The way back Information Resources Project

Consultation Report:

Needs and views of people who have attempted suicide and their family and friends

Hunter Institute of Mental Health

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beyondblue Depression. Anxiety.

MOVEMBER FOUNDATION

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SUMMARY

Background

People who have attempted suicide are at particularly high risk for subsequent suicide attempts and death by suicide. After an attempt, people commonly describe feelings of great shame, isolation and hopelessness; and both individuals who have attempted and close family and friends describe feeling overwhelmed and ill-equipped to navigate through the initial crisis, let alone know if and how things could get better in the longer term.

To respond to this need for information and support, *beyondblue* partnered with the Hunter Institute of Mental Health to develop information resources for people who had attempted suicide and their family members and friends.

The development of these resources were informed by a range of strategies including a scan of the research evidence, a review of existing written resources and consultations with stakeholders in suicide prevention, emergency medicine and mental health more broadly.

An integral part of the consultation process was obtaining the views of people 'with lived experience' of suicide attempt(s), including those who had previously attempted suicide as well as people who had supported a family member or a friend following a suicide attempt.

This report provides an overview of the key themes that emerged from this consultation process. The outcomes were used to inform the development of *The way back* information resources, but can also be used to inform broader strategies to support people who have attempted suicide nationally.

Methodology

A total of 37 people with lived experience of a suicide attempt, including 22 individuals who had attempted suicide, nine family members or friends and six people who fell into both categories, participated in the consultation. The average age of participants was 40 years (range 18-79 years) and the majority were female.

Participants were recruited through *beyondblue's* blueVoices and Suicide Prevention Australia and were aged over 18 years, not currently experiencing symptoms of mental distress and identified that the suicide attempt had occurred more than 12 months prior.

Phone interviews were conducted by staff with social work or psychology experience at the Hunter Institute of Mental Health and followed a semi-structured interview script that covered the importance of talking about suicide and suicide attempts, the types of conversations currently occurring, the barriers and enablers to talking about suicide and suicide attempts and the sort of information that would be most helpful for people after a suicide attempt. The research was approved by the Hunter New England Health Human Research Ethics Committee.

Interviews were recorded, transcribed and analysed for key themes.

Key Findings

Driven by a strong desire to tell their story, participants shared intensely personal aspects of their lives that included descriptions of past feelings of absolute hopelessness, despair and experiences of their world being "turned upside down".

In addition to themes that emerged in response to specific questions, there were two major themes that emerged across all of the questions.

1. **Suicide and suicide attempts are highly stigmatised in the community.**

Participants spoke about the stigma as stemming from societal institutions such as religions (suicide as a sin), the law (suicide as a crime), medicine (suicide as a mental illness) as well as general cultural beliefs that value 'toughness' when people are facing adversity.

> *"The biggest and the oldest problem is the stigma attached to it, which then becomes associated with the fear of embarrassment, humiliation, guilt and feelings of failure."* (Male, family member)

2. **People who are suicidal can be reluctant to disclose their feelings and seek help.**

Participants identified that people who are suicidal can be reluctant to disclose their feelings and seek help because of expectations that others will respond with stigmatised and poorly informed views, or will be unable to assist.

> *"I was desperate to speak to someone, anyone, about how I was feeling. And I felt I couldn't and this made it really hard."* (Female, who had attempted suicide)

When asked what type of information would be helpful for people after a suicide attempt, four key themes emerged.

1. Information explaining that suicide attempts are not uncommon and affect people from all walks of life.
2. Personal stories of how people have lived through their suicide attempt(s) could be helpful.
3. Information to help family members, friends and the community understand why a person may contemplate suicide.
4. Practical information and strategies to help people navigate the issues that come up after a suicide attempt.

> *"To be able to provide people who are friends or carers with factual information about why and the reasons behind it. I think that's really important."* (Female, who had attempted suicide and family member)

Participants also emphasised that the primary role of information resources should be to support people have constructive and supportive personal conversations, and that they would have greatest impact when provided in the context of non-judgemental attitudes about suicide.

Conclusions

Consultations were conducted with people who had lived experience of suicide attempt(s) to inform the development of *The way back* information resources, however broader conclusions can also be drawn from the findings.

- It is possible to systematically investigate the needs and views of people with lived experience of suicide attempt(s) in a safe and supportive way and partner with them in the design and delivery of suicide prevention initiatives.
- People with lived experience identified a range of barriers to talking about what had happened and seeking support. These were generally related to stigmatised or poorly informed views about suicide that exist in the community and a lack of understanding about what people may be going through when they are suicidal.
- People with lived experience could benefit from data about the number of people affected by suicide attempts, information that assists friends, family members and the community to understand why a person may contemplate suicide and practical information that helps people navigate issues that come up following a suicide attempt.
- People with lived experience suggested that hearing the personal stories of others who had attempted suicide may have important benefits. For individuals, it may help them to understand what has happened, see that they are not alone and have hope for the future. They also felt that it may help the broader community understand what individuals experience before and after an attempt.
- People with lived experience of suicide attempt(s) are important partners in suicide prevention.

CHAPTER 1: BACKGROUND TO THE CONSULTATION

1.1 Introduction

Suicide is a major public health concern in Australia. It affects individuals, families and communities. As a society we continue to struggle with how to understand suicide, how to support people who have been affected and ultimately in how to prevent it.

