anger, and negative self-image. One participant stated that s/he had not thought there were particular circumstances under which an individual would take his/her own life. Additionally, four individuals mentioned hopelessness as a reaction to the circumstance while not naming it as a circumstance of its own.

The second question under beliefs held before the loss asked "Did you think there was any particular kind of person who might take his/her own life?" Five participants stated they didn't think there was any particular kind of person or that to the contrary, all groups are affected ("crosses all socio-economic status, religions"). The remainder of the responses reflected categories already given above, reflecting life circumstances, mental illness, and personal psychology.

The third question under beliefs held before the loss asked "Did you think there was anything someone else could do to prevent an individual from taking his/her life?" Sixteen participants responded yes, although seven of the responses implied that they no longer believed this. ("Then, I thought you could just talk them out of it," "Silly, egotistical idea that I could intervene.") Three participants said no ("If someone wants to, they would") although one of those seemed to be implying that this was because the person was out of contact and so could not be helped by the participant. Three participants stated they had not thought about it prior to their loss. One participant stressed that others could help but not prevent suicide.

The final question about beliefs prior to the loss asked "Did you believe that individuals had the right to take their own lives?" Very few participants had a clear answer to this question, with many indicating their beliefs had changed since the loss. Overall, fourteen participants agreed, but many indicated feeling conflicted about their responses. Seven disagreed and were sure of their answers ("Kervorkian was wrong," "Not before and not now...(life is a) gift from God.") Two responded by saying they did not have the right to decide this for others ("I'm not the one doing it," "My faith is one of judge not."). Of the fourteen who agreed, only a few gave unconflicted responses, mostly around the idea of terminal illness. Others reluctantly agreed, adding comments that indicated they wished the circumstances that led others to this choice could change and thus change the decision or that they still disagreed with the decision:

Comes back to the Biblical question of free will—I struggle with this. Our lives are made of choices—friends make choices we don't agree with—hard thing to say that they have the right.

I can see circumstances in both before and after why people might—shouldn't be a crime—murder/suicide not acceptable, suicide bombing not acceptable. He had the right.

Attitudes Towards Suicide After the Loss

Following the retrospective questions about participants' beliefs and attitudes towards suicide before the loss, participants were asked whether any of their beliefs changed since the loss or, if the participant had not recollected any beliefs or attitudes prior to the loss, asked what they now believed. The four participants who had not recollected any firm opinions prior to the loss all now expressed the belief that suicide

was related to mental illness, specifically mentioning depression and bipolar disorder. Four participants stated their beliefs had not changed; these participants had endorsed mental illness, difficulties in childhood, and difficult life circumstances/personal struggles. In total, 19 participants felt their beliefs had changed, or as noted above, now felt they had beliefs. Six now endorsed mental illness as a cause of suicide, with several adding comments about the difficulties faced in seeking mental health treatment or the lack of general knowledge about mental health issues ("I believe the mental health system is lacking, not accessible, atrocious and that anyone who wants to take their life has a mental illness. It's a disease, not taken seriously enough." "Is there some way to forewarn family? That the risk is so high?") Four participants initially stated their opinion as to whether suicide could be prevented had changed, with two stating it could be prevented and two stating it could not; others would indicate later that their attitudes had also changed. Three participants now believed that any person could suicide. Other responses given by the remaining six participants included changing one's belief that the individual would not go to heaven; having a less judgmental attitude; believing that suicide is a selfish choice; feeling that suicide is not completely explained by mental illness; thinking that it is a mystery why some people attempt/complete and others don't; acknowledging that having a professional experience/understanding of suicide is not the same as having a personal experience and gives new perspective, and now having an interest in survivor issues.

As with the original question about beliefs, participants were asked several follow-up questions to more fully explore how their beliefs might have changed. When asked under what circumstances someone might take his/her own life, five participants indicated the need to highlight that stress and difficult life circumstances were even more challenging to an individual with mental illness ("To a mentally ill person, a tragedy could be spilt milk."). When asked whether there was any particular kind of person who might take his/her own life, four participants felt that there was no particular kind of person or that any person might commit suicide. Seven participants now stated that the individual had a mental illness. Two individuals reversed their initial responses, with one not believing that those who complete suicides are not cowards and the other now believing that suicide is an "out."

Participants were asked whether they now thought there is anything someone else could do to prevent an individual from taking his/her life. Although only four participants had initially changed their response to this question, with two changing to yes and two changing to no, the answers given to this question suggested much more conflict and doubt, with very few participants clearly endorsing a yes or no answer. In the original question about beliefs before the loss, sixteen had indicated they thought others could help, three said others could not, three had not thought about it, and one stressed that others could help but not prevent suicide. The most common theme was a "yes, but" response suggesting an underlying hopelessness about the possibility of preventing an individual from eventually suiciding. Participants discussed helping someone at a moment in time—delaying or interrupting the process—but were no longer sure that the individual would not later suicide.

I don't think you can. Maybe sometimes.

I think it's a lot harder than I thought it would be. Support is great, but only prolongs it. Could stop him that time, but he'd have eventually done it.

Definitely, (but) too hard for me to do.

Don't think (you) can prevent it—not with love, support, counseling—if it's going to happen—(you) can do everything in your power, but if that abyss comes over their mental state, can't help—no guarantee.

After, not so sure, but you have to try.

Key people could break through, suicide might still be end result, but people could help.

Once someone makes up mind—can't help them.

If person determined—nothing anyone can do, might postpone it—they will find a way.

Yes, make sure right facility, right meds—look over it all—don't depend on doctors.

Might still influence opinion, but not if mind is set.

Not necessarily—things might help, but not necessarily.

Have an obligation to help them. Still think some people we can't prevent.

Only if they have the right medications or the right type of cognitive therapy.

In certain cases.

I think (you) can interrupt the process sometimes.

I used to think so, question it frequently now—we did so much—got him to see a psychiatrist—trying to get him to rehab—so much energy. I think some people can be helped, (but) not a guarantee.

Finally, participants were asked if they believed that that individuals have the right to take their own lives. The answers given reflected a change in participants' understanding of the causes of suicide and the feelings of those left behind. Of the fourteen participants who originally answered yes or yes with some conflict, two changed to no and one was still conflicted ("part says yes, part says no"), mentioning that it was

different if the person was terminally ill and the family had a chance to say good-bye.

Others stressed that they would not make this choice but agreed that others had the right.

None of the participants who had answered no changed their answer to yes. Participants questioned whether suicidal individuals were able to make that choice ("are they in a sound state of mind?") or suggested that the illness had removed the choice from them ("it's not a choice for them—no right or wrong—like cancer metastasizing."). Several suggested that the suicidal individual should have an awareness of the impact of this decision.

Seeking Information Before the Suicide

This section was originally designed to ask participants who knew their individual was at risk for suicide what information they had sought or been given prior to the suicide. As noted above, the question of "at risk" was not well defined, with participants clearly being concerned about their individuals but not sure if they remembered thinking the individual would attempt or would attempt again. Participants were therefore given the opportunity to respond to this question even if they had not remembered being aware or clear that their individual was at risk. Of the seven participants who had stated they had not known their person was at risk, three stated they had not sought any information; one stated s/he had not but someone else had tried to give information; two thought they might have looked up information about the antidepressant medication their individuals were taking, and one had helped the individual find information on mood disorders and health care providers. Of the six participants who indicated they had been unsure if their person was at risk, two did not seek any information; three sought information about mental health topics such as medication, depression, and substance abuse but not in relation to the individual who eventually suicided, and one individual sought a great deal of information, including information about suicide and suicide prevention, depression,

substance use disorders, and treatment options. This participant had been one who reported knowing that their individual had made past attempts prior to the suicide. It is worth noting here that eleven other participants had acknowledged knowing about their individual's past attempts prior to the completed suicide, an issue to be further explored in the next chapter.

Of the ten participants who had reported knowing their individual was at risk, eight initially stated they had not sought or been given any information about suicide and two stated they had sought or been given information. Of the eight who had not sought or been given information, three participants reported being in the mental health field and having information already from past training or from current experience. Of the remaining five, three indicated they had sought information on related topics, including mood disorders, medical conditions, and treatment options. Of the same remaining five, one of the three noted above and one other participant acknowledged having been given information about emergency services by a mental health professional. The last participant of this group of five indicated that having "been around alcoholics" all his/her life, s/he knew how to find her individual if s/he disappeared. Of the two participants who stated they had sought or been given information, one reported having found information about suicide while researching bipolar disorder and having been given information by the individual's treatment team and from display information at the mental health agency and one reported having sought and been given information on related subjects (depression, mental health, addiction) but not specifically about suicide.

Follow-up questions regarding whether the information had been easy to find, whether the information had been helpful or not, and how it was helpful or unhelpful proved to be poorly designed, due both to the length of time various participants had been struggling with their individual's illnesses and what the meaning of "helpful" was in the context of the eventual suicide. Five participants remembered the information as easy to find. One participant remembered seeking information over many years, one sought information as the individual's illness worsened, and one remembered seeking information after the individual's suicide attempt. As to whether the information was helpful or not, seven participants remembered the information as being helpful in terms of coping with the situation, understanding the illness or the medications, or being able to give that information to the individual. Five remembered the information as not being helpful either because "I didn't know what I was looking for" or because the attempt to seek information was upsetting in some way (one participant remembered reading that "all suicides are preventable," another that s/he had been told by the individual's psychiatrist following an earlier attempt that the psychiatrist wouldn't be able to speak with the participant.).

