



# Experiences of families, carers, and community members impacted by suicide in the ACT

A report prepared in partnership between the Centre for Mental Health Research, The Australian National University and Relationships Australia Canberra & Region Prepared by: Kerrie Gallagher, Scott Fitzpatrick, Michelle Banfield, Amelia Gulliver, Alison Calear, Stella Conroy and Philip Batterham

Acknowledgements: We gratefully acknowledge the contributions of all participants, families, carers, and communities who shared their experiences and those of their precious loved ones. We offer our deep respect and gratitude for all that you have trusted us with. We also acknowledge the loved ones lost to suicide and the guidance they provided throughout this project.

Thank you to Alison Brooke, Paula Mance, Joanne Courtney, Siobhan Madden, Julia Tutty, Jeanette Holland, Ellie Kirk, Karen Etheridge, Melissa Bakhurst, Abbie Harrison, Felicity Hamilton, Glenn Althor, and Stephanie Hodson (Relationships Australia) and Alyssa Morse (ANU) for their assistance and support over the course of this project.

Funding: This project was conducted by ACACIA: The ACT Consumer and Carer Mental Health Research Unit, with support from the ANU Centre for Mental Health Research and Relationships Australia Canberra & Region. ACACIA is funded by a contract with the ACT Government. The funder played no role in the research.

Ethical approval for this study was granted by the Australian National University Human Research Ethics Committee.

Suggested citation: Gallagher, K.,† Fitzpatrick, S. J.,† Banfield, M., Gulliver, A., Calear, A. L., Conroy, S. & Batterham, P. J. (2023). Experiences of families, carers, and community members impacted by suicide in the ACT. Canberra: The Australian National University and Relationships Australia Canberra & Region. (†Joint first authors)

Centre for Mental Health Research 63 Eggleston Road The Australian National University Canberra ACT 2601 Australia Contact: scott.fitzpatrick@anu.edu.au CRICOS Provider No. 00120C

All material in this report is provided under a Creative Commons Attribution 3.0 Australia licence (<a href="www.creativecommons.org/licenses">www.creativecommons.org/licenses</a>). For the avoidance of doubt, this means this licence only applies to material as set out in this document.



The details of the relevant licence conditions are available on the Creative Commons website as is the full legal code for the CC BY 3.0 AU licence (www.creativecommons.org/licenses).

# Contents

Contents	3
Executive Summary	4
BackgroundBackground	6
Aims	
Method	7
Key Findings	9
1. Disconnected spaces	9
2. Fragmented, episodic, and reactive care	13
3. Exclusion and marginalisation of families and carers	18
Integration of Key Findings	21
Recommendations	23
References	25

# **Executive Summary**

The aim of this project was to identify barriers to, and facilitators of high-quality clinical and psychosocial supports for people who died by suicide, based on the lived experience of bereaved family, carers, and community members impacted by those deaths by suicide in the Australian Capital Territory (ACT). To do this, we conducted semi-structured interviews with 17 participants, the majority of whom were clients of the ACT Coronial Counselling Service (ACTCCS). This service is funded by the ACT Health Directorate and provides free support to family, carers, and community members affected by a death investigated by the ACT Coroners Court.

The catalyst for this research project was the distress experienced by bereaved families and community members following the loss of a loved one by suicide. Many of these people yearn to share their stories and the stories of their loved ones, so that their experiences will contribute to the improvement of mental health and suicide prevention services and policies.

The three themes generated in this study describe both barriers to, and facilitators of good care. The first, disconnected spaces, highlights the sense of isolation, disconnection, and disempowerment experienced by those seeking services before their death as well as those providing care for them resulting from their interactions with health services. The gatekeeping of access to services via triage and assessment procedures, the attitudes of health professionals encountered toward deliberate self-harm, and the perceived disregarding of families' and carers' concerns about suicide risk were indicative of a health system in which people were increasingly seen as problems to be solved rather than persons in need of support and care. Training and incorporating trauma-informed and relational practices within services and systems will improve service providers ability to engage suicidal individuals, their families, and carers so that those accessing services can feel safe, respected, and truly supported [1].

The second theme of fragmented, episodic, and reactive care, describes a mental health system focused primarily on crisis management and the alleviation of symptoms rather than on the provision of holistic and coordinated care. As a result, care was often not culturally appropriate or sensitive and lacked continuity, causing harms to some, placing further pressure on families and carers, and in some cases, increasing suicide risk. This theme points to the necessity of case management involving multidisciplinary teams and holistic support when the person is at-risk, after discharge from hospital, and

for families and carers. Training for emergency services and health workforces in reflective practice, including how to discuss suicide and suicidality with service users, will ensure that they have the right support to prevent burnout and compassion fatigue.

