

Chapter 18

Disclosure of Youth Suicidality: Views from Lived Experience



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Living through a suicide attempt gives one a critical perspective that has not been consistently incorporated into treatment and suicide prevention approaches. The engagement of people who are willing to draw from their own experiences of being impacted by suicidal thoughts or behaviors (STB) to advocate for others with similar experiences is foundational to effective suicide prevention. Individuals who identify as suicide attempt survivors, suicide loss survivors, and those who have experienced a suicidal crisis can help others understand the complexities of STB, foster empathy through sharing, and generate hope for people at risk. However, lived experience perspectives have historically not been shared broadly, and this is to the detriment of the field's understanding of how best to prevent suicide and provide treatment to those most impacted.

According to the National Strategy for Suicide Prevention (2012) and the Surgeon General's Call to Action on Suicide Prevention (2021), lived experience should be highly valued in the creation and delivery of mental health care. Such perspectives add credibility and value to suicide prevention efforts by going beyond research and academic theory by ensuring that those most impacted by practices and policies are able to contribute to their creation and evaluation. Opportunities to incorporate individuals with lived experience include, but are not limited to, development of care pathways, peer support specialist roles, organizational messaging

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efforts, program evaluation, or meaningful roles on advisory boards for youth suicide prevention efforts. Quality improvement efforts such as a recent PCORI convening grant “Convening Lived Experience & Research Communities to Improve Patient-Centered Outcomes,” which brought together individuals with lived experience and suicide prevention researchers to discuss how to integrate lived experience into the design, dissemination, and implementation of research, may be a model for engagement. Lived experience perspectives are especially important when working within mental health service systems with marginalized populations, such as youth, who are often underestimated for not having enough “life experience” to have insight about their own needs. Suicidal thoughts and behaviors are complex and multi-determined; and as such, approach to prevention and treatment requires insight from those who have experienced it themselves.

An important theme that arises when listening to individuals with lived experience is that an early negative experience with disclosure of STB can greatly interfere with future engagement in treatment. Regrettably, there are many instances in which negative disclosure experiences such as shaming lectures or coercive referrals for hospitalization had a lifelong impact on a young person. The stigma around suicide often prevents communication of helpful information in a way that leads to positive support, and the myth that talking about suicide can put ideas of suicide into someone’s head is widely detrimental to suicide prevention efforts.

A critical area that the field of suicide prevention must continue to evaluate is the use of involuntary hospitalization as an undifferentiated response to youth suicidal ideation or behavior. This approach may contribute to physical or psychological harm and undermine the autonomy of those most in need of collaborative care. Although inpatient hospitalization may reduce immediate access to lethal means and decrease the amount of time an individual is left alone, this level of care typically offers limited proactive intervention. Rather, the focus of treatment is often on diagnosis, monitoring, stabilization, and medication management (Abas et al., 2003). Many crisis-oriented units focus on short-term safety goals and medication management while limiting the amount of interaction that patients have with family or peers on that unit. The experience of inpatient hospitalization is a major change from everyday life and can be very stressful, especially for young people who are removed from their typical environment, support structures, and coping skills (Lear & Pepper, 2018). This type of disruption can affect identity development also resulting in internalized stigma (Haynes et al., 2011; Polvere, 2011).

Importantly, hospitalization often fails to decrease risk for suicide and can even increase the likelihood of future hospitalization or suicidal behavior (Knesper, 2010). The days and weeks after hospitalization is a period of particularly high risk for further suicidal behavior and even death by suicide (Crawford, 2004; Knesper, 2010). Although deferring to hospitalization when STB is identified is frequently based in good intentions, most patients expressing suicidal ideation are not at imminent risk (Roaten et al., 2021). Disproportionate responses may contribute to devastating negative effects on youth and young adults.

We acknowledge that this chapter departs from traditional academic endeavors by centering on personal lived experience before providing recommendations.

Specifically, we highlight the lived experience of two of the authors during adolescence, with an emphasis on the disclosure of suicidal ideation while centering the importance of lived experience. We then offer insights to drive improved care in acute settings. Utilizing lived experience can help create supportive care environments that are patient-centered, recovery-oriented, and value-driven. To do this effectively, it is important to ask for input and guidance from people with lived experience. We conclude by arguing that when lived experience is valued by the service system, people with mental health diagnoses will face less stigma and experience more compassion when interacting with providers. Given the negative effects of inappropriate provider responses, it is crucial to incorporate insight from those with lived experience to identify the most effective and appropriate care options.