Support Groups

Participants had been asked in the demographic section whether or not they had been involved with any of the survivor of suicide groups since their loss. Given the nature of the recruitment process, it was presumed that most of the participants would have had some contact, and that this contact might have provided some of the information about suicide that some of the participants would have found following their loss. Group involvement will be discussed again in the section regarding where participants obtained information about suicide but is discussed in detail here since this information is noteworthy in several regards—first, that not all participants were active in groups at the time of the research call for participants; second, that not all participants had significant group participation, and third, that some participants reported feeling that the groups had been unhelpful.

Twenty-one participants stated they had some level of involvement with groups; the other two participants had not attended groups but had participated in awareness- and fund-raising walks (the Out of the Darkness Walks) sponsored by the American Foundation for Suicide Prevention (AFSP). One of the two who had not attended groups had also attended the AFSP's Remembrance Day and had attended the AFSP's workshop on how to facilitate a survivor support group but had not yet started a group. Five other participants stated they had participated in the walks; seven had participated in the Remembrance Day. Three of the participants who had attended groups also reported having been involved with internet support groups. Five participants reported either starting their own group or becoming facilitators in existing groups.

Level of involvement with groups varied among the 21 participants who reported having attended groups, from participants who attended a group only a few times to those who attended regularly to those who started groups. Information about this subject was spontaneously given since the original question was designed simply to determine whether the sample population came entirely from the support group population. As noted in the first chapter, additional research needs to be done regarding the quality and helpfulness of groups. Participants in this research reported markedly different experiences of group availability and helpfulness, as demonstrated by the following comments/vignettes: A partner reported that the internet groups were "the only way I survived." However, s/he is no longer part of the group because s/he "can't take hearing new people, [but is] still in touch with other people from before." As to in-person groups, s/he commented that they were "horrible—my God, it doesn't get better? They were bawling two, three years out (after the suicide)."

A sibling reported having gone to group once after the loss but didn't find it helpful because s/he found s/he was the only sibling in a group mostly of mothers. Later s/he found an online group for siblings that was helpful and now facilitates an in-person group.

A daughter reported having attended the Out of the Darkness Walk and being on the AFSP mailing list but does not have a group near her to attend, noting that the only local group is "a loss group, not for survivors."

A mother remembers seeking support and finding that "no one knew what to do with me" until the funeral director suggested she contact the Samaritans. "Samaritans facilitator sent info about the group, spoke with me on the phone. [It was my] first contact with a survivor—felt so good—somebody who understood." This participant later started her own group because she had seen in other groups that "survivors didn't heal—I wanted to heal. Saw no progress—it bothered me."

A daughter stated she has "stopped going to meetings. Everyone has lost a child and being a mother, it's heartrending to hear their stories. I felt guilty talking about my situation."

Another topic not directly asked in the interview but which came up frequently was how participants initially found the concept of "survivor." Until discovering this concept, participants were finding mostly information on general grief and loss supports. This is another area that needs research, since the concept of "survivor" appears to have limited meaningfulness outside the field of suicidology, preventing survivors from quickly being referred to appropriate services. Participants noted several ways of having first come into contact with the term survivor, from past experience with suicide, to coming across the term in books or online while researching suicide, to being referred by various agencies, including funeral directors, prosecutor's offices, and help lines such as 211 in Connecticut and InfoLine in New Jersey. However, not all participants were referred by these agencies; it appears likely that since the resources are searched based on the location of the individual calling or by county, those areas without groups result in the caller not being referred.

Seeking Information After the Suicide

Regardless of whether they had sought information prior to the loss, all participants were asked if they felt the need to seek information about suicide after the loss. Nineteen participants stated they had, with varying levels of recalled intensity ("I was like crazy to get information." "I looked up everything, been on every suicide prevention page, everything I could get my hands on to read—really needed answers." "I'm sure I did, but it's a blur." "I just wanted to learn everything I possibly could that I should have known before."). One participant stated s/he had sought information, but not about suicide; however, his/her later responses indicated a need to gain an understanding of why individuals suicide. One participant stated s/he had not sought information but did come into contact with support groups and suicide information because s/he accompanied another family member to a group. ("I never would have done it....punched in the stomach...hard to look for help."). One participant stated s/he had not sought information about suicide but had looked for information on how to help family ("Part of my brain knew info would be helpful, but I needed to grieve."). One participant stated s/he thought she had not looked for information but recalled having attended an Out of the Darkness Walk prior to the current loss, realizing s/he already had some knowledge of survivor issues.

In response to the question of what information they sought, some participants were able to name topics, others only the information they found, such as names of books or websites. It was difficult for many of the participants to reconstruct the events that followed their losses, and it is possible that the information they remembered seeking or being given had a particularly positive or negative valence, as discussed below in the helpful/not helpful section. Topics mentioned included prevention (2), coping with loss/grief (7), mental illness/substance abuse (5), suicide (5), suicide methods (1), risk factors/warning signs (4), causes of suicide (5), treatment (1), support groups (5), helping family (2), afterlife issues (1), and survivor (7).

Ten participants gave the names of specific books or authors, five gave the names of specific websites, and seven mentioned pamphlets received from groups or the AFSP. The books covered a number of the topics listed above and included many of the firstperson survivor accounts suggested by support groups and survivor websites. Books named included:

After Suicide (several books by this title or a similar title) Andrew, You Died Too Soon; Corinne Chilstrom and E. Corinne Chilstrom Assessing and Managing Suicide Risk; Robert I. Simon Autopsy of a Suicidal Mind; Edwin S. Shneidman and Judy Collins Courage to Grieve; Judy Tatelbaum Darkness Visible; William Styron

Grief Handbook; John W. James and Russell Friedman Healing after Loss; Martha W. Hickman How I Stayed Alive When My Brain was Trying to Kill Me; Susan Rose Blauner How To Go on Living When Someone You Love Dies, Therese A. Rando I Wasn't Ready to Say Good-Bye; Brook Noel Living with Grief after Sudden Loss; Kenneth J. Doka Losing the Garden: The Story of a Marriage; Laura Waterman Morning Has Broken: A Couple's Journey Through Depression; Emme and Phillip Aronson My Friend, I Care: The Grief Experience; Barbara Karnes My Losing Season; Pat Conroy My Son, My Son; Iris Bolton Necessary Losses: Judith Viorst No Time to Say Good-Bye: Surviving the Suicide of a Loved One; Carla Fine Suicide Why?; Adina Wrobleski Survivors of Suicide; Rita Robinson Tear Soup; Pat Schweibert, Chuck DeKlyen, and Taylor Bills Touched by Suicide; Michael F. Myers and Carla Fine What Happy People Know; Dan Baker and Cameron Stauth When Night Falls (not found, likely Night Falls Fast by Kay Redfield Jamison) Why I Jumped; Tina Zahn and Wanda Dyson Why Me? Coping with Grief, Loss, and Change; Pesach Krauss Why Suicide?; Eric Marcus

Authors specifically mentioned included Kay Redfield Jamison, William Styron,

and Danielle Steele.

The websites specifically named were:

About.com (searched for suicide, bipolar disorder, and dual diagnosis).

1000Deaths.com (currently inactive, described on WebHealing.com as "The

suicide-survivors mailing list provides an electronic support group for people who have

had a family member, close friend or loved one complete suicide. Find subscription

information at 1000 Deaths.com.")

Oprah.com (searching for groups online).

Groww.org (Grief Recovery Online—loss site).

Suicidology.org (Website of the American Association of Suicidology).

Participants who mentioned AFSP materials were likely to have also been on that group's website without mentioning it by name (AFSP.org). Participants who responded to the call for research sent out by SPAN USA were also likely to have visited that website (spanusa.org).

Participants were asked how soon after their loss they began to gather or were given information about suicide. What was not asked, but some participants volunteered, was how long they continued to seek information. What was also not asked, but again some participants volunteered, was whether they were ready to receive the information given to them. Five reported having gathered information within a week. Twelve reported having gathered information within a month, with one participant noting that some information was given to him/her in that time frame but it took longer for him/her to seek any additional information. Five reported having gathered information one or more months after the loss, with three of those indicating that they were not ready in the earlier stages ("I was a robot for three weeks." "[A family member] had information from group weeks after—I wasn't ready for probably three months."). Of those who reported having been given information, eleven remembered having received it within a month of the loss; one remembered having received some prior to the loss and again about two months after. Two participants stated that they had not been able to use the information when it was given ("Had it within weeks, didn't use it for three months.).

Participants were asked where the information came from—most gave more than one response. Eight identified having gotten books from the library or bookstores. Thirteen found information through support groups and/or the AFSP. Ten stated they had used the internet. Three stated they received information from the police, coroner, or prosecutor's office and four from funeral homes/directors. Three stated they contacted mental health professionals. Five reported having information from family members and four from friends. Additional responses provided in response to the question of how the person was related to the participant included strangers, co-workers, outreach and public agency staff, and medical office staff.

