Supporting and Collaborating with Survivors of Suicide & Suicide Attempts

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Today's Presenters

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1

Learning Objectives

- Present evidence base for programs to support survivors and describe programs
- Describe ways of engaging survivors in state planning, advocacy, and programs
- Present evidence base for programs to support survivors of suicide attempts and describe programs
- Identify importance of survivors and attempt survivors playing key roles in youth suicide prevention

Important Definitions

- Suicide survivors family members, significant others, or acquaintances who have experienced the loss of a loved one due to suicide; sometimes this term is also used to mean suicide attempt survivors.
- $\circ \qquad \textbf{Suicide attempt survivors} \text{individuals who have survived a prior suicide attempt}.$
- Prevention a strategy or approach that reduces the likelihood of risk of onset, or delays the onset of adverse health problems or reduces the harm resulting from conditions or behaviors.
- Postvention a strategy or approach that is implemented after a crisis or traumatic event has occurred.
- Complicated Grief intrusive symptoms of yearning, longing for and searching for the decased, as well as four or more persistent symptoms of trauma as a result of the death. These symptoms of trauma include: avoidance of reminders of the decased, purposelessness, feelings of futility, difficulty imagining a life without the decased, numbness, detachment, feeling stunned, dazed, or shocked, feeling that life is empty or meaningless, feeling like a part of oneself has died, disbelief, excessive death-related anger or bitterness, and identification symptoms or harmful behaviors resembling those suffered by the decedent (Prigerson et al., 1999)
- Advocacy groups organizations that work in a variety of ways to foster change with respect to a societal issue.
- Best practices activities or programs that are in keeping with the best available evidence regarding what is effective.
- Evidence-based programs that have undergone scientific evaluation and have proven to be effective.

The Survivor Journey



Seeing Our Way Through

Staggering Statistics

- o Approximately, 30,000 Americans die by suicide annually.
- Each suicide produces at least six and as many as hundreds of survivors (Crosby & Sacks, 2002; American Foundation for Suicide Prevention, 2004; Provini et al., 2000)
- o 1 in 64 Americans is a survivor of suicide (McIntosh, 2006)
- 4.5 million American have been affected by the suicide death of a loved one (McIntosh, 2006)
- 7% of Americans reported being directly affected by a suicide in previous year (Crosby & Sacks, 2002)
- 1.1% stated an immediate family member had died by suicide (Crosby & Sacks, 2002)
- Between 650,000 and 1.8 million individuals attempt suicide each year (NSSP, 2001 & Kessler et al, 2005)

Research Shows That ...

Survivors must deal with the unique problems associated with a suicide death, including:

- a prolonged and intense search for the reason for the suicide (Wagner & Calhoun, 1992)
- feelings of being rejected by the deceased (Van Dongen, 1993)
- a distorted sense of responsibility for the death and the ability to have prevented the suicide (Dunn & Morrish-Vidners, 1987)
- and feelings of being blamed for causing the problems that began the suicidal ideation of the deceased (Silverman et al., 1995).
- Individuals grieving a suicide death also appear to have elevated levels of anger, family dysfunction, and feelings of social stigmatization (Jordan, 2001).

Research Also Shows ...

- Suicide rates have been shown to be twice as high in families of suicide decedents than in families in which a suicide has not occurred (Runeson & Asberg, 2003).
- Suicide survivors, similar to survivors of other types of sudden traumatic deaths, may have an increased incidence of traumatic or complicated grief and post-traumatic stress disorder (PTSD) (Jordan, 2001).
- Complicated grief has been shown to occur in adolescents and young adults as a result of a peer's suicide. Among these adolescents and young adults, complicated grief was associated with a five-fold increased risk for suicidal ideation after controlling for depression (Melhem et al., 2004).
- In addition, complicated grief appears to be related to both the onset of depression and a prolonged course of depression and PTSD (Melhem et al., 2004).
- Suicide survivors with closer kinship relationships to the decedent have been shown to have higher levels of complicated grief (Mitchell et al., 2004).
- Among survivors of suicide, complicated grief has been shown to be associated with a substantially greater likelihood of suicidal ideation in the month after the death, even after controlling for depression (Mitchell et al., 2005).
- Thus, suicide survivors who experience complicated grief are at elevated risk for suicidal ideation, and potentially their own suicidal behavior.

Research ...