A recurring concern from participants was the exclusion and marginalisation of families and carers as partners in the development and implementation of treatment and care plans for the people they were caring for. The third theme demonstrates how ineffective communication strategies and insufficient procedures for sharing information were a barrier to effectively engaging and supporting families and carers. Enhancing professional guidelines for identifying and engaging families and carers, incorporating these into professional development and training, and establishing clear processes for emergency services and health workforces to identify the support needs of families and carers will help empower and support them as partners in care, as well as to address their own health and wellbeing needs.

# Background

The experience of mental health issues is one of the strongest risk factors for suicidal behaviour [2], although there are also myriad psychosocial and demographic factors that influence suicidal behaviours [3]. Many people with mental health problems have had some contact with the health care system, providing a potentially critical opportunity to intervene to reduce the risk of harm. However, the current system in Australia does not always provide an effective and integrated service that is able to effectively cater to the full spectrum of needs from early intervention to severe mental illness [4]. This lack of effective service integration is particularly evident in the period following discharge from an emergency department or hospital following a suicide attempt or self-harm [4]. For those at risk of suicide and the families who support them, a fragmented and confusing mental health system may limit access to appropriate clinical and psychosocial services. Identifying opportunities for timely intervention and better characterising barriers to, and facilitators of appropriate care are critically important for ensuring that needs are met. The experiences of people who have attempted suicide, their families, and people bereaved by suicide suggest that there are clear areas that require improvement [5, 6]. These groups have much to offer to improve health care services in this field.

Suicide has a devastating and widespread effect on families, friends, and our community. There has been little overall change in Australian suicide rates over the past decade, despite new government initiatives. The Final Advice reports, prepared by the First National Suicide Prevention Adviser and the National Suicide Prevention Taskforce, has identified system reform toward a whole of governments approach, including creating the environment for a more connected and compassionate approach as key priorities [7]. This includes the implementation of evidence-based and compassion-focused workforce development to drive cultural change and improve the capability of all formal and informal workforces involved with people at times of suicidal distress.

The ACTCCS is a program delivered by Relationships Australia Canberra & Region (RACR), which provides counselling to anyone affected by a death that requires investigation by the ACT Coroners Court. The clients of this service are frequently families and community members affected by the loss of a loved one who has died by suicide, and the majority of those who have died are young people. Kerrie Gallagher, the

ACTCCS senior clinician, found that clients of this service experienced difficulties in supporting and accessing support for their loved ones and themselves in the period preceding and following their death. Many clients wished to share their stories and the stories of their loved ones in a formal way, so that their experiences might be used to improve the experience of others in the future. Examining the experiences of those who have lost loved ones, therefore, was seen to provide a unique opportunity for investigating these issues, ensuring their voices and lived experience are heard, and bringing them to the attention of health care practitioners, managers, and policy makers to effect meaningful change and improve health and social outcomes.

# Aims

The purpose of this research was to investigate the experiences of family, carers, and community members impacted by a suicide death in the ACT. We aimed to identify barriers to, and facilitators of care for people who died by suicide, based on the lived experience of those closest to them. We used these perspectives to develop guiding recommendations for improving ACT healthcare, community, and educational systems and their processes regarding suicide risk.

## Method

#### Data collection

We conducted semi-structured interviews with 17 participants in 15 interviews. Of these, 16 were clients of the ACTCCS who had experienced the loss of a loved one to suicide. One other, who had heard about the project but was not engaged with the service, contacted the researchers directly and asked to be involved. Two interviews were conducted with multiple participants at the same time as was their preference. In one case, both parents of the deceased were interviewed together, and in the other, two school community members were interviewed in reference to two suicide deaths in their school community.

The ACTCCS senior clinician conducted the interviews to maximise participant comfort and safety when discussing very sensitive issues. Interviews were conducted in-person and remotely via telephone/video call/online according to participant choice and COVID-19 restrictions. Interviews were recorded and professionally transcribed. Any names and

other potential identifiers were removed from transcripts to limit potential reidentification of participants.