When asked if they had sought or been given the information, nine stated they sought information, two stated they had been given information, and twelve stated they had both sought and been given information. This question was somewhat unclear, since two of the respondents who stated they sought information also noted that after finding the group, they were given information by the group leader or directed to other sources. As discussed above, it is apparent that finding a group or coming across the term survivor led many participants to other sources; whether their recollection is that this information was all sought by them or whether they perceived this as both seeking and finding appears to have been an individual perception not well clarified by the questions asked in the interview.

When asked whether the information had been easy to find, eleven stated it had been easy, nine stated it had not been easy, two stated some was easy and some was not, and one stated that finding the information had been a coincidence, having seen an advertisement for a group in the newspaper. The two participants who stated it had been both easy and not easy may have more accurately reflected the experience others had. One noted that it was easy to find the right section in a bookstore, but difficult to weed through the many websites. The other noted that "it's still who you know" in relation to finding helpful people to point out the right direction. The ability of each participant to use or have knowledge of internet search engines, libraries, and self-help resources such as 211 was not assessed—it would be an additional area of research to determine whether these resources are easily accessed not only by experienced help-seekers but by novices as well.

The nine participants who indicated the information had not been easy to find gave several explanations. Three acknowledged that any search had been beyond their ability to manage due to their emotional reactions and grief ("I couldn't operate the web, didn't drive much, hard to get to the library." "I was too overwhelmed, needed [family member's] support to look." "I eventually gave up [looking for local groups]. It took too much time."). Four stated it had been hard to find the right resources or enough helpful resources ("Not easy to navigate." "Took a lot of research and digging." "Even at Borders, I had to ask—psychology? Death studies?" "Clicked around, not that many out there—almost like a panic attack, want to read these forever [regarding personal accounts by survivors]). Two participants stated they had difficulty coming into contact with phone resources that were knowledgeable about survivor issues ("No one knew what to do with me." "Did a lot of calling—called the county—called [a local mental health agency]—called bereavement sources—called NAMI [none led to survivor groups or resources]). As will be discussed later in the section on how this search might have been easier, it is clear that participants' ability to come into contact with information was influenced by services in various counties of New Jersey and Connecticut.

When asked whether the information had been helpful, all but one participant agreed that at least some of the information had been helpful. The remaining participant had attended a group and felt that "it didn't fulfill anything within me." Responses to

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how the information had been helpful fell into several categories, including finding a shared experience/not feeling alone, understanding mental illness, normalizing feelings after loss, and coping with guilt and stigma. Surprisingly, although many participants had not continued with or even found groups other than at the AFSP Remembrance Day, the experience of meeting another survivor was important to many of the participants. In their own words:

The things I read about depression—never knew what it meant. I thought it was a feeling, not a condition. They just want to end their pain. Getting to know what he was thinking, his mindset.

It described my type of mourning, the pain in my heart, the confusion

I wasn't by myself—many other people with bipolar, had similar experiences. My friends were not in committed relationships yet—they didn't understand. (Online group) people let me cry.

There hasn't been one resource that was fantastic, most epiphanies came from someone else's story.

Made me think I'm not crazy. First survivor books were helpful—then repetitive. Groups—individual people—helped to tell people my brother was a good guy, wasn't a bum.

Knowing that different stages were normal. Understanding why this could have happened. Helped me think about what I do now, how I go on.

Good to meet other survivors—they understand.

Realized how prevalent suicide is—felt I wasn't alone.

Most helpful was catharsis—forced me to talk about it. An opportunity to do something—the walks.

Dynamics of stages following a suicide—especially in the period following the services—what do I say after? Bring it up or not—how to approach survivors.

Online group just let me keep talking—knew they were moving on with their lives.

Understanding that it's a biological illness—helps take the burden off you.

Repeated acknowledgement that death due to illness. Conference and walks really helpful—hearing other's stories, how they coped.

Better understanding of depression, bipolar, drug and alcohol use—suicide facilitators. Understanding the disease aspect. Helpful to understand his pain.

Feeling of "I'm not alone, this feeling is normal," versus "have I gone over the limit?" Grief versus depression—everyone too quick to jump today—this is a process, I don't need to be sedated.

I try to understand what he did and that I have choices. He chose to leave, I can choose to stay—in dealing with loss, can choose not to be overwhelmed.

Going to conference was amazingly helpful—progressively grateful I went. Just being with other people—don't have to explain, no stigma. To see others healing and helping.

Although most participants had stated the information had been helpful, they were asked if any had not been helpful and how it had not been helpful. Surprisingly, given the helpfulness of meeting other survivors, unhelpful or hurtful experiences in groups were noted by nine participants, although at least one of the comments was about a general grief group, not a survivor group. Others commented on finding it unhelpful to be with other survivors who had not moved past their grief—yet others commented what was not helpful was that the groups only met once a month or were difficult to find/hard to get to. Four participants stated that the information found was too technical, too limited, or would have been helpful prior to the suicide ("Like what to do when the police come."). One participant mentioned that it had been unhelpful to come across "suicide" websites that discuss or encourage suicidal behaviors. Four participants mentioned unhelpful comments from others that were hurtful to the participant but were not necessarily directed at the participant. Examples included comments from other survivors whose relationship to the individual differed from the participant's (i.e., parent

versus sibling) and feeling that the participant's loss was seen as less important or serious; reading survivor accounts and feeling that the author "got over it too soon"; and religious comments that may have been meant to be helpful but were hurtful to the participant ("S/he's in a better place."). It is probable that more participants had these types of experiences but did not relate them to information seeking.

Participants were asked what, if any, information did they wish they had earlier. This question proved to be another poorly designed item, since some participants answered regarding information after the suicide and others prior to the suicide. Regarding information after the suicide, four participants felt that they either found the information soon enough or would not have been able to look at it sooner ("Kind of out of it, in shock." "It wouldn't have helped—I wouldn't have looked.") One participant stated it would have been helpful to have everything sooner, then stated "but I don't know if I was ready—still have a ton of stuff [not looked at yet]." Three participants stated they wished the large events (AFSP's Day of Remembrance and the Out of the Darkness Walks) had been earlier at least in part because information was readily available as was information about local groups. Three participants stated they wished they had found groups earlier. One participant wished s/he had found the websites sooner. One participant initially stated s/he did not think there was anything needed earlier, but then added "I wish someone knew that first week—someone who could have come to see me. I did some really stupid things, almost gave up on life. Normalization would have helped." One other participant noted normalization as well, describing it as the "feeling or steps of what you're going to go through."

Nine participants' responses indicated that some information would have been helpful prior to the suicide. Again, this question was meant to ask what information was helpful in coping with the loss of a loved one, yet it was clear that many participants understood it as what might have helped them help the individual. This is a question that needs to be asked directly of more survivors in future research and will be addressed in the Discussion section. Type of information mentioned included prevention, warning signs, mental health (diagnoses and treatment), risk factors for suicide (previous attempts, individual risk factors), and privacy issues.

Participants were asked if there would have been an easier way for them to get information. Eight participants gave responses that suggested professionals or agencies of various types could have provided information or had more knowledge of survivor issues, including hospitals/emergency rooms, emergency personnel, nursing services, funeral homes, local phone books and local help lines, doctor's offices, public libraries, churches, and coroners. As discussed above, in some cases, these professionals/agencies did provide information, but there was no consistency across county or state lines. Five participants stated an outreach person who called or came to see survivors would have been helpful, although two noted survivors might not be ready to see outreach personnel. Two stated that having a specific phone number would have been easier ("where I could have called, and said I'm a survivor, send me the packet—including resources in your area, list of books, things you may feel, here's what's normal, info on suicide and why it happens—like from the AFSP."). One participant stated it would have been easier if someone had sent the websites. Six indicated they felt the information had been easy to find, either on computers or after connecting to a local group, and one indicated that finding the information had been part of an individual process ("I think I had to live it.").

Participants were asked what information had been the most helpful. Some participants gave answers that appeared to be in response to what had been most helpful in coping with the loss, not specifically about information. Sixteen gave answers that suggested the process of having a shared experience and normalizing that experience was the most helpful, whether it was through in-person or online support groups, attending AFSP walks or conferences, or reading survivor stories. Three participants stated books or other information on grief and the grieving process had been most helpful. Two participants mentioned information about suicide that decreased their guilt feelings and helped them explain suicide to family members. One participant mentioned her faith, another her family. Some participants gave more than one answer—one participant mentioned learning about depression, two stated helping others after the loss was helpful, one mentioned meditation, one mentioned taking part in support group facilitator training, and another spoke of trying to find healthy ways to deal with stress.

During the course of the interviews, another question that should have been asked—how did you find "survivor" as a concept or a search term—was answered by some of the participants. In hindsight, this was a serious oversight, and reflects the larger problem of why information was often hard to find—if you do not know what a survivor is, how do you help one or refer one to services? Participants who mentioned how they found the term were not always sure of their answers. Two stated they had called local help lines and had been directed to survivor resources. One saw an advertisement for a Survivors of Suicide group. Five had prior experience with the term from earlier experiences with suicide, NAMI, or the AFSP walks. Five thought they had seen the term while reading, either in information they found or in information sent to them after the loss.