Lived Experiences

Rowan's Lived Experience

When I was 16 years old, I felt like a relatively normal child, yet for a while I had been struggling with post-traumatic stress disorder (PTSD) in response to events occurring in the context of unhealthy relationships. I went in to visit my primary physician for a regular checkup. During that visit, I built up the nerve to disclose to her that I was thinking about killing myself. I let her know that I had experienced thoughts of suicide for a long time but that I did not have a plan or desire to act on my thoughts. It had taken a great deal of courage for me to share this, and unfortunately the result was an immediate referral to the hospital. I felt betrayed and powerless. This traumatic experience contributed to an intense distrust of talking about my passive suicidal ideation even though such thoughts remain present to this day. At the time, my provider asked me a few simple questions, but never asked about the intensity or quality of my suicidal ideation, or even if I had a plan or method to end my life. It did not make sense to me that the person I had reached out to for help encouraged such a restrictive level of care when I was not feeling unsafe. With some luck and fortunate connections, I was able to avoid a 72-h hold at a hospital that night. Because my mother is a social worker, she was able to find me an urgent therapy appointment for the next day. My family's advocacy was the primary reason that I was provided with other options of care that allowed me to avoid additional trauma and financial burden. In retrospect, I can understand that my provider was probably scared, uncomfortable, and unsure of what to do, and although she was concerned with my safety, she likely had no other tools except hospitalization when confronted with a teen with thoughts of suicide. I have witnessed this fear and discomfort in many providers with whom I have interacted over the years as a patient and as a professional. It is a fear that I understand deeply as a passionate youth advocate and as someone with a younger sibling who struggles with suicidal thoughts. But in my advocacy work, I have seen the harm that can be done when the care provided is based on fear. Examples are when fear of liability comes before

patient well-being and when providers lack specific training in managing suicide risk through care pathways that are informed by lived experience perspectives.

My provider's overreaction has stuck with me to this day. Providers should be aware that how they respond to youth in crisis contributes to whether they seek help in the future. I rarely bring up suicidal ideation with anyone now, and when I do, I sanitize my descriptions and make sure I label it as "passive" due to a fear of being hospitalized. If my provider had been trained to explore my suicidal ideation with empathy rather than fear and discussed the range of options available for me, then the result would not likely have been hospitalization to meet my needs. Rather, establishing a collaborative plan for safety would have been the priority and led to a better outcome. I would also feel more comfortable disclosing suicidal ideation to providers now.

In my work as a mentor and advocate for young adults with lived experience in Maryland, I frequently tell the youth with whom I work to be specific when they describe their suicidal ideation to their providers, and to be ready to advocate for what they want their care to look like, so they are not hospitalized without a clear justification. My job is to mentor and support young adults with lived experience who have an interest in advocacy and peer support, and that includes teaching them how to advocate for themselves and their recovery needs.

Amanda's Lived Experience

As I entered my teenage years, I began struggling with mental illness, including thoughts of suicide. My family didn't know anything about mental health care or how to get me help. I already felt like a burden and wanted to protect them, so I hid as much from them as possible. My depression worsened and when I was about 15, I had my first suicide attempt. When my mom took me to my primary care doctor after this attempt, my doctor lectured me about why I should want to live. I was struggling intensely, and instead of having a conversation about the pain that led me to seek to end my life, I was shamed for my act of desperation. My doctor told my mom that "I would be fine because I had vomited" and told her to take me home without additional precautions. I had to research my own mental health needs and treatment options. Then I had to personally educate my parents in order to get any type of mental health treatment.

When I was later admitted for inpatient hospitalization years later for a separate suicide attempt, I was horrified at the way people who were struggling to manage severe distress were treated by hospital staff. It was like those admitted had lost the right to be treated like a human simply for experiencing an emotional crisis. Personally, inpatient care has been minimally therapeutic, and really only ensured that I did not have access to things to harm myself with (even this was not effective). I have been on different types of psychiatric units and have found that more specialized units tend to offer higher-quality suicide-specific care. Nevertheless, the most helpful part of treatment for me has been the shared experiences and friends that I

have met along the way. The support and comradery that develops between people who truly understand what it is like to live through these struggles is empowering. Other things that have been helpful for me are connecting with clinicians who understand the process of level of care assessments and proper safety planning, which have allowed me to stay safe without being admitted to an inpatient unit for years since these initial distressing experiences.

Other Learning Experiences

In our advocacy roles, we have learned that many youth face unhelpful reactions when first disclosing their experiences of suicidal thoughts to adults who are under-prepared to respond effectively. Specifically, we have heard responses ranging from a young elementary student being told by their parents that they are “just overreacting” and “can’t possibly have feelings of wanting to die” to a 16-year-old being hospitalized without so much as a conversation.

Yet, we have also witnessed providers discuss suicidal ideation and past attempts in a curious and empathetic way which typically leads to better outcomes for young people. In one instance, a young woman screened positive for suicide risk at a primary care visit. Instead of immediate hospitalization, the provider conducted a brief suicide safety assessment and a collaborative safety plan. Her provider asked her multiple questions about what her suicidal ideation looked like, how it was impacting her, whether it was passive or active, and if she had a plan to end her life. Based on the safety assessment and commitment to her safety plan, the provider and patient together agreed that hospitalization was not necessary because the patient was not expressing active suicidal ideation and was not at imminent risk for suicide. The provider conducted a follow-up call with the patient. As a result, this young woman spoke highly of her interactions with providers and had a positive outlook on services available to help her through a suicidal crisis. The clinician’s process emphasized the patient’s agency in decision-making and safety planning. This positive experience set her up to be able to disclose suicidal ideation to providers in the future because she felt the provider would conduct further assessment to determine the appropriate disposition.