People who have attempted suicide are at significantly increased risk of suicide, particularly in the immediate period after the attempt (Harris and Barraclough, 1997). They commonly describe feelings of great shame, isolation and hopelessness. Both individuals who have attempted and those close to them also describe feeling overwhelmed and totally ill-equipped to navigate through the initial crisis, let alone know if and how things could get better in the longer term.

Despite this, research has found that less than half of those who make an attempt will seek assistance from a health or other support service. People have reported either wanting to handle the problem on their own or believe that treatment from a professional would not be effective. Of the 40% or so of individuals who do seek help from a general practitioner, hospital or counselling service, only a third return for further assistance after initial contact (De Leo et al., 2005).

When the specific challenges that arise after a suicide attempt are combined with relatively low engagement with services, it highlights the importance of ensuring that individuals and family members have easy access to evidence informed and quality information that responds to their needs.

1.2 About the consultation

beyondblue partnered with the Hunter Institute of Mental Health to develop information resources for people who had attempted suicide and their family members and friends.

A range of strategies were used to inform the development of these resources including a scan of the research evidence regarding the efficacy of different interventions after a suicide attempt, a review of existing written resources and structured consultations with stakeholders in suicide prevention, emergency medicine and mental health more broadly.

To complement these strategies and ensure the resources met the needs of the primary target audience, the project team planned and conducted a consultation with people who had attempted suicide and family and friends of people who had attempted suicide. Within this report, both of these groups are referred to as 'people with lived experience', in alignment with terminology currently used in Australia.

1.3 Specific considerations

Previous research has verified that individuals with lived experience of suicide attempt(s) appear to be the people best placed to provide advice and guidance about what will be helpful (Webb, 2010). However, the project team were also aware that there has only been very limited qualitative research with this target group (Hjelmeland & Knizek, 2010).

There are a number of reasons for the lack of consultation with people with lived experience. This includes difficulties in accessing participants, concerns about confidentiality, the resources required to provide appropriate support to participants and managing participant follow-up after participation (Lakeman & Fitzgerald, 2008). There is also the concern of the risk of generating a crisis as a consequence of speaking with people about very personal and traumatic experiences.

More recently, there has been some evidence to suggest that when people with lived experience of suicide attempt(s) or suicidality participate in research it is generally not associated with a decline in wellbeing and when it is, the distress is identified as being transient and does not outweigh the value of taking part in the research (Biddle et al., 2013). In fact, the study by Biddle and others identified that taking part in research can actually be beneficial for people with between 50-70% of people identifying a positive increase in wellbeing after sharing or reflecting on their experiences. Further, Lakeman, McAndrew, MacGahan and Warne (2013) suggest that the opportunity to tell one's story can provide people with lived experience of suicidality the space to make sense of their experiences while also "giving back" to the community.

1.4 The consultation report

This report provides an overview of the key themes that emerged from the consultation with people with lived experience of suicide attempt(s). The report provides an overview of the diverse and complex views, experiences and recommendations provided by participants.

- The views of people with lived experience of suicide attempt(s) (including family members and friends) have only infrequently been sought in the development of suicide prevention interventions and supports.
- There are a range of ethical considerations that need to be taken into account when looking to conduct research with people with lived experience of suicide attempt(s).
- Providing people with lived experience of suicide attempt(s) opportunities to participate in research that provides space to reflect on their experiences and "give back" to the community may offer benefits to both researchers and participants.

CHAPTER 2: CONSULTATION METHOD

2.1 Recruitment

In July 2013, the Hunter Institute of Mental Health approached *beyondblue*'s blueVoices and Suicide Prevention Australia to invite their networks of community members to participate in the consultation. The invitation to participate was disseminated electronically by the member organisations.

People who were interested in participating registered their interest by email or telephone with the Hunter Institute of Mental Health and an initial information and screening interview was conducted. The screening process involved:

- Confirming that the person was aged over 18 years;
- Confirming that the person was comfortable talking about suicide and suicide attempts;
- Confirming that the most recent suicide attempt occurred over twelve months ago;
- With permission, undertaking an assessment of the person's level of psychological distress using the Kessler Psychological Distress Scale (K10).

A total of 55 people registered interest in taking part. Of these, 48 completed a screening interview. A total of 11 people were excluded because they reported a high level of psychological distress (K10 score >20, n=7 [Kessler et al., 2002]) or because the suicide attempt had occurred less than 12 months ago (n=4).

2.2 Participants

A total of 37 people completed the consultation interview. Twenty-two people were individuals who had attempted suicide, nine were family members or friends of a person who had attempted suicide and six people fell into both categories.

The majority (76%) of participants were female with an average age of 40 years (range= 18-79 years). Two participants identified as Aboriginal or Torres Strait Islander and a small minority (5%) indicated that they had not been born in Australia.

Over four fifths (84%) of participants indicated that they had a diagnosis of mental illness and nearly half identified that they were currently seeing a mental health professional.

2.3 Interview protocol

Interviews were conducted by tertiary qualified staff at the Hunter Institute of Mental Health who had either a social work or psychology background. All interviews were conducted by telephone and followed a five question semi-structured interview script that included:

1. How important do you think it is to talk about suicide and attempted suicide in the community?
2. What types of conversations or information about suicide or attempted suicide are occurring or available in the community?

3. What things do you think make it hard for people to talk about suicide or attempted suicide?
4. What things if any, do you think would make it easier to talk about suicide or attempted suicide?
5. If information was available for people immediately after a suicide attempt, what do you think would be most helpful?