At the conclusion of the interview, participants were asked if there was anything related to what had been discussed that they would like to add. Included in this section are some comments made during the interview about what participants' felt they needed but did not get while attempting to help their individual.

I wanted a psychological autopsy, didn't have the energy at the time. I would have liked his brain to go to some kind of study. First time depression, kids out of the hospital in a week, parents have no idea what to do. Need a celebrity like Anna Nicole to make it public and serious. Son's friends, mean so much if they called or wrote, they think they'll make me cry. It's like they never existed.

Even when I went to the therapist—he didn't lose anyone—I had a hard time. Didn't find it helpful—he kept telling me I taught him more than he taught me. He tried to understand. (In regards to being interviewed.) I've done this a couple times—early on—found it helpful, healing.

Two weeks after he died—warning labels (on antidepressants about increase in suicidal ideation)—now bipolar is disease du jour.

It was important for you to hear my mom's history.

Have to put love someplace else. Get to a group—listen to other people—let them hear other people's stories. I'm a guy—who am I going to talk to? I need a group.

Like we take health—people should know more (learn about mental health issues). Went to a private therapist (to discuss effect on marriage). A lot of people in group did. Sought clergy, spiritual help. Group every two weeks—not enough. Need a network of trained therapists. If more people knew what to do in a crisis.

That's what needs to be out there—when they feel better is when it happens. I think the disease state has to get down to street level—Anna Nicole Smith—publicity. I just wish the stigma would be lifted. You find out people don't know what to say.

Best thing was having family and friends—shame if people don't have any.

Suicide needs to be taken seriously, and it's not. If system were different, we'd have fewer suicides.

Because I'm a facilitator—learned more than I would have otherwise—helped me grow and given me a purpose. Group has done me as much good as for the people who have been through it.

Why didn't anyone give me even a pamphlet—what to look for. Clear cut signs, 10 most common signs. Male, 65 years old, started smoking, pacing—didn't realize connection. Pamphlet given to him.

Having decent books on library shelves. (She realizes as we are ending that she can request her library buy them.)

(Local substance abuse treatment center) as a model: Got lots of info before and after, basically a referral center, warm, inviting library, sat one afternoon, read stuff about substance abuse. Weekly lectures, really where I started to find options for me and for treatment for spouse. My refuge every week. Went to about 30 lectures, free or low cost. Helped get intervention services. Spouse went to lectures also—family w/consumer. Foot in door in non-threatening way—don't have to make commitment-don't have to bare your soul.

More support before—maybe don't know how to reach out for it, how to make a difference.

Survivor/Researcher Status and Experience

It became clear to me at the start of this project that many of those consulted were not certain of the feasibility of the study given the presumed reluctance in the field to approach survivors for research. When I approached the survivor organizations and the support group leaders, it was obvious that my position as a survivor provided access that others might have had more difficulty securing. During the interviews and even during the recruiting phase, the issue of my survivor status was frequently raised. Although I would hope that future research would not be limited to survivor-researchers, a discussion of how I came to this topic and the personal issues it raised may be of some help to those interested in research with survivors.

As noted previously, I lost a friend to suicide in 1994. We had gone to high school together and continued our friendship during the struggles we both faced after dropping out of college—my depression and eventual return to work, her increasingly complicated symptom presentation that eventually made it impossible for her to work. Over the course of the next decade, her illness worsened, and she had multiple suicide attempts and hospitalizations. We had many discussions of her illness and treatment sometimes she would call for support and sometimes for the needed encouragement to reach out to her providers. I would find out she was in the hospital when she called me from the patient phone or when her mother would call to tell me where she was. One night, I sent the police to her home, fearing she had or would hurt herself following a conversation in which she was unable to promise me she could remain safe, only to find later that she had gone to the emergency room on her own before they arrived. I can still remember waiting to hear back from the police or emergency services, trying to decide if I should go to her home, and finally calling again when I couldn't bear the wait any longer.

My friend had survived after her overdose, and while not fully able to communicate and obviously not recovering quickly, we had the hope she would survive. As her condition worsened, we continued to be optimistic, but eventually she fell into a coma and died. Thus, there was no "surprise" when she died, as so often experienced by survivors, but the shock and disbelief were not allayed by either my prior experiences or by my recent visits to her bedside. The phone call I received from her mother telling me she had died stands out in my mind—I remember I was preparing to leave to visit her, and I remember standing in my kitchen crying for what seemed (and may have been) hours. This was my experience of suicide loss. Within a few months after her death, I returned to college with the idea of eventually going to graduate school for a degree in psychology. At that time, my impetus was to change my life in a positive way, inspired by the determination with which my friend had attempted to work even while ill—if she struggled to find meaning and to achieve all that she was able, certainly I could as well. I had no thought of eventually working with suicidal individuals. I did not know what a survivor was or that I was one. I did not look up any information on suicide or seek out any support groups. My supports were the people in my life who had known about my friend and consoled me in my loss. I did not experience any significant guilt although I was remorseful that I had not returned a call she had made to me shortly before her overdose—there had been many such calls over the years, and I thought I had come to terms with the idea that someday she might not be there when I called back.

The years I spent obtaining my bachelor's degree went by rather uneventfully with respect to my friend's death, although my abnormal psychology course began to raise my awareness of the extremely complicated issues surrounding therapy and medication from the providers' perspectives. It was not until I began graduate school that I experienced some of the issues that I would eventually realize were "survivor" experiences, most notably the feeling that it was not safe to talk about my experience due to the not so well hidden belief that families (and, in my mind, by extension, friends) contributed to if not caused the suicide. I also found that the descriptions of suicides were nothing like I had experienced, with many of the cases we studied being described as complete surprises with little or no warning. I felt I could not discuss my experience since much of the material I was reading appeared to either blame families or question the mental health of individuals who befriended suicidal individuals. I also felt nothing in common with others who had lost individuals to suicide since I too, based on my experience, thought they must have been in denial about what warnings the person had given. I still had no idea there was a concept of survivor, much less literature and groups, since this topic was never presented in a classroom setting.

It was not until I saw a brochure for a local conference on suicide that included a survivors' day that I realized there were supports. The conference was an odd experience for me, since by the time I went, my friend had been gone for about eight years. Other survivors at the conference had more recent losses or had been to previous gatherings. Although there may have been others in my situation—finding the conference years after the loss—at the time I felt I was the only one. The conference began to expose me to the reality that there is no "survivor experience" but instead a group of people who struggle with their losses in unique ways. I also became more aware that not every individual was like my friend and that many survivors truly were surprised by the suicide, even if with hindsight there might have been signs of trouble.

By this time, I had begun thinking of dissertation topics. I was also doing an externship in a state hospital and was discovering that inpatient work was more interesting and more rewarding than the outpatient work I had been doing. I started to think that perhaps, as a final tribute to my friend, I might pick a topic related to suicide, and eventually decided that I would like to research a survivor issue with the goal of adding to the prevention literature. This decision would cause me to rethink my experience of my friendship as I began to question what, if anything, I wished I had known or had done differently—and led me to this work.

As I worked on my dissertation proposal, I took a job that provided me the experience of working with the families of the severely mentally ill, which helped to crystallize my topic. It was hard for me to learn how little time clinicians spent explaining to families the nature of mental illness or the risk of suicide. Of course, I understood the "client centered" perspective as well as the privacy and confidentiality issues that made it difficult for clinicians to speak with families, as well as the institutional limitations on their time. I was also very aware that this information was hard for families to hear and process, and that even a well-intentioned clinician could not properly educate a family at one meeting. Gradually, I came to the set of questions discussed in the results section, with the hopes of documenting what families could remember being told by professionals as well as the results of their efforts to find appropriate literature on their own.

I was unprepared for my own anxiety and the uncertainty with which I began the recruitment process. At first, it appeared an insurmountable task to get the word out to possible participants, but when participants began to call and email me, the reality of having to explain my research and to ask if they would be willing to let me, a stranger, ask questions about their experience, was overwhelming. I realized that if anyone had asked me to be a participant about my friend's suicide shortly after her death, I would become increasingly anxious and distracted in the days prior to each interview, rechecking my itinerary frequently and struggling to staying organized and focused (in one case losing my interview questions, in another, putting a dent in my back fender as I thought about the upcoming interview rather than the pole behind me). My anxiety

would reach a peak as I sat down with the participant and would slowly subside as the interview began and progressed and finally ended. This calming was due to my initial fears being allayed that the person was not ready to handle being interviewed even though I had already emailed or spoken with them and assessed their ability to participate. This is likely the main finding that I would offer to future researchers—survivors can and will discuss their experiences without undue distress if adequately assessed for readiness to participate.