Interviews focused on participants' accounts of their experiences, expressed as their own story. Interviews were largely participant-directed. However, some prompting questions were used to elicit responses to specific research questions of interest around service delivery. Questions were provided to participants prior to their interviews to ensure they were comfortable with what they may be asked, and specifically to provide an opportunity for participants to organise their thoughts and feelings about their experience. The topics included challenges navigating the health system, issues with confidentiality, and potential gaps in accessible services. The design of the project, and creation of these questions was informed by the principles of trauma-informed and restorative practice. These principles were used to ensure the interviews did not create harmful, unintended consequences for participants, and they felt responded to in a respectful and safe way with a view to addressing and repairing harms previously caused [8, 9]. Questions used appropriate language to avoid causing significant distress. The following questions were used to guide interviews and are indicative of the key areas of research focus:

- 1. What was your family's experience in the time leading up to the death of [your family member], for example in the months, weeks, and the days prior?
- 2. What were the experiences of health services or social services that [your family member] received prior to their death?
- 3. What challenges did [your family member] and your family experience in navigating or accessing the health system?
- 4. What was helpful/what was unhelpful?
- 5. What information/supports/services would have been useful to you at this time?
- 6. What changes would you like to see made to the ACT system to better help support people and their families to help prevent suicide in the future?

#### Data analysis

The topics in these questions formed the basis of the analysis. Qualitative data was analysed using the Framework Method [10]. This is a systematic and flexible approach

to analysing qualitative data. The Framework Method is appropriate for thematic analysis of textual data, particularly interview transcripts, where it is important to be able to compare and contrast data by themes across many cases, while also situating each perspective in context by retaining the connection to other aspects of each individual's account. An inductive approach was used, whereby coding focused on identifying recurring patterns in the data, moving from particular experiences to a more general set of descriptive categories.

#### **Participants**

The age of participants varied from 20-65 years. The relationships to the deceased included parents (n=9), grandparents (n=1), spouses (n=2), aunts or uncles (n=1), siblings (n=1), children (n=1), and school community members (n=2).

# **Key Findings**

The findings have been organised around three interconnected key themes that were developed from inductive analyses: i) Disconnected spaces, ii) Fragmented, episodic, and reactive care, and iii) Exclusion and marginalisation of families and carers.

# 1. Disconnected spaces

Participants reported contact with services often resulted in feelings of isolation, disconnection, and disempowerment for those seeking services before their death, as well as those providing care for them. Rather than pulling people in, services invariably pushed people away, creating insurmountable barriers to the provision of appropriate care.

Emergency services and hospital emergency departments acted as gatekeepers to care, with families describing the difficulties they had in getting family members the appropriate level of care in crisis situations.

One of the [ambulance] officers was very good, and the other one... I had real concerns about, that he just wasn't believing us, because of the façade that Dad was presenting...His comment to myself and my daughter [was]..."Oh look, he doesn't seem all that bad. I don't think we really need to take him." [Participant 8]

This reluctance to accept family member's concerns about the risk they believed their loved ones were experiencing was perceived to be a common reason for people not receiving care, as were the processes of screening and assessment carried out in some clinical settings. In cases where people had previous presentations for suicidal distress or crisis, this history was not always taken into consideration when assessing presenting suicidal risk. Both processes worked to marginalise carers, who felt their loved ones were denied timely and appropriate levels of care. In one instance that related to a son's diagnosis and treatment by a general practitioner over the previous six months, the actions of community mental health services served to prohibit access to the specialist mental health care the parents felt he required.

I don't know what capabilities or skills they had, but they basically went through a screening process for him, and just said you're a low risk something, go and see a GP, get a mental health plan, and they can refer you to headspace. And make sure you get a lot of...eat healthily and exercise. That was the gist of it. [Participant 6]

In several cases, the attitudes and responses of hospital emergency department staff to suicidal ideation suggested these were not sufficient conditions for admission.

They discharged her, despite me saying she's still suicidal...They said, we can't keep people there just because they're suicidal. [Participant 1]

In one case involving presentation to the hospital emergency department, an expression of suicidal intent did not result in face-to-face assessment by a psychiatrist.

He has mentioned, not just to myself but other family members, [that] he would like to kill himself, and he would like to take a handful of pills. I said he has a desire to do this, and he has a plan. And we talked some more, and he said OK, I'll go and talk to the psychiatrist on-call. He went away and he came back, and he said the psychiatrist isn't going to come in and review him because he doesn't meet their criteria. [Participant 8]

Opportunities to collaborate in care, build trust, and create safety are a key component of trauma-informed practice [11]. Handled sensitively, assessment and triage can be a relational activity used to establish trust and talk comfortably about suicide and safety. An apparent lack of regard for those in distress and the wait at the hospital emergency

department that often ensued was described as a particularly upsetting and alienating experience.

I've been with her [daughter], sitting waiting for hours to be seen because it's not a serious enough thing to see someone immediately when they're feeling suicidal; so getting more and more agitated and more and more distressed while she's in the process of waiting to be seen, because it's not that urgent. [Participant 1]

Indeed, many questioned whether the hospital emergency department was a suitable environment for those in crisis.