The consultation was approved by the Hunter New England Health Human Research Ethics Committee.

2.4 Data analysis

Interviews were transcribed and a manual thematic review and analysis was completed by one member of the interview team. Comparative coding for a subset of the interviews was undertaken by two other staff members at the Hunter Institute of Mental Health.

CHAPTER 3: RESULTS

Driven by a strong desire to tell their story, participants shared intensely personal aspects of their lives that included descriptions of past feelings of absolute hopelessness, despair and experiences of their world being "turned upside down".

In addition to themes that emerged in response to specific questions, there were major themes that emerged across all of the questions. All themes are summarised below.

3.1 Major themes

- **Suicide and suicide attempts are highly stigmatised in the community.**

Participants spoke about the stigma as stemming from societal institutions such as religions (suicide as a sin), the law (suicide as a crime), medicine (suicide as a mental illness) as well as general cultural beliefs that value 'toughness' when people are facing adversity.

> *"People don't know how to react … They don't know whether or not to talk about it … There's definitely still a stigma."* (Female, who has attempted suicide)

> *"The biggest and the oldest problem is the stigma attached to it, which then becomes associated with the fear of embarrassment, humiliation, guilt and feelings of failure."* (Male, family member)

- **People who are suicidal can be reluctant to seek help.**

Participants stated that people who are suicidal can be reluctant to disclose their feelings and seek help because of expectations that others will respond with stigmatised and poorly informed views, or because of expectations that others will not understand or would be unable to assist. An exception to this was people's experience in having contact (via the internet or in real life) with other people who had attempted suicide.

> *"I was desperate to speak to someone, anyone, about how I was feeling. And I felt I couldn't and this made it really hard."* (Female, who has attempted suicide)

> *"I was just so hurt after my relationship ended that I couldn't trust anyone… I also couldn't risk the possibility of embarrassment or ridicule if I said anything."* (Male, who has attempted suicide)

- **Family and friends reported difficulty in identifying warning signs prior to the attempt.**

Prior to a suicide attempt, family member or friends expressed difficulty in identifying warning signs or appreciating that changes in the person's behaviour and thinking were associated with suicidal intent. When they were worried, they identified often feeling unsure about what to say and there was a preference for not saying anything rather than risk saying the wrong thing. After

a suicide attempt, family and friends struggled to understand why it had occurred and questioned if they could have done more to prevent it.

> *"I think it's very scary for everyone in that it's such an unknown – why would someone want to do that? … And when people are confronted with it … it's overwhelming."* (Female, family member)

- **There is a need for more information about what people who attempt suicide and their friends and family may experience.**

Participants identified that there needs to be a lot more information (including personal stories) provided to the community about what suicidal people and their family and friends may be experiencing and how to provide support.

> *"After my attempt, it would have helped me a lot if I had seen some people who had actually recovered from the depths of despair … to see a light at the end of the tunnel and think that I could also have a happy, functioning life again."* (Female, had attempted suicide)

- **The presence of a mental illness can increase the discomfort and even fear that others have in discussing suicide or providing support to someone in need.**

Participants' responses often stemmed from their own experiences of mental illness or the mental illness of the person they cared for. These experiences influenced their perceptions of stigma, the barriers to talking about suicide and also their suggestions for what information would be good to provide after a suicide attempt.

For the majority of those who had been diagnosed with a mental illness, there appeared to be a conceptualisation of their suicide attempt(s) within psychological frameworks and explanations, for example, chemical imbalances in the brain. There was a strong sense that few in the community appreciated the impact that a mental illness may have on a person's thinking and behaviour especially when it is suicidal. Moreover, participants considered that the presence of a mental illness added a heightened discomfort and even fear in others about discussing suicide or providing support to someone in need.

- **People who had attempted suicide spoke about despair and pain and being unable to see alternatives at the time of the attempt.**

A significant number of respondents who had attempted suicide but did not disclose a current diagnosis of a mental illness spoke about their own experiences and the reactions of others in more lay terms. In relation to their own attempts, they often talked about having experienced absolute crisis, despair, pain and desperation and having been unable to see an alternative to suicide. They identified that they felt that most people in society were not comfortable talking about such intimate and intense feelings and thoughts and this discomfort results in a taboo-like fear of talking about suicide.

3.2 Themes from specific questions

3.2.1 Why it is important to talk about suicide

Participants identified that talking about suicide and suicide attempts was critical in supporting people both before and after an attempt. They stated that if general conversations about suicide were occurring in the community before an attempt, people would feel more familiar and comfortable talking about it.

> *"I think it's essential that we talk about it … It's one of those unspoken subjects that needs to be brought to the fore in the community, to be understood … [in order that people can] provide compassion and support to those who both attempt suicide and those who have family members and friends who may be impacted."* (Male, family member)

Participants suggested that talking about suicide would encourage individuals to identify themselves if they were personally experiencing difficulties and needed assistance, and that it would also enable close individuals in a person's network to be sensitive to warning signs as well as feel more comfortable about asking if someone was suicidal and offering support.

> *"I was desperate to be able to speak to someone, anyone, about how I was feeling. And I felt that I couldn't and this made it really hard."* (Female, had attempted suicide)

> *"I think it is extremely important [to talk about suicide]. If people were more open to discussion about it and to know about signs to look out for, you may not be dealing with the size of the problem you currently are."* (Female, had attempted suicide)

Participants also considered that if there were constructive conversations occurring in the community, individuals who had attempted suicide might feel less guilt and shame and less of a sense that they had done something wrong. Participants believed this guilt and shame could be alleviated by knowing that it is not uncommon for people to attempt suicide and by hearing the personal stories of others – especially those who can provide hope for the future.

