

# ***PLEASE TALK TO ME. PLEASE INCLUDE ME. I WANT NURSES TO UNDERSTAND.***

A REPORT ON CARER PERSPECTIVES ON EMERGENCY  
DEPARTMENT NURSING PRACTICES FOR A PERSON  
WITH BORDERLINE PERSONALITY DISORDER

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In consultation with:

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## Needing Help?

### Emergency assistance 000

If you need emergency assistance phone **000** for police, ambulance or fire services

## Crisis support lines 24/7

**Kids Helpline** - 1800 55 1800 or <https://kidshelpline.com.au/>

**Lifeline Australia** – 13 11 14 or <https://www.lifeline.org.au/> (available 24/7)

**MensLine Australia** – 1300 78 99 78 or <https://www.mensline.org.au/> (available 24/7)

**Beyondblue** – 1300 22 4636 or <http://www.beyondblue.org.au/> (available 24/7)

**Suicide Call Back Service** – 1300 659 467 or [www.suicidecallbackservice.org.au](http://www.suicidecallbackservice.org.au) (available 24/7)

**Qlife**- 1800 184 527 or <https://qlife.org.au/> (available 3pm until midnight)

**SA Health Mental Health Triage Services** – 13 14 65 (available 24/7)

## Additional supports

**Your General Practitioner**

**Current support services you may be engaged with**

**Friends or family who may be supportive**

**A Minister of Religion**

## Dedication

This report is dedicated to the carers and loved ones who are no longer with us. We acknowledge the challenges they faced and the hopelessness they experienced. We also acknowledge the contributions that their lives have made towards improving our understanding of challenges in accessing services and ways in which we can overcome them.

## Condolences

We wish to extend our thoughts and condolences to the many families, partners and friends who have lost someone they love. We acknowledge the distress that you have experienced as you move forward, your courage and your strength, as you find peace, comfort and healing.

## Acknowledgement

We wish to thank Sanctuary BPD carer support group for their continued support and dedication in their work to improve the lives of carers and consumers.

We also thank Mind Australia Ltd. for continuing support of the Lecturer Lived Experience Position, which was associated with this project.

## A note for readers

This report includes content about high levels of distress and suicide related information. Some of the content may cause discomfort or distress for readers. Should you experience any discomfort or distress, we encourage you to make use of the services listed on page 2 of this report, or other supports that you currently have in place.

We respect the authentic voices of carers who participated in this study; however, we have made some slight wording changes where needed to communicate suicide and self-harm using non-stigmatising language.

## Abbreviations

BPD:	Borderline Personality Disorder
ED:	Emergency Department
GP:	General Practitioner
NHMRC:	National Health and Medical Research Council

## Foreword

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When my husband had a heart attack and was taken to the ED, I was not only informed what the issues were, and what the plans were to treat him, but I was welcomed as someone who could give information about what had brought on the symptoms and a background to his health. At the same time, I was comforted and supported by staff in the ED.

Why then am I ignored and made to feel at fault when I take my daughter, who is diagnosed with BPD, to the ED, when she has either self-harmed or indicated she is so distressed that she feels unsafe? Why is there such a difference in the way families are treated?

Families are so often the informal “case managers” or the de facto crisis intervention workers. Families are the ones who handle calls when loved ones talk of feeling suicidal. We are not trained to be the “informal case managers” yet we do the job, supporting them in their daily lives and trying to keep them safe. By the time we feel we need to take them to an ED, we ourselves are distressed, and often traumatised, by their self-harm or talk of suicide.

Nursing staff could alleviate much of our distress by treating us with compassion and empathy and even at times, some TLC. We too need information, support and comfort just as carers of a family member who presents in the ED with a physical illness. Yet often we are at best, ignored, and at worst, discriminated against when we try to talk to nursing staff and clinicians. This makes us carry an even greater burden while caring for our loved one.

I would like to encourage nurses to see that we can help. We can give much information about what might have led up to our loved ones feeling so unsafe that they needed to present at ED. We can be one of your best resources in treating our family member. We are not the enemy.

Please see us as part of the triumvirate of mental health staff, the consumer and the family, trying to keep our loved ones safe and living their lives as well as possible.