Who wants to go to ED, let alone if you're experiencing some form of psychosis or suicidal ideation. There's all these lights, there's noises, there's beeps, it's sterile, it's just not the environment. [Participant 2]

In the case of other mental health services, availability and staffing issues meant that those in need were often unable to access services in a timely manner.

When someone is in that state where they need help, I personally believe myself that sending them away with only an appointment maybe in three weeks' time, is only going to impact further on that mental health. [Participant 7]

As well as its potential to worsen existing mental health issues, problems with service availability and staffing also established a pattern of fragmented, episodic, and reactive care that was detrimental to the therapeutic relationship and the continuity of care required by many experiencing ongoing and complex mental health issues.

When I initially needed to talk to someone, it was like we can see you in two months' time. Well, actually, I need someone now. I don't need you in two months' time because it's too late. Who knows where you'd be in two months' time...You've got Lifeline, you've got the on-call immediate response people, but it's that relationship that you need to develop, and that continuity that I think is the beneficial one. [Participant 11]

Upon being admitted to services, participants described a range of isolating experiences for those they were caring for.

Long story short, nobody spoke to him. Monday, I came back because all Saturday, all Sunday we were there with him. Monday, I came back, nobody spoke to him still. We were there about 10 or 11 [a.m]. I think they just saw that we were just waiting, and then a person in charge at the time called him to a meeting room to talk to him less than five minutes. [Participant 10]

These experiences of isolation and disconnection explain how, despite the best intentions of many to access services, care was made increasingly difficult to access by several intersecting factors: low mood, previous bad experiences of services, and the absence of connected, engaged services that provided holistic, person-centred, relational practice.

There's no system in place... that would reach out to him as the vulnerable individual...[Without a] necessarily sufficiently active agent that somehow engages him and says...[name], it probably would be good if you came in, or at least even just saw your GP, [or] went and saw some other specialist of some kind. [Participant 3]

It shouldn't be so hard for [her] to access the services, but she didn't feel she could do it on her own. So, I had to go and open every door for her...And to me that all came down to not listening, not hearing her, or seeing, you know, the difference, in the behaviour, the demeanour, just everything. [Participant 16]

The responses of some service providers also had a detrimental effect on the relationship between those experiencing significant distress and their loved ones. In several cases where family members actively sought support from services for their loved ones, service provider disengagement drove a wedge in these relationships, isolating family members and leaving them without support.

I just walked out of A&E feeling absolutely devastated that I'd gone to this length, and we were being told that he didn't meet their criteria. Off you go. And I was now taking home a dad who was very alienated from me, very angry about my confessions in front of him. And I just thought, where am I going to get help? Where do I go to now? [Participant 8]

Over the longer term, the cumulative effects of these isolating, adverse experiences with health services compounded the hardships experienced by individuals and within relationships and family life.

From the first suicide attempt up until that second suicide attempt, and then obviously his death six months later...[We] didn't know where to turn, [we] didn't get any support...We felt lonely. We started feeling isolated. You know... even our close friends didn't get it. We weren't really able to talk with them...It was...very stressful. More stressful than his actual death. [Participant 9]

## 2. Fragmented, episodic, and reactive care

Participants consistently described a mental health system that was fragmented, reactive, symptom-focused, and based around the needs of services rather than service-users. For example, navigating the mental health treatment pathway to access the appropriate level and quality of care was reported as a challenge by participants.

It was very difficult understanding what all these things are [psychiatrist, psychologist, general practitioner] and what the pathways were. Some of the pathways weren't around the [person], they were more around the admin and the Medicare. [Participant 6]

A lack of clear information-sharing protocols and referral pathways within and across states and territories impacted care coordination. For those with complex or comorbid conditions, a lack of integrated care was a barrier to the provision of holistic, personcentred care.

She went into a residential alcohol thing once, and they discharged her to the psych unit then they wouldn't take her back because of her mental health issues...You know, that sort of thing. We can't have her here, she's got mental health issues. And she'd go to [the] mental health unit, we can't have you here to detox...You have to try and come up with a system that treats the whole person and recognises that often these are symptoms of that underlying issue. [Participant 1]

Service fragmentation and the lack of joined-up-care was most evident in the experiences following discharge from services. Despite the importance of access to

suicide aftercare in current suicide prevention strategies, services tended to focus on crisis mitigation, and there was little continuity of care for those discharged following the incidence of intentional self-harm or suicidal behaviour.

[The] hospital didn't even see why they should be admitting her and keeping her there when we brought her back. Because why was it their job to look after her? And then they discharged her from hospital. I had to find a private psychologist for her. There was no support offered on discharge from hospital. [Participant 1]

When support was offered, it was often piecemeal and did not adequately meet the needs of people.