When the interviews were over, I found myself more exhausted than I would have anticipated, and struggled, as so many graduate students do, with the task of sitting down to begin analyzing and writing. An unexpected and additional challenge came when I lost my dissertation chair, Dr. John Kalafat, to an untimely death. We had spoken of my initial findings and he had been very excited and supportive in a way that I found nonstigmatizing of my participants' experiences. As we discussed how little information about suicide the participants had sought or been given, he lamented that suicide remains the most taboo of topics and that clinicians continue to have difficulty with this topic. At that time, I felt that with his support, I would be able to present my research with the support of a well-known suicidologist—which I hoped would allay any concerns that I was too survivor oriented. Although I was lucky enough to replace him with another supportive faculty member, the significance of his loss on this final work cannot be underestimated.

After meeting with my new chair and attending Dr. Kalafat's memorial service, I attempted to begin writing again. I found that I became anxious and increasingly concerned with the debt I owed to my participants and the need to both protect their

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identities and to tell their stories. I started to recognize that I was still struggling with issues of stigma that I thought were resolved long ago and had to come to terms with what, if anything, I would disclose about myself in the work—and what I would say about my friend. While writing the results section, I realized that part of my procrastination was due to my concern about my friend's family's reaction should they find out I had discussed this publicly—some of the family had acknowledged the nature of her death and others had not. Ultimately, I came to the slow realization that many of my concerns and much of my anxiety were due to a resurrection of my feelings about my friend's suicide and the idea that when my dissertation was finished, I would be losing her again, since the long process of getting my undergraduate and graduate degrees had been, at least in part, a way of both keeping her with me and of denying her loss. I also had to begin to come to terms with questions I thought I had resolved—what, if anything, do I wish I had known earlier, and what, if anything, do I wish I had done differently?

CHAPTER IV

DISCUSSION

This chapter discusses the issues that arose in interviewing survivors and the main findings of the study, presents the limitations of the study, and discusses implications for clinical practice, training, and future research.

Issues in Interviewing Survivors

When this project was first discussed, the researcher received feedback from various sources that recruiting participants might be extremely difficult, with the additional concern that all of the participants would likely be recruited through the support groups, issues discussed in more detail in the section below on problems with the sample. Other concerns included the appropriateness of interviewing survivors at all given the potentially traumatic nature of the loss and the research criteria that the loss would have had to occur less than five years prior to the interview. Still more concerns were raised about the possibility of conducting some of the interviews by telephone and not in person, with the resulting inability to see first-hand how well the participant had coped with the interview. As noted in the section on being the researcher, these concerns followed the researcher throughout the course of the interviews. One result was that the researcher contacted all of the participants by phone or email after the interview to see if they had experienced any additional reactions they might want to discuss and to have the

opportunity to speak again about possible referrals for additional supports. Participants who had expressed interest in this information were provided with the referrals in this follow-up call/email.

It is worth noting that the three agencies contacted for assistance with recruitment had varying levels of internal review before allowing the researcher access to their members. SPAN-USA did not ask for additional information and sent the researcher's contact information out readily. The AFSP had its own internal review, which required the submission of the dissertation proposal; after the proposal was reviewed, the AFSP sent out the researcher's call for participants to New Jersey chapters and members since that was where the research was based. The AFSP agreed to consider sending additional messages out if the researcher did not enroll a sufficient number of participants. Initial contact with the American Association for Suicidology's Survivor Chair was not returned; contact with the Research Chair was also unsuccessful since the feedback was to contact the Survivor Chair. The researcher eventually stopped pursuing the AAS for assistance until a new Survivor Chair was named. This Chair agreed to publish the call for participants in the survivor newsletter but was informed that the research would need to be submitted to the AAS's own Institutional Review Board first. Unfortunately, at that time the AAS did not have an active IRB, and was reviewing all research through a university IRB with which the then-president was affiliated. As the AFSP was nearing approval by this time, the researcher discussed with the dissertation chair whether the effort should be spent on pursuing AAS approval since the application to the IRB was extensive; it was decided that this effort would be made only if a sufficient number of participants were not enrolled.

Since the time this researcher recruited participants, the AFSP and SPAN-USA have joined together as a single agency. Although it is appropriate for all organizations, especially those sponsoring research, to set their own requirements, it was somewhat difficult to navigate the various levels of oversight in a timely fashion. This is mentioned as a helpful suggestion to future researchers since the other options for recruiting survivors—word of mouth, contacting other clinicians—did not result in any enrolled participants. Other methods of accessing future participants—funeral directors, hospitals, police departments—are likely to have their own concerns or review processes.

As to the challenge of deciding whether participants would be able to cope with the potential stress of the interview, it is worth noting that some individuals who contacted the researcher and appeared to be still actively coping with high stress levels did not respond to follow-up calls or emails. One individual who the researcher judged too stressed to be interviewed at the time of contact was not interested in a follow-up several months later. Since there were other individuals who expressed interest and did not follow-up, no firm conclusion can be drawn about why these individuals did not follow up, but it can be presumed that this self-selecting out process may have been protective in nature as the individuals determined their own ability to participate.

The interviews that were completed by phone presented a special challenge since it is more difficult to assess whether a participant is distressed. The participants interviewed by phone were fortunately able to tolerate the interviews well. Since scheduling interview times is frequently a multi-step process, most participants had been in contact with the researcher several times by phone or email, which did provide additional support for their tolerance. However, given the information gained from the interviews that some participants had histories of mood disorders, suicidal ideation, and even suicide attempts, a more formal screening process might be considered depending on the nature of the interview.

The researcher had offered to conduct the in-person interviews either at the participant's home or at a convenient location. Over the course of the interviews, several issues arose. First, although not directly asked, the researcher realized that some participants did not want to be interviewed in their homes since that had been the location of the suicide. Second, the alternate locations varied in their levels of privacy and comfort. Future researchers should consider pre-screening for issues with participant's homes and consider whether it would be feasible to arrange to have specific interview sites even though that might mean the participants have to travel. With that said, however, New Jersey participants who were offered interviews at the researcher's graduate school were usually too far from that location for it to be convenient.

In regard to the length of time between the loss and the interview, the decision had been made to limit the time period to five years in order to include mainly participants who might have had access to computers and the internet; however, having access or knowledge was not an inclusion criteria since it was also understood that not everyone chooses to use computers or chooses to use them to seek information. The decision as to the time period meant that some losses were within the year prior to the interview, others up to six years. There was particular concern expressed about interviewing participant's whose losses were recent; however, if future researchers seek to avoid many of the problems uncovered in this research and seek to assess current availability of information or supports, the inclusion criteria will need to be even more time limited, resulting again, as noted above, in a possible need for a more formal screening process.

Finally, as noted above, many participants were willing to share their stories and clearly sometimes felt a need to tell their story to the researcher in excess of what was required for the research. Although this proved to be of later importance to the research, it was an additional stress both on the participant and on the researcher as the interviews exceeded the initial expected length of time to complete. It would be unwise to assume that survivors are unique in their need to be understood and to have a chance to speak with a perceived professional about their experience, but the additional fact of this researcher being a survivor cannot be understated and needs additional investigation in future research to determine whether survivors would be as open with a non-survivor, particularly a perceived professional, often shortly after the loss.

Changes in Participant's Attitudes towards Suicide

As discussed in the results section, the main changes in participant's attitudes towards suicide were a shift to understanding suicide as due to mental illness and a decreased belief that suicide can be prevented. These two findings are related and provide perhaps the most important finding of this research and also indicate a need for additional research. Although many of the participants had acknowledged mental illness as a factor in their understanding of suicide both before and after their loss, their understanding of and attitudes towards mental illness were not assessed during the interview. Most importantly, their understanding of how to help someone with a mental illness was not assessed—the question was whether they felt that there was something another individual could do to help a suicidal individual. They were not asked if someone could help an individual with depression, or bipolar disorder, or a substance abuse problem. Some participants gave responses that indicated they were trying to help with these problems—help the person seek treatment, medication, rehabilitation—and also indicated that they understood that the individual who suicided might not have been thinking clearly at the time. As noted above, many participants described in detail the struggles they and the individual had had, sometimes over many years, which now allows for a discussion of some of the barriers faced in helping individuals with mental illness.

As described in the section on being the researcher, this researcher experienced some of the challenges of attempting to be supportive to an individual with mental illness that were described by the participants—calling crisis services, finding out my friend had been hospitalized again several days into an admission when she finally felt well enough to call me or when her family called me, losing hope that she would ever return to work and realizing how much worse that made her feel. Looking back, I realize I never expected to have any contact with her providers since I was only a friend—however, due to privacy laws or the reluctance of some individuals to allow family contact, some of the participants, who were all family members, also did not have contact or were refused contact. It is impossible to expect family members to be adequately supportive in the absence of contact with treating professionals and appropriate psychoeducation programs. Recommendations to include the family in the treatment of suicidal individuals are not supported by either the current privacy regulations or reimbursement rates that limit the number of sessions provided. Additionally, services that are only offered during the day, including inpatient family meetings, are an added burden to family.

One possible conclusion as to why the participants became less convinced that someone could help a suicidal individual is the misunderstanding that suicide is always an impulsive act that cannot be predicted—participants made comments as to how their individual was "doing better" which led to some of the confusion about the question of whether they thought the individual was "at risk." There is significant research as to both the raised risk of individuals who have attempted previously as well as the associated risks for individuals diagnosed with mood and psychotic disorders. Given the responses of the participants, this information is not being adequately disseminated as demonstrated by the participants' confusion as to whether their individual was "at risk."

