

How suicide stigma adversely affects the bereaved: What health professionals need to know

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Losing Jesse

- Our journey began 11 years ago with the suicide death of our oldest child, Jesse, who died at age 31.
- Our lives were instantly turned up-side down and we became “Suicide Survivors”, bereaved by suicide.



Some Statistics


- Today there are about 38,000 suicides yearly in the US.
- For every 100,000 persons in the US, 12 will die by suicide yearly (about 1 in every 100 deaths).
- Suicide is the 12th leading cause of death for all age groups, and the second leading cause for the college aged.
- It is estimated that for every death by suicide there are at least 6 survivors affected, numbering into the millions of people affected over time.

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- How many in our audience know someone in their family, remote or close relative, friend, co-worker or patient who died by suicide?
 - How many here were negatively impacted by a suicide death?



Jesse's death: The perfect storm

- Trauma
- Low-self esteem
- Recreational and self-medicating drug use
- High performance expectations and pressure from his fiancée
- Impulsivity

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- My wife Beverly, a clinical social worker and I, a sociologist, were challenged to make sense of our tragedy.
 - We discovered limited scientific information available on survivorship.
 - Fortunately, we joined forces with two experts in the field of suicide bereavement, Jack Jordan and John McIntosh, who helped nurture our research project.
 - We were privileged to also have the help of 575 bereaved parents who participated in this largest survey ever of traumatic loss.



DEVASTATING LOSSES

How Parents Cope
with the Death of a Child
to Suicide or Drugs

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John L. McIntosh | Beverly Feigelman

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Our Child Loss Survey

- began in 2006, and included bereaved parents from all over the US & Canada that lost children.
- These parents completed an exhaustive 27 page survey that probed death characteristics, demographics, grief difficulties, mental health, treatment seeking behaviors and questions about marital relationships.
- The survey included: 575 cases of which 462 were bereaved by suicide loss, 48 drug-related death survivors, 42 other traumatic, mostly accidental, death survivors & 24 whose children perished from natural deaths.



Our study (continued)

- Respondents were solicited from support groups, clinicians' patient rosters, and outreach from previous respondents.
- We had a 72% rate of cooperation, much higher than most mailed surveys.
- My being a survivor/researcher helped inspire cooperation among potential respondents.
- Our analysis embraced qualitative and quantitative dimensions of the subjects studied.
- The study was supplemented with participant observation data collected from survivor support groups over the last 11 years.



Our study embraced a broad array of questions about parental adaptations after suicide loss:

- Suicide stigma
- Drug-related deaths and parental grief
- The impact of multiple losses and only child loss
- How parents survive: Early and later years after loss
- The role of peer support groups in helping the bereaved advance their healing.



Subjects investigated (cont.)

- Internet support groups for suicide survivors
- Personal growth after suicide loss
- Gender differences in grief
- How a child's death affects marital stability



Suicide stigma: a historical view

- Can be traced back to the Middle Ages.
- Suicide decedents' bodies were often mutilated after the deaths to purge them of evil spirits.
- Dying by suicide led to a prohibition that the body could ever be buried in a church cemetery.
- The church would exact a financial penalty upon the bereaved family to compensate for the reduced future contributions to family tithe obligations.
- Usually property would be confiscated and the family would be forced to move away.



Suicide stigma today

- Suicide is still considered a crime in some parts of the US.
- Insurance companies deny compensation if an insured suicide deceased dies within two years after having been issued a new policy.
- Occasionally compensation will be denied if the suicide deceased dies under the influence of drugs.
- Today, as our research shows, the biggest problem the suicide bereaved confront is **the informal stigma** associated with suicide: being denied solace and support.



A few of our significant findings:

Suicide stigma

- More than half of all suicide survivors reported one or more family relationship strained (with one or more family member acting hurtfully to them) during the past year.
- 32 percent gave similar reports for close friends' responses.
- Our stigma scale was highly correlated with greater grief difficulties, complicated grief and PTSD and depression.



Suicide stigma findings (cont.)