So [she] rings them [Home Assessment and Acute Response Team], and I'm at home at the time, I know that she's ringing them, and I know that she's been told to ring them. And she gets off the phone to me, and she says, "Well, that was a waste of time, they've just given, all they've done is give me the number to the Suicide Call Back Service". And that's it. So, despite the fact that, you know, she, initially she feels safer knowing that she can call them. And then she calls them, and then all they do is give her the number for the Suicide Call Back Service. It's like they've wiped their...washed their hands of her. [Participant 17]

This lack of continuity of care placed considerable burden on family members and carers who were shouldered with the responsibility of caring for their loved one without adequate support or resources.

So you're giving me a person who was suicidal a few weeks ago, who you can't predict if he's taking medication, who you told me needs to stay for three to six months under your treatment, who mostly likely will need a depot [slow release medication injection] and you're not giving him depot, you're giving him to me to be responsible for him without the plan, without the name, without anyone treating him. You're telling me there is some team looking after him. [Participant 10]

Participants described as particularly helpful those instances where multidisciplinary case conferencing and integrated care was part of normal practice.

What was helpful was them starting to bring in lots of people who knew her to make sure they were all coming off the same page and things like that...[who] knew what was happening. [Participant 1]

For many participants, it felt like once the immediate crisis had been mitigated services discharged people into the same environment that may have caused the distress in the first place, without any strategies or plan in place.

[She] ended up in the hospital a couple of times, and regardless of what the situation was that brought her there, they were happy to just release her to us. And that, that was not something that was a good situation...At least to say, alright let's have a little decompression. Let's have some time and space out of the environment in which the, that event happened from or was caused by. And I think at that point in time then that person should be required to deal with some of those issues. Now, whether it be psychologists, psychiatrists, whatever is available, they need to deal with some of those issues, and they shouldn't be put back into the original environment until some of those issues have been dealt with. Now, if it is, let's say a mental health issue at which there is not going to be any improvement then everyone involved needs to be aware of that, and they need to be aware of that as the unit. So, they can't talk to one person and say this, and then talk to the other people and say something different. [Participant 12]

For others, whose loved ones had been receiving treatment, often without any discernible benefits, there were similar concerns about the kinds of treatment provided.

They were concerned to help him, but there seemed to be a lack of therapy and coping strategies. This comment might seem unfair, as [name] would never agree that he had mental illness and lacked cooperation. However, there must be many vulnerable people who act this way, and it seems strange that in the 21st century there have been apparently no techniques developed to deal with this. [Participant 5]

One participant expressed concern about the reliance on medication and the treatment of symptoms without taking into account contextual or psychosocial factors that may have influenced suicidal thoughts or actions.

There was an underlying issue, [but] no one had time for the issue. They were trying to give him medication. They didn't care about patients and wellbeing and getting them better. It's only as long as we medicate you enough so you're a zombie and you don't commit suicide\* we're fine. That's how I read it. [Participant 10]

For others, the primary concern was the prescribing of medication by general practitioners without any supervision or follow-up.

His GP put him onto some medication to manage his anxiety. I guess my concern around that was the GP put him onto medication, and when I asked my husband, do you have any follow up, [he replied] no, the GP doesn't need to see me again. So, I had some concerns around the fact that the GP could put him on quite significant level medication, but not actually coordinate follow-up. [Participant 11]

The extent to which people were engaged by health services and professionals in their treatment was of concern to several participants, with some questioning the appropriateness of clinical approaches, resulting in those in need not fully participating in their treatment.

He felt as if people were just telling him what to do. He'd been in this situation for all of these years, where he'd had people telling him what to do. I think he was just fed up with it. And it might well have been a factor. I'm sure he felt powerless, I'm sure. I'm sure he did. [Participant 4]

Just how sensitive service responses were toward an individual's culture, needs, and preferences, and the triggering effects of language on those young and vulnerable, was also raised by two participants. In the first case, one participant described how the young person experienced a significant loss of hope for improvement or recovery after being given a diagnosis of depression.

Perhaps more serious was the comment made to [name] in the third appointment with a psychiatrist, which [name] reported to us as him having been told that his depression was something he would have for the rest of his

<sup>\*</sup> The language reflects that used by participants, although we recognise there is variation in the terms people use.

life. We only have [name] account of the comment, and it may have been made in a fuller context of treatment options, etc., but nonetheless it might have been a very confronting thing for [name] to hear and have had a corrosive impact on his assessment of his prospects for the future. [Participant 3]

In the second case, that of a young woman with an infant daughter, the realisation that she might have her child removed from her care due to her mental health struggles triggered a range of powerful emotions and a growing distrust of services whom she felt had misled her.