> *"Emphasising that it's so common- and it doesn't seem that common because it's not talked about very much. But it's something that so many people go through and yeah- that you're not alone is a huge thing."* (Female, had attempted suicide)

Similarly, participants identified if family and friends had more information, they may be better able to understand why the situation had occurred, their own reactions and how they could get through the challenges involved.

> *"It's very scary for everyone in that it's such an unknown … After the suicide attempt, you sort of felt insulted … that they would want to do this with their life and*

it becomes quite a personal issue … Why they would want to do that? … Why are they being selfish against you?" (Female, family member)

"It was an absolute crisis – although my wife and I have been in the [Emergency Services] … and seen a lot of horrific things, I have never experienced anything more traumatic than the time my daughter tried to take her own life … You've got to educate people in this situation very, very quickly … about why this may have happened, about the trauma they and their child are going through." (Male, family member)

"People are not aware … that there are so many other people in society going through the same things… It doesn't take away the pain or anything but it kind of, in a sense, doesn't leave you so isolated." (Male, family member)

3.2.2 Conversations about suicide and suicide attempts that are occurring

There were a number of themes that emerged when participants were asked about conversations about suicide and suicide attempts that were occurring in the community. In general, participants believed there was a community silence when it came to suicide and that when conversations occurred they were often negative or unhelpful.

"People might talk about it a bit but they might not necessarily be saying the right things or have the right attitude towards it." (Female, had attempted suicide)

There is a community silence about suicide

Participants almost unanimously said that suicide was rarely talked about and is not the type of subject discussed by people unless "they have to."

"It's not something that people openly discuss … People don't want to ask … [It's] something that's tip-toed around." (Female, had attempted suicide)

"If you said to someone that you've got cancer, they're always very supportive and want to help you. But if it's suicide … people tend to shut off very quickly." (Female, had attempted suicide and a family member)

Conversations can be negative and unhelpful

Few people identified hearing or being involved in constructive conversations about suicide in the community and most people were able to provide comprehensive descriptions of a range of negative views and beliefs expressed either directly or indirectly to them in the past.

Participants often talked about the difference between their experience or their understanding of suicide and what they heard from other people in the community. To illustrate this, some examples of community views about suicide identified by participants compared with participant's own interpretations are summarised in the table below.

Stigmatising attitudes heard in the community	Participants' own experience and understanding of the suicide attempt
Suicide is a selfish act	*"All I was thinking about was how selfish I was by being on the planet … I wanted to suicide so that I wouldn't be a burden on my family … I was actually thinking I was being unselfish."* (Female, had attempted suicide and a family member) *"I think a lot of people have the opinion that it's a selfish thing to do … When in fact … it feels like the only option because you just don't want to be a burden on society or your family."* (Female, had attempted suicide)
Suicide attempts are attention seeking	*"Attention seeking … wasn't the reason … I just wanted to escape from everything, to try and shut down for a while and not to have to feel anything anymore."* (Female, had attempted suicide) *"People don't attempt suicide because they want to hurt people or they're angry or trying to seek attention … That's not the reason."* (Female, had attempted suicide)
People who attempt suicide are weak, cowards	*"It's actually a pretty difficult decision to make. You really can't be that weak."* (Female, had attempted suicide)
Suicide is taking the easy way out	*"People who have this type of opinion obviously haven't experienced any sort of mental health problems."* (Female, had attempted suicide) *"They don't understand what the pain is like … it is just beyond comprehension… and you'll just do anything to rid yourself of it, to escape from it… You don't think rationally about what will happen to your family."* (Male, had attempted suicide)

Some conversations online are meaningful and helpful

In contrast to the majority of experiences that fell into the categories described above, some participants identified that the internet was one of the few forums where they could either observe or participate in meaningful conversations around suicide. Although these participants were also quick to point out that the internet was an extensive source of information about possible methods for their suicide attempt, it also was one of the few places they found where people engaged in open and honest discussions about how they felt.

> *"I think you hear the most about it now through social media …blogging and things like that … You can actually read about somebody who is just like you – a parent, a young person, whatever… and you think "wow, that's me", you can relate to them. And they're not afraid to talk about things … so you're more likely to talk and share things because you can relate to them."* (Female, had attempted suicide)

3.2.2 What makes it difficult for people to talk about suicide and suicide attempts?

People who had attempted suicide generally responded to this question by describing what made it difficult for them to talk about their own suicidal thoughts or past attempts. In contrast, family members and friends talked about what made it difficult for them to either tell others about the suicide attempt(s) of the person they supported or share their own reactions about what had happened. Participant responses were influenced both by their actual or anticipated experiences.

> *"I'm not ashamed to tell people … The only thing that concerns me is that people do judge you."* (Female, had attempted suicide)

At the most general level, themes could all be grouped under the broad heading of 'stigma' or societal messages that 'suicide is bad.' However, to be more specific about the nature and origins of this, the themes have been categorised according to either:

- their association with major societal institutions: religion; law; medicine; and Australian culture; or
- individual's self-censoring because of feelings of shame or a sense of wanting to shield others from distress.