Seeking Information Before the Suicide

Continuing the discussion above, one of the most important findings of the study was that participants did not seek information specific to suicide even though many of the individuals who suicided had made prior attempts that were known to the participant. However, many had sought or been given information regarding the illnesses with which their individual was struggling—mood disorders, substance abuse, etc. Some participants were clearly involved in trying to get help for their individuals, including mental health treatment—this was not an anti-psychiatry group or a group that saw these illnesses as moral failings or shortcomings. One issue that was not directly assessed but is of importance is what type of relationship the participant had with the individual who suicided—not all of the individuals lived with the participant. Additionally, not all of the previous attempts reported had necessarily been recent, and participants were not asked how they knew about the individuals—16 of the 20 individuals who died were known (although not necessarily by the participant) to have made at least one prior attempt and all had received some type of mental health or substance abuse treatment. How did the participants come into such little contact with information about suicide?

It may be presumed that either participants were not given the information that one attempt raised the likelihood of their individual attempting again or they were given this information and found it too difficult to process. Both are likely based on the researcher's experience working in a family support setting in New Jersey and on inpatient units in New York and Connecticut. In speaking with families about serious mental illness and suicide, it is often taken for granted that the family will not be able to process all the information needed to support their individual. Families may be referred to education programs and support groups run by local mental health agencies or by NAMI (National Alliance on Mental Illness) but many families do not attend. Giving families information about these resources does not adequately prepare them for the likelihood of another attempt if they do not utilize these resources, yet attempting to process not only the diagnosis but also the prognosis is difficult as well, although this is acknowledged to be a standard of care for patients who allow family contact.

Family contact is another area of concern. When clinicians are able to speak with families, it is often perceived as an information-gathering opportunity needed to help treat the patient, which is valuable, but does not necessarily help the family understand either the illness or how to best help the individual. From a family-systems perspective, speaking to one or perhaps two family members is not necessarily helpful since those individuals may not be either the patient's main sources of support or the members of the family who have the authority to make changes. In this sample, although parents might

have expected to be contacted, it is unlikely that the siblings, aunts, uncles, and cousins would have been involved.

What was not adequately assessed since participants did not seek information about suicide prior to the loss is whether that information would have been helpful or easy to find. Although many sought or were given information on related topics and found that helpful, that cannot be compared to actively seeking information about suicide. While many readily available brochures on various illnesses, such as those found on the websites of the National Institute of Mental Heath, the Depression and Bipolar Support Alliance, and NAMI, discuss the issue of increased rates of suicide, it has not been established that simply reading a brochure, as the participants may well have done, leads to an understanding of the level of risk associated with a given individual.

Seeking Information After the Suicide

As noted above, the most striking finding is that the concept of "survivor" is still not well known and frequently led to delays in participants being appropriately referred to groups or to survivor information. Although one participant noted "there has to be a group for this somewhere" not all participants were prepared to persist in seeking help, some were not even able to seek information at all.

One clear finding is that the concept of "survivor" or "bereaved by suicide" has not yet entered the common language of either clinicians or the general public, leading to delays in survivors finding relevant information. Although many participants reported having met with another survivor as being what was most helpful, it may also be presumed that attending a group or another survivor event also provided the framework within each survivor goes about integrating their experience, including being provided with literature on other survivors' experiences.

The participants, as detailed in the next section, were above average in income and education, leading to the question of how other survivors' experiences might have differed. Although many participants turned to public or free sources—libraries, help lines, calling local agencies—many also used the internet or were able to buy books either at bookstores or online.

Limitations of the Study—Problems with the Sample

The limitations of this study are so many and its flaws so varied as to make it both useless and useful at the same time. As with other qualitative research, the results have led to more questions than answers, and as with other small samples, the results cannot be generalized outside the individuals interviewed. What follows in this section is a discussion of the problems with the sample and issues with the interview, both in content and in relevance.

The sample was almost entirely Caucasian (22 of 23 or 96%) with an income level at or above the national average of \$50,000 (18 of 23 or 78%) and an education level well above the national average (85% of the U.S. population reports having completed high school and 28% have at least a bachelor's degree; 100% of the sample have completed high school and 61% have at least a bachelor's degree [14 of 23]). These statistics imply that the sample has a much higher than average rate of computer ownership and access to and ability to use public resources; however, these questions were among the many discovered as "missing" during the course of the interviews. The fact that the sample was mainly white, educated, and middle-class is likely a reflection of how the sample was gathered—by contacting agencies (AFSP and SPANUSA) that the participants had found for support. Survivors without access to computer or community resources are, by implication, less likely to have been included; while this work cannot speak to their experiences of seeking information, it would not be surprising to find that their experiences may have been even more difficult.

It should be noted that the sample was almost entirely female (20 of 23, 87%). Although the experiences of the three male participants were not notably different than the experiences of the female participants (had not sought information prior to the loss, had some knowledge that the individual might have been at risk or had been in treatment, did seek information subsequent to the loss), the small number of male participants raises the question of whether their experiences can be generalized. Of course, a sample of only 20 females is also too small for generalization, and the question of how gender might have affected not only the participants' experiences but also the likelihood that they would have responded to the research advertisements is unknown.

The fact that the sample was comprised of participants who were already in contact with survivor/suicide organizations cannot be overlooked as a significant limitation. Whether they had found these organizations on their own or were referred by others—family, friends, or local agencies—the participants had all come into contact with some type of survivor organization, and in fact many of them cited that experience as most helpful to them. How the interviews and responses would have differed with a sample of survivors who had not had this contact is left to future research.

Continuing with the difficulties noted above, the responses provided in answer to the Ways of Coping questionnaire might also have differed had the sample not been from those already in contact with the survivor agencies. The Ways of Coping was administered in part to see if there was a relationship between coping styles and information seeking, although information seeking was not directly assessed by the questionnaire. The area of how public health information is disseminated and used by individuals is a broad topic that was not adequately assessed by any of the available coping measures. It is probable that information seeking is related to other variables in addition to those measured by the questionnaire, such as education and income level, personality structure, and cultural background.

Limitations of the Study—Problems with the Interview

The most significant limitation of the interview is that it was retrospective. Answers to questions regarding attitudes about suicide prior to the loss, recollections of information seeking prior to the loss, and knowledge of the individual's risk for suicide prior to the loss may all have been heavily influenced by participant's later experiences. Answers to questions about information seeking subsequent to the loss were also retrospective; in some cases, participants were recalling events up to five or six years prior to the time of the interview. As has been demonstrated in the research on "flashbulb" memory (Weaver, 1993), memories retrieved from the time of significant events are as likely as other types of memory to be incorrect or influenced by subsequent events.

With that most significant limitation noted, others arose as the interview was administered. As noted in the Results section, participants felt that the Ways of Coping instrument did not adequately allow them to respond to many items as those items may have asked about ways of coping that were "not possible" in the case of surviving suicide, such as trying to talk to the individual involved. How completing this questionnaire prior to the start of the actual interview may have influenced participants' responses was not an area of assessment (i.e., there was no attempt to vary when the questionnaire was completed).

Many of the interview questions turned out to be problematic in that they were either unclear or open to too many interpretations. The length of the interview itself with informed consent, the Ways of Coping, and the interview—often exceeded the expected 90 to 120 minutes due to the depth with which some participants responded to individual items. These problems might have been avoided or partly avoided by having piloted the interview during development; however, the concern that not enough participants would be found for the research (which turned out to be untrue) prevented the researcher and the committee from requiring a pilot.

As to the items that turned out to be unclear, the first problem area was the section that asked about attitudes towards suicide. In an attempt not to use another questionnaire, the broad areas assessed in full questionnaires were shortened into the open-ended questions asked in the interview. However, by distilling broader areas into single questions, participants were "put on the spot" to answer questions that might have been considered challenging if not uncomfortable even to those who had not experienced suicide. Again, the purpose of these questions was to understand whether participants' attitudes might have influenced their information seeking experiences, but the effect of asking these questions at the start of the interview is unknown, particularly with respect to their subsequent recollections of the events that occurred prior to and following their losses. The questions regarding the race and ethnicity of the participant and the individual lost to suicide were difficult for many participants to answer, an issue described by many researchers as related to the privilege of Whites to not be aware of race and ethnicity. Participants were not asked about their religious or spiritual beliefs or affiliations, past or current, a significant oversight that was somewhat resolved by some participants discussing their beliefs in the attitudes towards suicide questions. These difficulties result in the sample not being well understood or described in contextual terms of race and culture, compounding the problem that the sample is not diversified.