That was the beginning of [name] struggles because she thought she wasn't given the correct information, or whole information, and she just thought voluntary care, you know, was to have support and a break... I explained the process, you know, you have to prove yourself fit... For [name], that was really, really hard. She just absolutely fell apart. [Participant 16]

There was also the potential for physical health services to retraumatise individuals, highlighting further the importance of language, trauma-informed practice, and relational rather than transactional processes of care, especially when assessing work-related injuries and when emotional distress may already be present.

She had a very traumatic upbringing to say the least and obviously his questioning brought that trauma well and truly to the fore when she was already in mental distress. But what made it even worse for [name] was that she wasn't warned that she would be asked this question [about her childhood]. And then she waited a period of two weeks to get that report, and all these details of her childhood were then provided to that unsupportive workplace for them to have. [Participant 17]

For families and carers, contradictory and inconsistent verbal messaging from health professionals had the potential to derail collaborative recovery planning and to marginalise them as co-carers of vulnerable, at-risk people.

We did have some family meetings but even there some of the communication was so different between the times that we would have our parent meetings with the professional versus when we would have the family meeting with that same professional...So, all of a sudden, we were in a situation prior to having

our points accepted, agreed upon, and reinforced basically, and then have that turn around and all of a sudden not being supportive of any of those issues. [Participant 12]

## 3. Exclusion and marginalisation of families and carers

Experiences of marginalisation and exclusion were a consistent theme across participant interviews. This took different forms. Some felt that they were not listened to by health professionals, especially when trying to convey their concerns about suicide risk.

I remember when she was in hospital, in her room, there was a sign up saying, if you have any concerns, you know your child better than us, please tell us. They didn't listen...The main issues I guess were trying to find someone who would actually take in and listen to what we were trying to say to them. I think that's really the main obstacle we had. [Participant 7]

So, the following day I missed a call from a person from the HAART team [Home Assessment and Acute Response Team]. Called them back... and I said, so when will you be coming to visit? And he said, we're not. And I said, but the person yesterday said that you would be coming to review dad today. No, no, there's no need for that. Imagine how your dad would feel if a huge group of people walked into your house. Yeah. So, made me feel...and I thought this is diabolical...I can't believe it. This is supposed to be the service that one calls when you've hit the wall, when you desperately need help. When you feel that your loved one is going to commit suicide or do something terrible. [Participant 8]

For others, the withholding of information by health services meant family members were often unaware of exactly what was going on. While seemingly done out of respect for confidentiality, family members struggled to obtain even the most basic information about how to support their loved ones and it was not clear if consent was ever sought from service-users to nominate family members as designated carers or to share information with them.

We weren't given clear information and were balked at any time that we tried to even get information...because of his age. Even just general information about what was available...You know, no one came and said, 'Look, OK, we can't

talk to you about [name] because he's over 18, but here's the system and here's what you can do'...People would throw us, you know, a brochure or whatever. [Participant 9]

At the other end of the scale, one participant described how the failure of health services to share information with them about their son's suicidal thoughts had significant repercussions for how they acted, or more importantly, did not act, to put in place measures that may have prevented his suicide.

That was my number one thing...just being kept at arm's length. Again, we don't know what [name] said or didn't say. If we were more involved in this, who knows? He may have done it anyway, but we certainly would have been totally different. You can imagine if someone, the ideation was known, we would have just been so much different. You're kind of in the dark. [Participant 6]

Participants understood the need for confidentiality, but several of them struggled to get information on how best to support their loved ones, putting them in a difficult position, especially for those living under the same roof.

Yes, she was in that between stage of being adolescent and an adult. They had to treat her more as an adult but in this situation, because she was coming back into this environment, we needed that information. [Participant 12]

Indeed, it appeared as if confidentiality was used to avoid working with and supporting carers, as at times there was a complete disregard for family members and the active role they were being asked to take by health services as co-carers of those in need of support.

I think sometimes, a little more attention to actually talking to me, finding out how I was feeling about being a support person, how I was feeling about the fact that she's tried to kill herself several times, but she's been admitted to hospital or whatever. Rather than just, here you are, take her home, the discharge plans are...It was more that it was about, the discharge plans are she's going home, she can contact this person, she can do this, she's got this person and place. [Participant 1]

Recognition of potential conflicts within family relationships and their impacts on young people's mental health pose a clear challenge to health services. Together with confidentiality concerns, this may, in part, explain the reluctance of some health professionals to disclose information to family members.