Barriers arising from religious beliefs

A significant minority of participants stated that religious beliefs about suicide impacted on their own as well as other's capacities to openly discuss suicidal thoughts or their reactions to an attempt by a close family member or friend.

> *"Coming from a religious background … it's a sin … If you commit suicide you're going straight to hell."* (Female, had attempted suicide and a family member)

Barriers arising from the law

When discussing aspects of stigma that prevent people from talking about suicide, a small number of participants raised the issue of words commonly used in the community and their origin in law. For example:

> *"I think a lot of it's in the language that people use … It's the classic terms that people COMMIT suicide. Well, you commit a crime … [to be correct] it's death by suicide … but because you say 'commit', you're saying that you've … broken the law. You're putting it in a category straight away. And it is ignorant."* (Male, family member)

Barriers arising from experiences with the medical system

While some participants described extremely positive and helpful responses from doctors, nurses and mental health workers, many shared stories of very poor responses. The barriers for individuals who had attempted seemed to cluster around three issues.

Firstly, a sense that medical staff did not understand the depths of despair and suffering that was being experienced.

> *"I don't think GPs realise what it takes for you to get to them … You've had this inner fight for some time and then you finally work up the courage to ask for help, which involves another admission of failure when you're used to being so well and highly functioning … And if after getting up the courage, you get a knock back like someone tells you you're not exercising, you should get a massage, go for a walk … I just completely hit a wall."* (Female, had attempted suicide)

An exception to this actual or anticipated barrier was when the health professional appeared to have personally experienced mental illness.

> *"When you've been unwell you can really spot it in other people … you can identify if they are depressed or anxious … But if you haven't been unwell, it's very hard to spot and that's how people get to the suicide point …If that person then tries to reach out and the person they're asking doesn't have an understanding of it, they try to fix [the situation] by saying watch a movie … I saw several GPs [that didn't help] and then finally went to one who had suffered depression … She was brilliant … monitored me all the way … was completely thorough … It's sad to have to rely on someone that's had depression to actually get the understanding you need from a health care professional."* (Female, had attempted suicide)

Secondly, participants described experiences and expectations that the health response would use a medical model of assessing, diagnosing (labelling) and treating (with active interventions such as medication and/or involuntary admission), rather than providing people with an opportunity to fully talk about their thoughts and feelings.

> *"For me, I didn't even tell the treating team at the hospital that I had suicidal thoughts because I didn't want to get labelled with a personality disorder or something. Because once you get that sort of label … you're not actually getting the right treatment for your suicidal thoughts… So I just tell them that I'm depressed. But even then, there's the fear that you will be locked away in a facility saying "we must keep you safe"… There is this fear of what people will do to you once you disclose."* (Female, had attempted suicide).

> *"From my experience, doctors and nurses- they think medication is the answer [when] maybe someone just needs to talk … When I ended up in hospital after my suicide attempt by overdosing, I left with more drugs coming out of hospital that I did going in."* (Female, had attempted suicide and a family member)

Thirdly, participants reported experiences in emergency services that suggested they were less deserving of attention and treatment.

> *"The doctors get really annoyed when they're dealing with attempted suicide … I felt they were really hostile towards me … They get really pissed off because they are trying to save lives and here you are coming in after you have tried to take your own life."* (Female, had attempted suicide)

Family and friends also discussed barriers to talking about suicide and suicide attempts in the context of medical services, but their concerns stemmed from different sources – their frustrations with not being able to engage in discussions because of patient confidentiality.

> "*The whole interface with the Emergency Department was a whole other story for me … I don't recall anybody asking me about what had been happening [prior to my son's suicide attempt] … I didn't know if the doctors were drawing any parallels or conclusions … Although he was a young adult, we still provided a lot of advocacy on his behalf and there are times where the patient confidentiality scene means you are just cut out of the loop."* (Female, family member)

> *"[In the psychiatric ward] There was just very poor support and poor information gathering and giving … There seemed to be an issue around confidentiality because you know I was given next to no information whatsoever. I don't even know what my mum came out of the hospital with- what diagnosis. No one told me about that. I asked for a meeting with the psychiatrist … They met me in a bit of a rush and I gave them as much information as I could … But nothing came the other way. But in saying that there was an expectation I was the carer and so I was going to take care of her when she came out of hospital."* (Female, family member)

Barriers arising from Australian cultural beliefs and values

Both individuals who had attempted suicide as well as family members and friends spoke about a range of cultural values and beliefs that inhibited their own and other community members' capacities to talk about suicide and suicide attempts. These could be related to barriers mentioned above (such as religious beliefs) or have their own distinct basis. Common examples include values around being 'tough' and coping with whatever adversity you are facing, while suicide and mental illness were perceived as something to be feared.