The questions asked about where the participant lived at the time of the suicide and if they had moved, when they had moved, were meant to gain an understanding of where they might have sought services and information prior to and subsequent to their loss. What was not asked directly but fortunately came up during the interviews was where the individual who suicided had been living. Although the relationship to the individual was asked, the physical proximity and current relationship status at the time of the suicide was not asked. Some participants were either at a distance from the individual or were somewhat estranged from the individual—situations that likely impacted their knowledge of the individual's status and their own information seeking behaviors, which will be discussed further later in this chapter. This issue might have been addressed during the recruitment phase by including criteria related to the distance between the participant and the individual; however, since information seeking has not been studied in either population (those living near or far), this issue may be regarded more as a finding of the research than a true limitation. Participants were asked to briefly describe the suicide. Responses to this question varied in length and detail; often participants appeared to need to tell the story of their individual's life, discussed above in the section on interviewing survivors. However, important features of the events—such as whether the participant had been the person who found the individual after the suicide or how the participant found out about the suicide—were not deliberately probed, although the answers were often spontaneously given.

Implications for Clinical Practice

There are two set of recommendations for clinical practice—one for individuals who are caring for or are involved with an individual who is at risk for suicide or who has already attempted, a second set for survivors.

Although it goes against the client-centered perspective and current privacy standards, it is hard to understand how the mental health profession will be able to lower suicide rates without adopting a more systems-based perspective. We have a duty to protect individuals from harm by our patients under the Tarasoff laws but no equivalent to warn a family of ongoing suicidal ideation in a patient. On the contrary, the expectation is that we will treat the suicidal ideation and do our best to protect the patient and that it is the patient's choice to involve the family. Research on chronic illnesses such as schizophrenia show better outcomes for individuals who are able to access social supports and for those whose families participate in multi-family support groups, which include the consumer/patient as well as involved family members. Access to such groups is limited due to lack of clinician education and funding sources. Although it may be difficult to convince families to attend and may be a burden on their time, it would be

worthwhile to assess whether in addition to lowering other symptoms, these groups also reduced suicidal ideation and attempts/completions.

Short of providing more multi-family groups, it would be important to assess current standards of family education. Many agencies, particularly those under JCAHO, have adopted procedures for providing and documenting patient and family education, but few are able to evaluate the impact of such procedures on the family. Given the experiences of the participants in this study, there is a disconnect between information provided (if provided at all) and information processed. In this researcher's experience, surveys are provided to the patient asking if the staff answered their questions, explained their treatment, and so forth—but no such measure is given to the family.

It would be naïve to suggest that involving the family would be possible in all cases or even clinically recommended, but given the persistent number of suicides in the United States each year and the often-expressed willingness of some family members to be more actively involved in treatment, there seems to be little reason or excuse not to implement more family and evidenced based approaches to assess their impact on rates of suicide attempts and completions.

As to survivors, the finding that the concept of "survivor" is still relatively unknown needs to be addressed both at the training level and at the agency/professional level. Even clinicians who do not treat or want to treat survivors should be aware of the available resources and also be aware of the issues survivors face in the aftermath of suicide. It is especially important to note the change in survivors' attitudes towards suicide found in this small sample when assessing for suicidal ideation in a survivor their sense of helplessness in being ultimately able to prevent suicide has not been adequately explored either in terms of their own suicidal ideation or attitudes towards other loved ones who might be suicidal.

The issue of support groups I approach with great caution. Although many, if not most, of the participants expressed that meeting another survivor at a group or at a survivor event was one of the most important things in helping them cope, many also expressed being hurt or angry while attending groups. As discussed by Cerel, Padgett, Conwell, and Reed (2009), survivor support groups have sprung up around the country facilitated by individual survivors and/or professionals who may or may not be survivors themselves and are sponsored by suicide organizations, mental health organizations, churches, or just the facilitator. To say that the idea of a "survivor group" exists is somewhat limited by the many ways in which these groups are run. That said, Cerel et al.'s (2009) call for research into the nature and efficacy of groups is supported by this study, which found, surprisingly, that some participants, while finding the experience helpful, did not continue to attend. Should further research provide support for survivors' having access to groups, the argument could then be made to find ways to provide them to those survivors who expressed interest but were either too distant from the group's location or had other barriers to attendance, such as work schedules or child care issues. It would be particularly important to study the effects of online groups given the recent findings on social networking and internet communication that suggest the ways in which individuals interact online differs from in-person contact.

Implications for Training

Not every graduate student in the various mental health disciplines intends to work with suicidal patients or patients with serious mental illness. Graduate programs are expected to provide basic training in a variety of areas with the expectation that students will go on to gather additional experience and knowledge as post-graduates, eventually becoming experienced clinicians. With that said, I would like to suggest that changes might be made for those who do wish to work with those populations.

In my first year, the initial training on assessing for suicide was held in several settings, including the school clinic and the counseling-center practica site, stressing the need to assess each client for suicidal ideation. Of particular importance was who to confer with at each site and how to access emergency services if needed. While this was invaluable training, it framed the situation a crisis moment—training on treating a suicidal individual was left to later coursework and clinical experiences.

Although taking a history of personal and family suicide attempts and completions was included in this training, the issue of a client being a survivor was not framed in such a way as to allow for that to be a potential focus of treatment. I certainly had no idea that there were resources for survivors. My training in serious mental illness took place mostly at practica and my internship site, where families were regularly invited in for family meetings. My practica in substance abuse stressed the need for family involvement but could not make it a requirement for treatment, even when the treatment was court-mandated. The only setting in which family involvement was guaranteed was in my practica working with children with Tourette's Syndrome—and even there, it was often a struggle to frame the treatment as a family treatment and not just for the child. I was fortunate to have been trained in settings where the expectation was that family involvement was important, but was again trained within the limits of each setting. When I took a position at Intensive Family Support Services (IFSS), a New Jersey state grant-sponsored program overseen in Middlesex County by the University of Medicine and Dentistry (UMDNJ), I was introduced to the research on family psychoeducation and support. I was also introduced to NAMI, which had been instrumental in getting the funding for IFSS. I began to learn from the families' perspective how difficult it was to gain information about their individual's diagnosis, treatment, and prognosis given the time constraints placed on many clinicians. I also learned how invaluable local clinicians found IFSS to be as a referral source, particularly when there were clinical reasons for the family to be seen elsewhere, such as the patient being too symptomatic to engage in family sessions.

This set of experiences has led to the understanding that "treatment as usual" for the seriously mentally ill and those with chronic or recurring suicidal ideation is maintenance treatment at best, an argument made nationally by those seeking mental health insurance parity and those railing against the privacy laws that are interpreted in ways that prevent family involvement even in times of crisis. This research provides no answers to these issues, but suggests that training should make students aware of these areas of concern in order for them to engage in these discussions from the perspective of what treatments should be made available rather than adapting their treatments to what is expected at any given setting.

Implications for Suicide Prevention

Two findings stand out—first, that information about suicide is still difficult to adequately disseminate to those who need it most and second, that survivors are willing to be engaged in research. One participant expressed the wish that a psychological autopsy had been done after her son suicided—although not every family would rise to this level of engagement, the opportunity to begin to work with survivors on suicide prevention and not just on survivor issues is an opportunity that should not be wasted.

This study asked participants about their attitudes towards suicide, missing the related question of attitudes towards mental illness. Much of what is publicized about suicide and mental illness relates to depression; participants had reported that some of their individuals had been treated for depression, but also for anxiety, bipolar disorder, schizophrenia, and substance abuse. It has been my experience that it is incredibly hard for families, particularly during first episodes, to process a diagnosis of bipolar disorder or schizophrenia, much less comprehend the increased risk for suicide, again indicating the need for ongoing family support. It is a challenge for professionals, not families, to find a way to educate the public about the link between multiple diagnoses and suicide risk and the link between certain risk factors, including past attempts, and increased risk. Survivors, at least those in this sample, are willing to help.

Suggestions for Future Research

The need for future research has been documented by many, including the AFSP and the NIMH upon completion of the 2003 conference on survivor issues. What has been raised in this study only adds to the list of areas that are still not well understood.

Although disseminating the concept of "survivor" is clearly needed in order to have survivors more quickly referred to services and resources, it may be worthwhile to seek an understanding of what had made it difficult for this concept to enter our language and the language of mental health. It may be presumed that this is due to the ongoing stigma related to suicide but that presumption may impede efforts to increase awareness. Following the need to find better ways to increase awareness is the need to better understand the ways in which the public seeks mental health information. This study did not assess how participants first realized a need for mental health information, only whether they sought it prior to the suicide. Participants who accessed help lines and called local mental health agencies had varying levels of success in being referred to appropriate resources; individuals who contact these agencies might be surveyed about their experiences.

For individuals who access information about mental illness and suicide, it would be helpful to begin to research what understanding they take away from the information and whether that understanding produces any changes in their relationship with their loved ones, especially for individuals who are not able to access intensive supports such as multi-family groups or psychoeducation programs. Given how little time most clinicians are able to spend with families, the need to effectively communicate important information is crucial.

Research with survivors is still in the early stages, with much of the work done related to the grieving process or assessing interventions. The need to bring survivors into suicide prevention research is highlighted by this study. However, it is still unclear whether survivors will feel safe participating in research with non-survivors given the poor experiences many have had with professionals. It would be valuable information to survey survivors as to what types of research questions they might be willing to participate in as well as asking whether they would be willing to participate in research conducted by non-survivors.

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As noted by many, there is a need to research the effects of the various support groups. Since this is often the only "treatment" survivors may engage in, it would be important to have an understanding of the advantages and disadvantages of groups in order to make appropriate referrals.