- Results showed more grief problems, complicated grief, depression and suicide thinking when the bereaved experienced more suicide stigma.
- Our stigma scale correlated highly with all these elements, whether one was newly bereaved or a long-standing suicide bereaved parent.



Examples of stigma reported

- One surviving mother was told by her own mother “I’ll spend Mother’s Day with you if you promise not to talk about your child. Mother’s Day is a day for the living.”
- Losses were sometimes compared to the deaths of pets.
- “You should feel better now, since all that drama associated with your child’s difficulties is now over.”
- “He (or she) is with God now”, (without regard to whether the bereaved was religiously inclined or not).
- Avoidance was a common response; with close relatives or friends no longer calling or returning phone calls, and neighbors acting distant to the respondent.



Stigma examples (continued)

- Almost half of our suicide survivors reported hearing blaming comments, **blaming the deceased child** for being selfish, or inconsiderate **and/ or the parent** for not getting the child the right kind of help.
- Such blaming comments led many survivors to experience **disenfranchised grief**, where significant others denied the bereaved the legitimacy of their right to grieve.
- Many bereaved felt unrealistic pressures to “move on” after the death.
- Yet, most bereaved expected their grief to be lifelong.



Do others deaths evoke similar stigmatization as suicide?

- Death by drug-overdose (of a prescribed medicine or fatal mixing of a prescribed drug with a recreational drug) is often classified by attending physicians and medical examiners as “accidental”.
- But, there is frequently ambiguity about the suicidal intent of many decedents dying from “accidental” drug-overdoses.
- Do these deaths spare bereaved parents from stigma or do they face similar shunning and isolation as suicide-bereaved parents.
- This was another question we investigated.



Drug-related deaths

- Our research comprised the first-ever comparative study of the drug-death bereaved. We studied 48 parents whose children died from drugs and compared them to the parents whose children died from suicide, ordinary accidents (N=42), and those whose children died from natural causes (N=24).
- We hypothesized that the accidental death designation of a drug overdose would not spare these parents from being stigmatized.
- Results suggested that drug-death-bereaved had stigma experiences paralleling those of suicide survivors.



Drug-death bereaved (continued)

- About half reported hearing blaming comments from friends, family or co-workers.
- The drug death bereaved showed higher scores on grief difficulties, complicated grief, PTSD, and depression, much like the suicide survivors, and significantly higher than those reported by accident and natural death survivors.
- In America, the drug-death bereaved rival the suicide bereaved in size, eclipsing their numbers in yearly deaths.
- Both suicide survivors and the drug-death bereaved are greatly under-served groups.



What do the suicide bereaved expect from health providers?

- They expect doctors to show them solace and support but instead often find avoidance.
- As one suicide bereaved mother reported:
“After my son died, his pediatrician since infancy, never called us, never sent us a sympathy card, nor attended the memorial service in our small town. In sharp contrast, when my dog died, I received a condolence card and sympathy calls from our veterinarian’s office.”



A British study (McDonnell, et al. 2012) of family doctors of the suicide bereaved:

- All 19 suicide bereaved respondents reported wanting to have contact with their child's family doctor after the death .
- None of these doctors reached out to them, even though they knew of the deaths.
- Only 2 of the 19 reported post-loss interactions (that they had initiated) were altogether positive.
- The rest reported insensitive or inappropriate responses that caused them to withdraw from seeking help for medical and/or mental health problems.



Other studies show problems among GPs with suicide risk populations

- In one study, conducted in three different California medical settings and in Rochester, NY, **only a third** of the GPs studied queried patients about their suicide risks even after patients showed high levels of anxiety and depression in their initial intakes (Feldman, et al., 2007).
- Another more recent study confirmed the above findings with a sample of Baltimore doctors who watched videos of depressed patients and were asked how they would have handled these cases: **only a third** would have asked about suicidality in these patients (Hooper, et al. 2012).