A lot of these issues that we have with students that are on our high needs radar, there's relationship issues within the family. And there's been something, some kind of trauma from that, within that family that has triggered this spiral. And there's very, very few that I could say, or list that I carry around with me all the time in my head that don't have some kind of family issue that has gone before. [Participant 15]

However, some participants described instances where they felt judged by health professionals or where their well-intentioned actions were wrongly interpreted.

She [mother] felt actively shoved out, kept at arm's length. And he is 18, and we don't know what [name] was saying to him [GP] about us. So maybe there was something in that as well. I don't know. But I suspect [mother] was probably pushing hard to find out more and want answers. What's this, what's this? Because you would, it's your son. [Participant 6]

As previously noted, this did not stop services from discharging people into these same environments without any attempts to work with and support families. The absence of assistance and information provided to families by health services was a common source of concern among participants. For those with little or no previous experience of mental health issues or suicide, this was an especially overwhelming and worrying time.

Failing to engage us and explain how we can care for [name], like it was as dramatic as it can be. Like none of us ever had any experience with mental health at all. We weren't really sure and nobody was guiding us if [name] was really unwell. [Participant 10]

Well without a doubt we didn't know what to do. We were told, you know, one thing or another, or what have you from different people from different agencies. But basically nothing, nothing worked. It didn't matter what we tried, how we tried to approach the situation, nothing worked. [Participant 12]

The value of having a case worker who could liaise between the service-user, family, mental health professional, and relevant health or social services was discussed by one participant as a way of mitigating some of these issues.

This is a new experience and one we have no experience with and, you know, we're scared and all that sort of stuff and [they] don't know what to do to help us. So those two [for example, a case manager and psychiatrist] would work together and help, you know, all of us. And then that would achieve a plan for moving forward. And that's the key thing. [Participant 9]

The wellbeing of families and carers was also a significant issue voiced by participants.

With everything that happened, not once did I get asked if I needed to speak to someone. Which, as a main carer, if I'm not doing well, it's certainly going to inflame the situation. [Participant 7]

The potential for a peer-support or carer-liaison person was raised by one participant as a way of supporting families.

When people have various forms of illness like cancer, there's often a lot of volunteer support available to support the person and their families. And I mean, this is a different area where people might feel vulnerable dealing with people with mental illness, but you know, could there be an option for people like that to help out? Also not just the clients, but as you pointed out again, a lot of parents and carers we saw at these facilities looked very tired, and vulnerable. [Participant 4]

# Integration of Key Findings

The three critical themes to emerge from the research were i) disconnected spaces; ii) fragmented, episodic, and reactive care; and iii) the exclusion and marginalisation of families and carers.

The first of these themes, disconnected spaces, described feelings of isolation, disconnection, and disempowerment experienced by those seeking services before their death as well as those providing care to them. The gatekeeping of access to services via triage and assessment procedures, attitudes toward deliberate self-harm by practitioners, and the overlooking of families' and carers' concerns about suicide risk

were implicated in shaping these experiences with significant consequences for service user/family/caregiver-provider relations and ongoing service engagement.

The second theme highlighted the fragmented, episodic, and reactive nature of the care provided. Care was viewed as focusing primarily on crisis management and aimed to alleviate presenting behavioural and psychological concerns rather than building relational connections. This decontextualisation of individual distress meant that care was often not culturally appropriate or sensitive, causing harms to some and undermining trust in services. Inadequate and uncoordinated care following a suicide attempt and/or discharge from hospital contributed to discontinuity of care, increased pressure on families and carers to be active and knowledgeable co-carers, and in some cases, to elevated suicide risk.

The third theme, exclusion and marginalisation of families and carers, highlighted how, despite the pressure on families to provide support for their loved ones in the absence of appropriate follow-up care, ineffective communication strategies and insufficient procedures for sharing information and supporting families and carers prevented services from doing this effectively.

These three themes suggest that the health system, including primary care services and hospitals in the ACT, have significant gaps in supporting people who experience suicidal distress and their families. Fundamental to all these themes and addressing these gaps, is ensuring that the system is family inclusive. Understanding the family context and appropriately including family members when providing support, with consent, can contribute to better outcomes and provide opportunities for more effective and efficient care. This approach includes family and significant others in care assessments, planning, and treatment when individuals access health support [12, 13]. As highlighted by the families in this research, health practitioners can only spend limited time with an individual and it is important to leverage the knowledge and ability to provide ongoing intervention within an individual's own support network.

Based on the experiences and accounts generated by participants in this study, we provide nine key recommendations to better support people in suicidal distress and their families, which may result in fewer deaths and better health and social outcomes.