> *"I think from an Australian cultural perspective, it's get over your depression or whatever you are going through and cope with it."* (Female, had attempted suicide and a family member)

> *"When I was growing up if I told my parents that I was really anxious or really depressed, their mentality was "well, just harden up". That's all I got when I was growing up – just harden up … there's no point crying, it's not going to change anything."* (Female, had attempted suicide and a family member)

> *"I think that males in particular find it harder to talk about issues like that because they feel they should be manly and not talk about that stuff … I know it's a bit of a stereotype, but it does happen in my experience."* (Male, had attempted suicide)

> *"When the subject of suicide comes up, it's like people get very scared and you get labelled as being crazy … People fear it a lot … like it's contagious in some way."* (Female, had attempted suicide and a family member)

Barriers arising from internal feelings of shame and guilt

Both individuals who had attempted suicide as well as family members and friends described experiencing enormous feelings of guilt, shame and embarrassment and how these feelings had led them to not want to discuss what had happened with others. For example, one mother described that after her son's attempt:

> *"I felt enormously incompetent … Was it my parenting skills? Did I miss the signs? … There is this guilt factor that makes people not want to talk about it … They think that others will be asking "How could that have happened? What's been going on in that family that led to this?" I think this is a huge barrier to people having conversations about it."* (Female, family member)

Similarly, a participant who had attempted to take her own and her baby's life was very conscious of the guilt and shame involved and explained that even several years later, she still hadn't discussed it with her close family:

> *"It's just such a hard topic emotionally … It's just such a painful memory … What could have happened could have been so horrible … that you just want to put it in the past."* (Female, had attempted suicide)

Others talked more generally about the shame and guilt they felt.

> *"You definitely feel guilty and you don't want to talk about it much."* (Female, had attempted suicide)

Barriers stemming from a sense of altruism

A number of participants expressed a sense of wanting to shield others from being upset in learning about a person's suicidal thoughts and behaviours. For example, a parent said that after her son attempted:

> *"In my own situation, there was this great need to protect others from distress… I felt very responsible in that I didn't want to trouble other people with what was incredibly distressing news."* (Female, family member)

Similarly, when speaking about the intense and intolerable pain that they felt prior, individuals who had attempted suicide described not wanting to tell close family and friends because:

> "*The topic is very confronting and it is distressing to hear someone else's pain … You don't want to scare them or feel like you're burdening them.*" (Female, had attempted suicide and a family member)

3.2.3 What makes it easier to talk about suicide and suicide attempts?

In light of the complex range of barriers described above, a number of participants appeared to find it difficult to be specific about what could make it easier for people to talk about suicide and suicide attempts. Many people who had attempted suicide as well as family members and friends spoke of the need to 'break down' the stigma and this often included addressing stigma associated with mental illness as well as suicide.

As mentioned previously, their hopes in this regard were twofold: to provide immediate comfort and supportive environments for suicidal individuals or family members in distress; and, as a prevention/early intervention measure, to create more informed and supportive environments.

The most common suggestion from participants about how to make it easier for people to talk about suicide was to provide the community with more information.

> *"I don't think there's very much information around ... Even in my own travels, I don't see a lot within GP rooms, psychologists' rooms ... I don't see a lot there for people to get hold of."* (Female, had attempted suicide)

> *"It's really important for them [family and friends] to have information available to them to know how to deal with that kind of situation [a suicide attempt]."* (Female, had attempted suicide and family member)

3.2.4 What information would be helpful after a suicide attempt?

The type of information that participants identified would be helpful for people after a suicide attempt and that would support community discussions about suicide included: clear messages that attempting suicide is not uncommon and affects people from all walks of life; personal stories of how people have lived through suicide attempt(s) to help provide hope; information and education to help people understand why a person may contemplate suicide ; and practical information to navigate the issues that come up after a suicide attempt.

> *"The isolation is one of the biggest things that is so hard to combat. Even when you know that you've got loving family and friends around, when it gets to that place where you're so completely isolated, just feeling locked in or adrift. You know being told by someone trustworthy that you're not alone and that you're not being judged and that it's not something that's wrong with you- that's really important."* (Female, had attempted suicide)

You are not alone: More information about the frequency of suicide attempts

Participants believed that more information about the frequency of suicide attempts would help both individuals and families know that they are not alone. They also stated that if the rates were reported more widely, the general community could better understand that suicide attempts are not isolated events that rarely occur.

Participants suggested that the information should appear regularly in the media as well as being circulated in schools, workplaces, sporting and community organisations.

> *"When it happens to people, they do feel alone and they feel that they're the only ones and it's not happened to anyone else and they don't really understand the high prevalence of it."* (Female, family member)

> "*It was good to know there was a lot of people around that were like me. It made me feel not so alone."* (Female, had attempted suicide)

Connection and hope: More personal stories

The promotion of personal stories was advocated by a vast majority of both individuals who had attempted suicide and family members and friends. Hearing about others' experiences was identified as very helpful because it enabled people to see that they were not alone.

Participants also identified that hearing of others' experiences helped people to better understand what they were going through themselves and provided hope for the future.

> *"You want to know that other people have got through what you are going through."* (Female, had attempted suicide)

> *"I was reading a magazine and it had people's personal experiences in there and just reading that made me feel a bit happier. Well, not happier, but it calmed me down a bit because I knew I wasn't alone and I started realising that what I was feeling wasn't like not normal. I felt like I was an outsider, I felt like I was the only one in the world feeling this. So, after I read other people's stories and found out I wasn't alone and I wasn't the only one feeling that sort of stuff, that helped a lot."* (Female, had attempted suicide)

> *"If someone's going to talk about (this) subject, they have to have credibility. Now if you have a psychiatrist or GP or teacher stand before you and say, well people suicide because of these reasons blah, blah, blah, it's like a clinical explanation, but when you hear it from someone who's been there, it adds a different weight to it … You then have a different connection with them because you know they are talking from experience and they are speaking with integrity and credibility."* (Male, family member)

While many participants appeared to feel strongly about the need for personal stories, some also seemed to feel trepidation about whether this would be possible at a broad community level. It was difficult to discern whether they considered the barriers were due to the dominance of

professional voices in decision making or if they were unsure about whether people with lived experience would be prepared to share very personal and traumatic aspects of their lives.