Finally, it would be important to survey the many survivors currently active with the various suicide prevention organizations about their attitudes towards suicide. At the end of this research, I was left with the idea that some survivors are active in survivor fund-raising and awareness campaigns because they do not feel that suicide is preventable and would prefer that funds are directed to survivor services. Although survivor services are in clear need of additional funding, I would hope that the ultimate goal of all suicide research is to prevent suicide and the creation of new survivors. My own experience in coming to terms with the idea that there is more I could have done to help my friend has been difficult, yet my experience and the experiences of the participants in this study lead me to believe that it is by learning from our experiences that we, as survivors, can make important contributions to understanding suicide and to suicide prevention.

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APPENDIX A

Interview

(Begins with completion of Informed Consent form if not completed prior to interview.)

I am interested in learning about how information about suicide is found and used by the public. In particular, I am interested in learning about how individuals who have lost someone to suicide may have come into contact with such information and whether it was helpful. Hopefully, this research will find ways to improve the quality and accessibility of this information.

First, I would like you to complete a questionnaire that asks about how you have been coping since the loss of your loved one.

Second, I will ask you about your beliefs about and attitudes towards suicide.

Third, I will ask some basic questions about you, your loved one, and the events that took place.

Finally, I will ask some specific questions about your experience related to seeking or being given information about suicide.

If talking about your loss or answering questions about it becomes distressing, please feel free to ask to stop the interview, either for a break or to discontinue your participation. Any information that identifies you or your loved one will be disguised in the final work.

(Administer Ways of Coping.)

Thank you for completing the questionnaire. Now I would like to ask you about your beliefs and opinions regarding suicide. People have ideas about suicide that they form from the many influences in our lives—family, religious leaders, teachers, books and movies. To the best of your recollection, what personal (religious, philosophical, political, etc.) beliefs or opinions about suicide did you have <u>before</u> your loved one died? (Use probes below if this information is not spontaneously offered.)

Under what circumstances did you think someone might take his/her own life? Did you think there was any particular kind of person who might take his/her own life? Did you think there was anything someone else could do to prevent an individual from taking his/her life?

Did you believe that individuals had the right to take their own lives?

Have any of these beliefs changed since your loved one died?

If you feel you didn't have any beliefs or opinions about suicide prior to your loved one's death, what do you believe now about suicide? (Use same probes if needed.)

Under what circumstances do you think someone might take his/her own life? Do you think there is any particular kind of person who might take his/her own life? Do you think there is anything someone else could do to prevent an individual from taking his/her life?

Do you believe that individuals have the right to take their own lives?

Thank you, now we can move on to the questions about you and your loved one. This information is needed so that those who participated can be described in general in the final work; no identifying information, such as a name, will be used.

Your gender Your age Your race/ethnicity Your family income (0-25; 25-50; 50-75; 75+) Your highest year completed in school Your residence at the time of death (state, county, city) If different than current, when did you move Relationship to deceased Name of deceased (for interview purposes only) Gender of deceased Date of death Age at death/Date of Birth Race/ethnicity Brief description of events Prior attempts, if any If prior attempts, did you know about them before person died Is this the only person you have lost to suicide Is this the only person in your life who has made suicide attempts Ever in treatment, to your knowledge Ever diagnosed, to your knowledge Diagnosis if known Ever took medication, to your knowledge Taking medication at time of death If ever in treatment, what do you know about the type of treatment (therapy, day programs, hospitalizations, etc.) Were you aware that this person was at risk for suicide If so, how did you know Since your loss, have you been involved with any survivor support groups?

Now I would like to ask you about information you may have sought or been given about suicide. People cope with loss in many different ways. One of those ways is to gather information. Many people who have lost a loved one to suicide become interested in learning more about suicide. I am interested in learning what types of information you had about suicide both <u>before</u> and <u>after</u> your loss. This information might have come from any type of source.

First, if you had been aware that your loved one might have been at risk for suicide, I would like to ask about your efforts, if any, at gathering information about suicide before your loss.

What information, if any, did you seek or were you given about suicide before your loved one's death?

Probes if needed:

Risk factors Warning signs Causes of suicide Prevention Emergency services/crisis resources Mental illness/depression Mental health treatment

Where did this information come from? Did you seek it out yourself or did someone give it to you? If you sought it out yourself, was it easy to find? If someone else gave it to you, how was that person related/known to you? When did you seek out this information or when was it given to you? Was this information helpful to you? How was it helpful? If it was not helpful, how was it not helpful?

Now please answer some questions about information you might have received or sought <u>after</u> your loss.

Did you feel the need to gather information about suicide after your loss? What information did you seek? Probes if needed:

Risk factors Warning signs Causes of suicide Prevention Emergency services/crisis resources Mental illness/depression Mental health treatment Resources for survivors Information about survivors

How soon after your loss did you begin to gather information? Where did this information come from? Did you seek it out yourself or did someone give it to you? If you sought it out yourself, was it easy to find? If someone else gave it to you, how was that person related/known to you? If someone else gave it to you, when did they give it to you? Was this information helpful? How was it helpful? If it was not helpful, how was it not helpful?

Looking back over all the information you eventually found or were given, what, if any, information did you wish you had earlier?

Would there have been an easier way for you to get that information?

What information would you say has been the most helpful?

Thank you for your time and participation. This is the end of the interview. Before we finish, is there anything related to what we have discussed that you would like to add?

APPENDIX B

Informed Consent

Information Seeking by Survivors of Suicide

You are invited to participate in a research study that is being conducted by Kristen K. Gawley, Psy.M., who is a graduate student in the Graduate School of Applied and Professional Psychology at Rutgers University. The purpose of this research is to examine the ways in which individuals who have lost a family member or friend to suicide came into contact with information about suicide and whether that information has been helpful. The goal is to help improve the quality and accessibility of this information.

Approximately 20 subjects 18 years and older will participate in the study, and each individual's participation will last approximately two hours. The study procedures include completion of a questionnaire and an interview designed by the researcher.

- Subjects will first be asked to complete a questionnaire about how they have been coping with the loss of their family member or friend. This will take approximately 15 minutes.
- Subjects will then be asked a series of questions designed by the researcher, including questions on beliefs about suicide, the events that took place, and the individual's experiences seeking or being given information about suicide. The interview is expected to take approximately 90 minutes.

The information in the study records will be kept strictly confidential. Data will be stored securely in a locked cabinet and/or restricted-access computer and will be made available only to persons conducting the study unless you specifically give permission in writing to do otherwise. No reference will be made in oral or written reports that could link you to the study.

There are minimal risks to participation in this study. You may become distressed during or after the interview since it asks questions about the death of your family member or friend. If this occurs and you feel that you need more counseling than the researcher is able to provide at the time of the interview, the researcher will provide you with information about local support services.

Participation in this study may not benefit you directly. However, the knowledge that we obtain from your participation, and the participation of other volunteers, may help us to understand the ways in which information about suicide is obtained by concerned family members and friends and how helpful that information may or may not be.

Subject's initials: _____

Participation in this study is voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions with which you are not comfortable.

This research is confidential. Confidential means that the research records will include some information about you, such as the details about your age, family income, education, and details about your loss and your relationship with your family member or friend. I will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. Any quotations from the interview material will be disguised so that no individual participant can be identified.

Please initial here if you would like a copy of the results mailed to you:

If you have any questions about the study procedures, you may contact Ms. Gawley at (732) 236-8820. If you have any questions about your rights as a research subject, you may contact the Sponsored Programs Administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human Subjects Office of Research and Sponsored Programs 3 Rutgers Plaza New Brunswick, NJ 08901-8559 Tel: 732-932-0150 ext. 2104 Email: humansubjects@orsp.rutgers.edu

You will be given a copy of this consent form for your records.

Sign below if you agree to participate in this research study:

Subject	Date
Principal Investigator	Date

This research protocol was approved by the Rutgers Institutional Review Board for the Protection of Human Subjects on 11/1/2006 and expires on 10/31/2007.

APPENDIX C

Advertisement

You are invited to participate in a research study that is being conducted by Kristen K. Gawley, Psy.M., who is a graduate student in the Graduate School of Applied and Professional Psychology at Rutgers University in New Jersey. The purpose of this research is to examine the ways in which individuals who have lost a family member or friend to suicide came into contact with information about suicide and whether that information has been helpful. The goal is to help improve the quality and accessibility of this information. The study procedures include completion of a questionnaire and an interview designed by the researcher and is expected to take between one and two hours to complete. This research is confidential. No reference will be made in oral or written reports that could link you to the study. The interview may by completed by phone or in person if the researcher is able to drive to your location within a reasonable time. Adults (age 18 and over) who have lost an adult (age 18 and over) family member or friend to suicide within the past five years are welcome to contact Ms. Gawley by phone at 732-236-8820 or by e-mail at kkgawley@eden.rutgers.edu. Thank you for taking the time to read this request.

This advertisement and research protocol was approved by the Rutgers Institutional Review Board for the Protection of Human Subjects on 11/1/2006 and expires on 10/31/2007.