- o Jordan and McMenamy (2004) state that "careful longitudinal research with a diverse, community-based sample of survivors would greatly increase our understanding of the challenges involved and the coping skills required after a suicide;" such research would also provide insight into the majority of survivors who do not seek organized or professional assistance following a suicide.
- Suicide survivors often do not seek out formal or informal support or mental health treatment. Only about 25 percent of 144 nextof-kin survivors surveyed by phone reported receiving any help since the suicide, despite seventy-four percent indicating a desire for help (Provini et al., 2000).
- In another study, half of bereaved survivors felt a need for professional mental health treatment, but only one quarter actually sought out help (Dyregrov, 2002).
- Most individuals who receive help do so soon after the death, but suicide survivors also appear to have difficulty initiating a search for help on their own (McIntosh, 1993).
- Initiating a search for mental health care or peer support may be challenging due to extreme grief or difficulty locating resources in a community.

Survivor Suggestions

Top two suggestions for coping after suicide loss include:

- "seek out other survivors"
- "find a support group in your community or a chat room on the internet where you can connect to others who are now residents in your strange new land" (Myers & Fine, 2006)

"Support groups provide one of the most valuable resources for suicide survivors. Here, you can meet and talk with (or just listen to, if you prefer) people who are in your shoes. You can openly express your feelings and experiences with a group of caring individuals who will never judge you..." (Jackson, 2003).

Connecting with other survivors "reassures me, once again, that I am not alone, and gives me the courage and language to reach out to others for support" (Myers & Fine, 2006)

Support Groups

- Mutual support groups have been described as the most common form of bereavement intervention due to their convenience, low or no cost, and perception of being less threatening than formal mental health treatments (Levy et al., 1993).
- While many survivors do not seek out formal or informal support of mental health treatment, support groups for suicide survivors are widely available.
 - The Suicide Prevention Resource Center (SPRC) website (www.sprc.org) links to directories of support groups across the United States compiled by the American Association of Suicidology (AAS) and the American Foundation for Suicide Prevention (AFSP).
- Many view participation in a support group as an essential part of working though bereavement following the suicide.

Are there groups out there?

- See AAS (<u>www.suicidology.org</u>) or AFSP (<u>www.afsp.org</u>) websites
- There are also online support groups (www.spanusa.org/onlinesupportgroups)
- A survey of 149 survivor groups in the US and Canada in the early 1990's provides most of the information that is known about survivor groups. The study found that most groups had been in existence for 8 - 9 years and provided services to less than ten people in monthly or twice-amonth meetings (Rubey & McIntosh, 1996).
- Survivor support groups vary in their format and design.
 Key group characteristics include leadership, membership, format, length and timing, and access to group.

Support Group Leadership

- "One of the key factors that makes or breaks a support group is the facilitator" (Myers & Fine, 2006)
- Consumer and family led services are quite common -serving almost 20 percent of mental health consumers (Wang et al., 2000) – and often supplement traditional mental health services.
- o McIntosh & Rubey's (1996) survey showed that
 - 21 percent led by a mental health professional only
 - 27 percent led by a combination of a trained facilitator and mental health professional
 - 10 percent were led by a survivor leader who has limited or no specialized training.
 - Overall, one quarter of the leaders identified themselves as suicide survivors.

Support Group Membership

- Some suicide survivors attend groups with people bereaved from a variety of types of death while others attend those specific to suicide survivors.
- Some groups are specifically designed for certain types of survivors. It is most common for children to have their own groups (Pfeffer et al., 2002)
- However, in larger communities and online, there are groups based on relationship to the decedent creating separate groups for adult children of suicide decedents, sibling survivors, and parents bereaved following a child's suicide (Cerel et al., manuscript).
- There is no evidence on whether groups based on relationships are more or less helpful than those for one type of survivor. In addition, most communities do not have enough survivors active in groups to support multiple groups, or separate groups for survivors of different relationship-types (e.g., child, sibling, spouse) to the decedent (Cerel et al, manuscript).