> *"I mean ultimately, if we ever get to the point of having people who have attempted suicide publicly sharing their stories to the extent of well this is the who, when and why … (that) might start to break down the stigma … Similarly, I think that people whose family and friends of somebody who has attempted suicide or died by suicide… if they were able to share their stories and experiences, it's really powerful … The power of the shared story is a great way of breaking down the stigma."* (Male, family member)

Understanding why: More information about why people attempt suicide and mental illnesses

Many participants further considered that it was very important that more information be provided about why people contemplate suicide and how mental ill health can impact on a person's neurological, psychological and emotional processes – impairing their judgement and capacity to see options and resolve problems.

They spoke about how having a better understanding of what could lead a person to consider suicide may help combat myths and unhelpful attitudes that perpetuate stigma about suicide.

> *"To be able to provide people who are friends or carers with factual information about why and the reasons behind it. I think that's really important."* (Female, had attempted suicide and family member)

> *"In my situation, my parents didn't know what to say and I didn't turn to them because I found they often felt uncomfortable about it… They tried to go off at me saying "it's a bad thing, you shouldn't have done that"."* (Male, had attempted suicide)

> *"It's very scary for everyone in that it is such an unknown…Why would they want to do that?"* (Female, family member)

Participants also strongly believed that mental ill health should be framed in the same way as physical illness – that it was not something to be feared; and that it was not something that people could necessarily control or which they should feel bad about.

> *"One thing that helped me when I wasn't well and the pressure and guilt [I put on myself] for not being able to function was what a nurse said to me "If you had a broken leg and you were in hospital, would you feel that guilty about it?" I said "No." She said, "If it helps you stop beating up on yourself, I can bandage your head because you have a broken head." It helped enormously with taking the pressure and guilt off myself for not coping."* (Female, had attempted suicide)

Knowing what to do: Practical information and strategies

Participants identified a range of practical information that they felt would enable people to be better prepared in managing the challenges that arise after a suicide attempt. This information included: warning signs and symptoms that someone may be suicidal; how to ask if someone is

feeling suicidal and how to respond if they say they are; and how to understand and manage your own reactions to a suicide attempt by someone close to you.

> *"I think that's the information that should be given out- ways to give attention, ways to help."* (Female, had attempted suicide)

> *"I think a very important one is information about how to communicate … it's the big one … and also information about building support networks is also a big one."* (Male, had attempted suicide)

> *"Probably the most important thing is to notice the signs of when someone might be attempting to suicide."* (Female, had attempted suicide)

> *"It's important to emphasise the ongoing nature of looking after your mental health and reaching out to people."* (Female, had attempted suicide)

> *"A really clear link to a phone number that you can call if you need to in the middle of the night."* (Female, had attempted suicide)

Role of information resources

While participants spoke of the importance of information resources, they emphasised that the primary role of information resources was to support and strengthen personal conversations between people. That is, information resources could not replace a good personal discussion and the impact of information resources would be optimal when community attitudes were also supportive.

> *"I think written information is really good, but I think that nothing beats being able to talk to someone freely and openly and just get it all out and be able to have someone tell you that you- it's OK, it's OK to feel like that."* (Female, had attempted suicide and family member)

> *"Face to face is so important as well… to have a specialist sit down and say to parents "the situation with your son or daughter is this… they will be traumatised"… and also for the parents to hear "you are going to be experiencing trauma as well and we will need to provide assistance for you also" … To hear that would go a lot way to helping them."* (Male, family member)

CHAPTER 4: CONCLUSIONS

4.1 Implications for *The way back* Information Resources Project

This consultation with people who had lived experience of suicide attempt(s) and family members and friends of people who had attempted suicide emphasised the critical need for people to be able to talk openly about their feelings and thoughts before and after a suicide attempt. It was clear, however, that positive experiences where others had listened and responded in helpful ways, in both professional services and the broader community, had been the exception rather than the rule.

Participants spoke of a range of barriers and highlighted the need for more accurate and practical information to be made available. The key message was that the most important suicide prevention work that could be done was that which combats stigma about suicide and builds the capacity of individuals, families, health services and communities to have open and supportive, non-judgemental and personal discussions about suicide.

The main vehicle identified by participants which they felt would help promote understanding for both individuals dealing with the aftermath of a suicide attempt, as well as the broader community (including health professionals), was hearing the personal stories of others who had been through the experience. Participants suggested that hearing other people's stories could alleviate the considerable sense of isolation that can be associated with suicidality. They also identified that these stories can also provide hope and belief that things can get better. Participants considered that these stories were also another way for other people in the community to understand why some people in extreme distress are unable to see any other options.

Information gathered through this consultation was specifically used to inform the development of *The way back* information resources and participants' views and opinions had a determining effect on many aspects. For example, the importance of personal stories informed the decision to use quotes throughout each resource from people with lived experience. This consultation finding was also consistent with previous research by Ghio and others (2011) who found that personal stories play an important role in the recovery of people after a suicide attempt. Similarly, in this consultation, participants identified that very practical information should be provided to individuals and their families after a suicide attempt including how to provide support and what actions to take if the suicidal behaviour recurs. This consultation finding was also consistent with previous research such as the study by Leggatt and Cavill (2010), and the desire for practical information informed the type and style of content covered in the resources.