Medical education must be changed

- Suicide is a real risk among the suicide bereaved and must be carefully evaluated.
- Our research found heightened suicide thinking among the newly suicide bereaved, and elevated depression levels lasting as long as 10 years after the death (in comparison with those noted for the non-bereaved).
- Other studies confirm these findings with some showing even higher suicide risks for the suicide bereaved.
- We did not find any elevated levels of suicide attempts in our sample, which was an especially rare event.
- Yet, some studies have shown heightened risks of completed suicide among the suicide bereaved.



Changing medical education (cont.)

- Greater completed suicides among children whose parents died by suicide, spouses whose spouses died by suicide and parents whose children died by suicide (Brent & Melham, 2008).
- Thus, careful screening of the suicide bereaved for depression and suicide risk will always be a worthwhile procedure.



Changing medical education (cont.)

- Many dying by suicide will see a GP or other health provider in the last three months of their lives.
- A recent Swedish study found about half had done so in last 3 months of their lives (Crump, et al., 2013)
- Other studies show between 75 to 90% of suicide decedents visited doctors within the last year of their lives (Cho, et al., 2013; Kondilis, et al., 2013; Liu, et al., 2012; DeLeo, et al., 2013).
- Thus, doctors and other health care professionals play a crucial role in suicide identification and prevention.



Why most doctors don't screen for suicide risk?

Some possibilities:

- Fear it might heighten suicide risks among their patients.
Yet, no research has found any increased suicidality among adolescent patients after asking about their suicide risks (Gould, et al, 2005; Deeley & Love, 2010).
- Personal discomfort and projection of own feelings of embarrassment and shame onto their patients.
- Reluctance to open up a Pandora's Box: to acknowledge their own perceived inadequacies with mental health assessment or difficulty managing time within their busy schedules to explore risks comprehensively.



Another thorny problem: Dealing with the suicide bereaved family

- Sooner or later all MH counselors will confront the problem of a patient dying by suicide.
- Two British psychiatrists advised: “The psychiatrist has an important role in the aftermath of a patient’s suicide, **both in communicating with the patient’s family**, other clinical staff and the authorities...encouraging and participating in discussion about the patient’s care...so that lessons are learned and the best standard of clinical practice is maintained (pg. 48, Campbell & Fahy, 2002).



Yet, the realities of therapist/ bereaved family contacts usually are very different

- Most bereaved family members want to talk to the therapist afterwards.
- Therapists usually show reticence to meet with the families, fearful of violating bonds of patient confidentiality or fearful of lawsuits.
- Usually communication between both parties is stilted and limited (McGann, et al, 2011).



Realities of therapist/bereaved family contacts (cont).

- Legal and organizational requirements regarding confidentiality can vary from place to place.
- Usually the patients' estate's representatives have a right to the file information after the death.
- This generally means that a child's parents or the married partner has the right to the information depending upon the marital and family membership status of the deceased.
- The authors advise, “when in doubt, err on the side of **empathically based compassionate outreach** when deciding what level of involvement to have with a family.”



How do the suicide bereaved heal?

- Our research showed that most survivors eventually reach a “new normal” for themselves, usually during the first 4 to 5 years after the loss.
- They have occasional bad days, like the death anniversary date, where the pain of loss comes back ever so sharply.
- Otherwise, they cope and go on in the best ways possible afterwards.
- Most are greatly helped by a combination of support from family, friends, professional counselors and peer support group participation.
- Many make new and important friendships from their contacts in the community of the suicide-bereaved.



Many experience personal growth

- Most all survey respondents, more than 2/3s, experienced personal growth five or more years after their loss.
- They felt they had been changed, had become more compassionate, caring and help-giving persons.
- Many assumed roles of leadership in helping the newly bereaved in peer support groups, became advocates in suicide prevention, or embarked upon other new careers or humanitarian enterprises.
- Personal growth and mental health problems appeared to be inversely correlated, suggesting that mental health professionals may want to encourage their survivor/ patients to participate in more care-giving activities to promote their own emotional healing.

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- For more information about the study, and *Devastating Losses* (NY: Springer, 2012) contact us at: feigelw@ncc.edu
 - **William Feigelman: 718 380 8205**
 - **Thank You Very Much!**