## Recommendations

- 1. Enhance professional guidelines for identifying and engaging families and carers of people experiencing suicidal crisis or distress so that they align with other jurisdictions (for example, NSW [14] and Victoria [15]). Incorporate these into professional development and training. Guidelines should specify the rights of families and carers to have information provided to them and for consultation on assessment, treatment, care, and discharge planning, and include guidance on facilitating consent of the person in distress.
- 2. Implement clinical education including regular upskilling of hospital emergency department staff and emergency services personnel in trauma-specific intervention and relational practice. Training and incorporating trauma-informed and relational practices within services and systems will improve the ability of service providers to engage people in suicidal crisis or distress, their families, and carers so that those accessing services can feel safe, respected, and truly supported.
- 3. Strengthen the training of all health professionals in family inclusive practice, but especially those involved in the management or care of those in suicidal crisis or distress. This includes ensuring a person's medical history, and, where appropriate, family and carers' knowledge/insights, are taken into consideration when assessing suicide risk.
- 4. Provide clearer guidance to GPs on appropriate timeframes for monitoring medication for efficacy and/or adverse effects, especially where there is any suicidal ideation.
- 5. Ensure training in reflective supervision for health professionals is implemented in accordance with relevant clinical education or professional development programs. This will assist in safeguarding the mental health and wellbeing of those working with people impacted by trauma and/or experiencing suicidal ideation.
- 6. Provide aftercare programs to all people who are hospitalised for suicidal thoughts or actions and ensure they have a minimum of three months' recovery

support with consistent, coordinated care planning involving relevant health and social services.

- 7. Consider a range of approaches to restructuring services and workforce development strategies, aiming for a 'no wrong door' approach to treatment of comorbid mental health and substance use problems.
- 8. Invest in developing effective and sustainable models of care to help bridge service gaps. This may involve implementation, rigorous evaluation, and sustainable funding for emerging programs that are non-clinical and peer-led. Establish clear procedures for hospital emergency department staff and emergency services personnel to provide warm referrals to those in suicidal crisis or distress, beyond hospital emergency departments.
- 9. Implement supports to prevent burnout, compassion fatigue, and moral injury in first responders and health staff to minimise its impact on care.

## References

- Singh, C.D., et al., Trauma-informed and relational approaches to service provision: Building community-based project capacity to respond to interpersonal violence through a national initiative. BMC Public Health, 2020. 20(1): p. 1-13.
- 2. Nock, M.K., et al., Cross-national analysis of the associations among mental disorders and suicidal behavior: Findings from the WHO world mental health surveys. PLOS Medicine, 2009. 6(8): p. e1000123.
- 3. Christensen, H., et al., Predictors of the risk factors for suicide identified by the interpersonal-psychological theory of suicidal behaviour. Psychiatry Research, 2014. 219(2): p. 290-297.
- 4. Robinson, J., et al., Raising the bar for youth suicide prevention. 2016, The National Centre of Excellence in Youth Mental Health, Melbourne: Orygen.
- 5. Maple, M., et al., Silenced voices: Hearing the stories of parents bereaved through the suicide death of a young adult child. Health & Social Care in the Community, 2010. 18(3): p. 241-248.
- 6. Shand, F.L., et al., Experience of health care services after a suicide attempt: Results from an online survey. Suicide and Life-Threatening Behavior, 2018. 48(6): p. 779-787.
- 7. National Suicide Prevention Adviser, Connected and compassionate: Implementing a whole of governments approach to suicide prevention (Final Advice). 2020, Canberra: Australian Government.
- 8. Parker, S. and V. Johnson-Lawrence, Addressing trauma-informed principles in public health through training and practice. International Journal of Environmental Research and Public Health, 2022. 19(14): p. 8437.
- 9. Restorative Justice Council, Principles of restorative practice. 2016, Norwich: Restorative Justice Counci.
- Gale, N.K., et al., Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology, 2013.
   13(1): p. 117.

- 11. Isobel, S., et al., 'What would a trauma-informed mental health service look like?' Perspectives of people who access services. International Journal of Mental Health Nursing, 2021. 30(2): p. 495-505.
- 12. Australian Institute of Family Studies. 2022. Family-inclusive aproaches when working with young people accessing mental health support, Melbourne: Australian Institute of Family Studies
- 13. Marynowski-Traczyk, D., et al., Mental health presentations to the emergency department: A perspective on the involvement of social support networks.

  Australasian Emergency Care, 2019. 22(3): p. 162-167.
- 14. NSW Government, Mental Health Act 2007 No 8. 2022: Sydney. Available at https://legislation.nsw.gov.au/view/html/inforce/current/act-2007-008
- 13. Victorian Government, Mental Health Act 2014, 2022: Melbourne. Available at https://www.legislation.vic.gov.au/in-force/acts/mental-health-act-2014/024