4.2 Implications for future research and practice involving people with lived experience

There were other learnings from this consultation that are important to highlight because of their implications for suicide prevention activity more broadly. Firstly, there was a strong level of interest from participants in taking part in the consultation and the success of consultation showed that it was both important and possible to systematically investigate the needs and interests of this target group in a safe and sensitive way. Our experience highlights that risk management concerns should not be a reason to avoid consultations with people with lived experience of suicide attempt(s).

Having said that, there were ethical issues that arose and that need to be considered. For example, there was a tension between balancing the need to minimise risk of harm from participating with unintentional outcomes due to exclusion criteria. The project team were overwhelmed by the level of interest from people wishing to take part and it was clear from the conversations during the screening discussions that everyone wanted to share their story.

By applying the eligibility criteria that had been developed to minimise risk of harm, 11 of the 48 people who had registered an interest in participating were excluded. These participants advised staff they were disappointed at not being able to take part and for some this felt like another rejection. This was the antithesis of the intention of the consultation process and it raises specific questions about what indicators should guide eligibility criteria and the importance of balancing the risk of harm of participating with the risk of harm of exclusion from participation. Consideration for providing additional support to those with high psychological distress could have been one way to overcome this issue.

Furthermore, the current process, and criteria for inclusion, meant that people's capacity and right to make informed choices about their own resilience and the strategies used to minimise risk were limited. For example, some of the people who scored highly on the measure of psychological distress indicated that this type of emotional experience was something they lived with day-in, day-out. Although the level of distress may have been a useful way of identifying current wellbeing, it was not necessarily the most valid way of identifying whether discussing past and difficult life events would result in acute distress that could not otherwise be managed by the person. Similarly, a small number of participants scored higher levels of distress in their third and final debrief call with a research team member, but were able to state what factors were causing this and wanted to be clear that it was nothing to do with having participated in the consultation.

The use of the phone interview also had benefits and disadvantages. Inviting people to provide details about their life and experiences without a face-to-face or existing relationship was at times challenging. However, this lack of 'connection' also provided space for participants to say as much as they felt comfortable without being distracted by monitoring any non-verbal behaviours of the researcher.

It should also be noted that while the recruitment strategy engaged a number of people who had attempted suicide and family members and friends, females were over-represented and it will be

important for future work to more explicitly explore how gender affects people's experience and understanding of the personal meanings of suicide attempt(s).

Finally, the purpose of consultation with people with lived experience is to ensure that suicide prevention strategies are informed by the views and perspectives of people who have 'been through it'. However, there are inevitable tensions and challenges that arise when looking at how to bring together the wisdom of the people who have 'been through it' with that of academic evidence and expert opinion. For example, it was clear from this consultation that people with lived experience wanted others to understand why someone may contemplate or attempt suicide and that the experience is not unique or indicative that a person is 'abnormal' or that there is something wrong with them. Thus, the challenge for the suicide prevention sector is how to acknowledge and communicate that the experience of suicidality and suicide attempts are not uncommon while also not inadvertently presenting suicide as a desired outcome. Working through how suicide prevention researchers and workers can invite, value and use the experiences of those with a suicide attempt, in combination with other sources of knowledge, is a priority area for the sector.

4.3 General conclusions

In summary, this consultation has:

- Provided new and meaningful information about what people who have attempted suicide and family members and friends of people who have attempted suicide believe should be considered in the development of resources for people who have attempted suicide.
- Emphasised that stigma about suicide is seen as the primary barrier to people having constructive, supportive and non-judgemental conversations about suicide including in times of crisis. Addressing stigma was seen as the most important suicide prevention activity that could be undertaken by the sector.
- Shown that it is possible to engage in safe and sensitive discussions as part of qualitative research with people who have attempted suicide and their family members and friends.
- Highlighted the importance of considering the value and risk of participation and non-participation (and how to assess and manage these issues).
- Shown that people with lived experience have an important and meaningful role to play in the design and delivery of suicide prevention initiatives.

CHAPTER 5: RECOMMENDATIONS

5.1 Recommendations for resource development

It is recommended that:

1. The development of suicide prevention resources for people who have attempted suicide should be informed by the perspective of people with lived experience of suicide attempt(s) (including family members and friends).

2. Information resources for people who have attempted suicide and their family members and friends should:

    a. Provide a clear message that attempting suicide is not uncommon and that people are not alone in their experiences of suicidality or supporting a person after a suicide attempt.

    b. Include personal stories of others' experiences and especially how people have rebuilt their lives in positive ways after a suicide attempt.

    c. Provide information that helps people understand why a person may contemplate suicide, as a way of combatting stigma and stereotypes.

    d. Provide practical information about what to do after a suicide attempt, how to talk about what has happened and what supports are available for people after a suicide attempt.

    e. Where possible, be provided in the context of a supportive professional relationship that offers further opportunities to talk about what has happened and what can be done to (re) build a positive future.

3. Opportunities to support online communities and develop other online resources (such as videos) should be investigated for feasibility and potential benefits.

5.2 Recommendations for suicide prevention more broadly

It is recommended that:

1. People with lived experience of suicide attempt(s) be invited to partner with organisations in the development and design of suicide prevention strategies.

2. Consideration is given to both the value of participating and the risk of exclusion from participating when research involves people with lived experience of suicide attempt.

3. A broad and multi-faceted approach to addressing stigma about suicide and help-seeking is taken, including community and health workforce strategies.

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