Survivor Group Format

Common format:

- o "We sit in a circle, with each person giving a brief introduction: first name, who was lost, when it was, and how it happened. I then ask the people who are attending for the first time to begin, because they usually have an urgent need to talk. The rest of the group reaches out to them by describing their own experiences and how they are feeling. The new people realize they are not alone with their nightmare. By comparing their situations with others, they also begin to understand that they don't have a monopoly on pain" (Fine, 1997).
- In Rubey & McIntosh's survey (1996), 76 percent of groups were described as a "sharing of experiences," while the remainder included a combination of lectures and sharing of experiences.
- Suggesting that sharing one's story is beneficial, Jackson writes, "In addition to receiving help, you'll find tremendous benefit in the help your testimony will undoubtedly offer to others" (Jackson, 2003).
- However, it is unknown if this type of sharing is beneficial or whether hearing and repeating traumatic stories may actually re-traumatize survivors (Cerel et al. manuscript)

Survivor Group: Open-Ended or Not?

- "For some people, support groups may not be that helpful or comforting" (Myers & Fine, 2006).
- We do not know who does or does not benefit from attendance at which types of groups.
- In Rubey & McIntosh's survey (1996), 85 percent of groups were open-ended with no fixed number of sessions, 11 percent involved a fixed number of sessions and the remainder included both formats.
- There is some evidence that the typical structure of support groups involving self-disclosure and sharing of feelings may not be helpful, and might actually be harmful, to individuals with a more avoidant style of coping, often characteristic of males (Jordan & McMenamy, 2004).

Survivor Groups: Other Effects

- o Nothing is known about the effects of ...
 - group size
 - duration of attendance
 - rolling admission versus closed group
 - use of different theoretical orientations such as family systems, or
 - setting such as someone's home, church, or a professional facility.

Support Groups: Preliminary Evidence = Effective?

- a theory-based group program for parents bereaved by their children's sudden death (including suicide, homicide or accidental death) which combines psychoeducation, skillbuilding and emotion-focused supportive discussion was associated with improved psychological functioning, reduced PTSD and improved physical health when compared to a nontreatment control group (Murphy et al., 1998)
- another helpful model is an 8-week group for all adult survivors of suicide that includes psychoeducation, adaptive skills and narratives about the death developed by each group member (Mitchell, 2003)
- a suicide survivor group for children which included a substantial psychoeducation portion for the children (as well as their survivor parents) appeared to show improvements in the parents' depressive symptoms compared to a notreatment control (Pfeffer et al., 2002)
- a one-session debriefing group intervention showed trends towards positive outcomes in terms of grief and perceived stress a month after the intervention (Mitchell et al., 1999)

Survivor Groups: Length & Timing

- Some groups are open-ended and some survivors attend these for years, while other groups end after a certain length of time. While it is unknown which kind of intervention is the most helpful, most bereavement group interventions are attended for such a short time that they seem to be of "insufficient strength and duration to make impact" in the life of the bereaved (Jordan & McMenamy, 2004).
- There seems to be no consensus about when is the optimal time for survivors to join a group after their loss.
- For example, the AFSP website states, "some survivors attend a support group almost immediately, some wait for years; others attend for a year or two and then go only occasionally -- on anniversaries, holidays, or particularly difficult days."
- Until recently, traditional attempts to reach survivors have been passive in their approach to helping survivors, waiting for the survivor to seek out services.

Access to Survivor Services

- There is some evidence that most referrals for survivors of suicide groups in the United States come from physicians or nurses, professionals who typically share referral information with survivors when the death occurs at a hospital (Rubey & McIntosh, 1996).
- Many suicide deaths occur outside of a facility and are pronounced at the scene; therefore, a hospital is never involved and cannot serve as a primary referral resource for survivors.
- Even when resources are available in communities, the length of time between the death and the survivor seeking help is often too long, partially due to a lack of knowledge of the resources by the survivors and by healthcare workers and other gatekeepers (Campbell et al., 2004; Cerel & Campbell, 2006).

Postvention: Active vs. Passive

- Reminder: Postvention = a strategy or approach that is implemented after a crisis or traumatic event has occurred.
- The active postvention model aims to reach out to survivors as soon as possible following the death.
- An example of the active postvention model is the LOSS team (Local Outreach to Suicide Survivors) originating at the Baton Rouge Crisis Intervention Center in which volunteers, mental health professionals and survivors receive specialized training and respond directly to the scene of a suicide.
- For survivors who seek treatment following a suicide, those who have received active postvention appear to seek services considerably sooner, and appear to attend support group meetings and attend more groups than those who received passive postvention (Cerel & Campbell, 2006).