Discussion

The lived experience of struggling with suicidal ideation and having difficult conversations of disclosure, as detailed in our stories above, have shaped our views of what kind of supports are helpful versus harmful. We recognize that unhelpful provider reactions are primarily caused by two things: (1) a lack of training on suicide-specific screening, assessment, and treatment for providers and (2) a tendency for providers to respond from a place of fear/discomfort. That fear may be due to

discomfort managing suicide risk, liability concerns (e.g., fear of being sued if a client dies by suicide), or misconceptions about the best ways to protect children. Most mental health clinicians feel that they have not been appropriately trained to adequately help suicidal youth (Schmitz et al., 2012). There are important lessons to learn from these anecdotes above that unfortunately are common among youth with suicidal ideation. To address these issues, we present recommendations for providers.

Recommendations for Discussing Suicide

As people with lived experiences, we make three recommendations for clinicians who encounter patients with suicidal ideation: (1) First, clinicians should do an internal assessment about what they feel about youth with suicidal thoughts so they can understand their personal biases and make sure they respond to young people who are struggling with compassion and without judgment. (2) Second, clinicians should listen to and fully discuss with patients what suicidal ideation means to the patient, ask about personal triggers and warning signs, and ask specifically what suicidal thoughts and behaviors look like for that person. (3) Lastly, they should provide options other than hospitalization taking into account the patient's support system and a willingness to contribute collaboratively to safety decisions.

The use of safety plans with suicidal youth is critical (see Monahan & Stanley, Chap. 9, this volume) so that nuanced decisions around safety and level of care recommendations can be made without unnecessarily restrictive hospitalizations. In our own lives and our work, we have witnessed a lack of options presented to youth and their families. We have seen youth hospitalized multiple times in a single year due to a lack of alternatives presented to the family, and we believe that the patient should not have to be an expert in mental health treatment systems in order to receive appropriate care, nor should they need special connections to guarantee appropriate supports. It is important for families to know that there are other options other than hospitalization which could better suit their needs. Intensive outpatient (IOP) programs, crisis counseling, an emergency therapy appointment, or peer support providers are examples of appealing alternatives.

Many communities are taking meaningful steps to reduce the frequency of hospitalizations among youth. One key approach is an increase in peer support specialists working in wellness and recovery centers, emergency rooms, and mobile crisis teams. Individuals in these roles are often adept at de-escalating someone in crisis and have connections and knowledge about the available services in the area. They are trained to take the time to sit with a youth who is in crisis and talk with them about the options available, which often allows the youth to find an option that is a better fit for their needs.

Additionally, evidence-based treatments are available that decrease the need for emergency department visits. We have seen hospital units who staff peer supporters and engage patients in creating a Wellness Recovery Action Plan (WRAP) and are

committed to making what can be a traumatic experience more recovery oriented. Providers should prioritize safety planning while educating youth and families about different treatment options that extend beyond crisis care and medication management. Patients prefer to be informed of treatment options (Bellairs-Walsh et al., 2020), and safety planning may increase perceptions of agency.

Training providers to have empathic nonjudgmental conversations with young people and improving comfort level in working with people who have thoughts of suicide is critical. A recent study found that individuals weigh the costs and benefits associated with disclosure of suicidal ideation and only disclose when the perceived benefits outweigh the perceived costs (Frey et al., 2018). They are most likely to disclose to a confidant, a person who has responded compassionately to disclosures of suicidal ideation previously, or someone who had known about past suicidal behavior and been emotionally supportive. Unfortunately, our experiences and existing research suggest that many providers have inadequate training for detecting and managing suicide risk. Many clinicians, especially those with limited experience, are unable to accurately determine when hospitalization is the best choice (Stulz et al., 2015). One reason for this is that few states require clinicians to receive formal training in suicide risk assessment and safety planning. For providers, suicide-specific treatments like the Collaborative Assessment and Management of Suicidality (CAMS; Gould et al., 2013; Jobes, 2012; Smith-Osbourne et al., 2017) or Lifeworks' ASIST: Applied Suicide Intervention Skills Training (Ashwood et al., 2015) may guide how to interact with a suicidal person.

Conclusions

Each of these recommendations requires a culture shift within healthcare systems and will require increased research and funding to meet the increased need for suicide prevention and treatment services in the USA. From our work, we know responding to suicidal ideation is an incredibly complex task that can have a significant emotional impact. Youth experiencing suicidal ideation should feel supported and empowered in the care they receive. We ask that providers enter into conversations about suicidal ideation with the intent to listen and ask questions, engage the youth in the process of safety planning, provide alternatives to hospitalization whenever safe to do so, and collaboratively decide how to stay alive.

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