Online Support Groups

- Online groups have become a popular option, especially for those survivors who live in an area without a formal support group or who may not want to disclose their identity as a survivor.
- Online groups can be for a specific population (e.g., those bereaved by the suicide of a spouse, child or sibling), and a directory can be found on SPRC's website (www.sprc.org) or the SPAN USA website (www.spanusa.org).
- o Several survivor organizations offer such groups, including:
 - Survivors of Loved Ones' Suicides (SOLOS)
 - Grief Recovery Online founded by Widows and Widowers (GROWW) (www.groww.org)
 - GriefNet.org (<u>www.griefnet.org</u>)
 - Yellow Ribbon Suicide Prevention Program (<u>www.TeenHelp.org</u>)
 - · And others

Are Online Survivor Groups Appealing?

- Online groups provide such services as regularly scheduled facilitated chats, e-mail discussion lists, and message boards (SPAN-USA, 2005).
- o The appeal of online support is evident: one e-mail discussion list alone receives between 1,000 to 2,000 e-mails a month, and the moderator of one group felt it is the "intimate, anonymous nature of the computer which allows a normally reserved, shy individual, who may also be feeling ashamed and guilty over their loss of a loved one to suicide, to share his or her deepest feelings" (SPAN-USA, 2005).
- However, there is no published research on online survivor groups, including questions about
 - the composition of the group
 - the length of time individuals participate in group, or if
 - the groups are associated with improvements in psychosocial and psychological functioning.

Next Speakers

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Next Speaker

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Strategies for involving survivors in prevention & advocacy

- o Ask for their engagement
- o Understand if they choose not to engage
- o Respect their contribution
- o Provide meaningful opportunities
- o Show simple kindness & caring
- o Become a quilt organizer
- o Start an SOS group
- o Become a trained gatekeeper (ASIST or QPR)
- o Offer postvention services/support
- o Know about survivor support groups
- o Invite to serve as:
 - Spokespersons
 - Advocates
 - Educators
 - Task Force members

Creating Change

- o Raise awareness
- Build support
- o Educate
- o Change rules or laws
- o Obtain funding
- o Improve services

Advocacy Tools

- o Letters, petitions, visits and calls
- o Web tools
- o Manuals and training
- o Fact sheets and reports
- o Symbols
- o Events
- o Media

What to ask elected officials for

- o Introduce legislation
- o Cosponsor legislation
- o Vote for/against a bill
- Enter a statement in the Congressional Record
- Write a letter to a federal or state agency on your behalf
- A letter to a Committee Chairman or Ranking Member on your behalf
- Arrange a meeting with other federal or state agencies or officials
- o Speak at an event
- o Something possible

How to communicate?

- Letter (stick to one issue)
- Visit
 - DC Office
 - State Office
 - District Office
- o Phone call

- o Fax
- E-mail www.spanusa.org (zip)
- o Town hall meetings
- Public activities/events









Take action online!



Go to www.spanusa.org > Click on View Updates

Top Ten Things You Can Do Now!

- o Write a letter to the local newspaper
- Join a committee working on mental health or suicide prevention issues
- o Make a phone call to your legislator or staff
- Visit your legislator
- o Call a talk show
- Write a letter to your governor
- Attend a town hall meeting
- o Join a community coalition
- Start a Lifekeeper Quilt
- Sign on to SPAN USA's Legislative Action Center

Advocacy for Life

What you can do:

- o Serve on local committees
- o Engage the local media
- o Have facts and arguments ready
- o Meet with decision makers
- o Identify and recruit "influencers"
- o Educate others
- o Share your story
- o Challenge ignorance

For future reference



SPAN USA's Action Center:

- Learn about current federal and state legislation
- Contact federal or state policymakers and media sources directly
- See and sign up for alerts on federal and state suicide prevention legislation

www.spanusa.org -- Fill in your zip code at top

See some examples of suicide prevention legislation (state and federal):

www.phppo.cdc.gov/od/phlp/suicidelegislation.asp

53

Remember...

- o Know what you want and why
- o You have the right to ask
- o Skills count
- o Persistence pays off in the long run
- Passion is power -- Advocate for what you believe

Closing Quote

 No act of kindness, no matter how small, is ever wasted.

> **AESOP**, The Lion and the Mouse Greek slave & fable author (620 BC - 560 BC)

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