Historically carers have been largely ignored in research of ED settings. This research project is therefore important to Sanctuary as it was the first-time carers felt they had a chance to have their voices heard in serious research. Here was their opportunity to collaborate with the researchers to generate new insights, knowledge which will hopefully lead to improved practice in the nursing and health professions.

**Judy Burke**

Sanctuary BPD Carers Support Group

March 2019

## Executive Summary

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This report provides a summary of a research project undertaken by the University of South Australia in consultation with Sanctuary BPD carer support group. The purpose of this project was to explore carers of a loved one with borderline personality disorder (BPD) and their perspectives on emergency care when a crisis arises. This occurred in two stages: 1) A literature review; 2) Focus group interviews. The project was conducted as part of the Honours Program within the School of Health Sciences, University of South Australia.

Stage 1 of the project involved a literature review which was conducted as a scoping review during April 2018. The scoping review allowed for the mapping of any existing research in order to answer the research question. A scoping review is appropriate when there is limited knowledge in an area. The results of the review identified carers as an important partner in the care and management of their loved one in a crisis. Further, the review highlighted that when a crisis arises, carers require timely and accurate information provided to them which is free from stigma but helps the carer to understand how to best support their loved one. The findings from this review resulted in a paper titled *“Carer perspective of people diagnosed with borderline personality disorder: A scoping review of emergency care responses”* and was published in the Australasian Emergency Care Journal (Acres et al. 2018).

Stage 2 of the project involved conducting a series of small focus group interviews with 13 participants who identified as a carer for a loved one with BPD living in South Australia. The purpose of this stage of the research was to explore the perspectives of carers regarding emergency department nursing practices. Thematic analysis of their views and experiences enabled the research team to identify four major themes: 1) ED is the gateway for crisis support; 2) Talk to us don't judge us; 3) A different level of care; 4) What I want you to know.

As common to many qualitative research projects, the findings of the study need to be considered in the context of study limitations. The study engaged a relatively small sample of carers using a focus group method. Purposive sampling enabled the successful recruiting of experienced carers, but also meant that participants were self-referred to the study. While not all participants were recruited from the one carer network, the recruitment approach used adds additional limitations to representative nature of the sample group, and to the way study findings can be generalised. This report explores the views of a sample of carers who have significant experience of ED care, and seeks to document and portray key issues as described by the participants.

### ED nursing: a gateway to effective crisis support

The views of carers in this study suggest that they see the ED as place of required support for a BPD health crisis. They are often referred by GPs and first responders. The accounts of carers suggest that ED responders do not consistently understand the nature of BPD related distress as a mental health condition. Subtle or overt discrimination towards people with personality disorders continues to arise from this misunderstanding, with the crisis being seen in behavioural terms. This occurs at the same time that carers are relating to the consumer's distress as a life and death situation requiring

an expert response. These experiences indicate that educational interventions are required to improve the capacity of ED nurses, or psychiatric liaison, to provide a consistent and high-quality response to crises involving self-harm and or suicidal ideation for people experiencing BPD. The response needs to extend beyond assessment into an evidence-based model of medical and nursing care.

## ‘Talk to us – don’t judge us’: communication, confidentiality and inclusion

Carers reported a range of difficult experiences regarding the quality of communication and confidentiality practices toward consumers and themselves. These included the experience of flippant, minimising and judgmental comments and ineffective questioning. Carers also reported non-communication and lack of information where it was needed. The research team heard about experiences of poorly managed consumer privacy in triaging areas, as well as multiple accounts of family carers not being included in treatment or discharge planning. Some carers did not feel trusted by nursing staff, and felt they were being implicated in the consumer’s distress, or background trauma. These points were shared in the context of other positive accounts of good quality, respectful communication. The study found, however, that poor communication and inadequate carer inclusion were the prevalent experience for participants. The findings here relate to the need for further education and capacity building on respectful communication and carer inclusion, where nurses are required to balance privacy provisions relating to the Mental Health Act and the Carers Recognition Act. Nursing staff need the skills to manage consumer privacy and carer inclusion at the same time and understand the ethical dilemmas that may be involved.

## A different level of care: improving service standards

Relating to the previous themes, many participants felt that there was a lack of care and compassion for them and their loved one. Carers described feelings of helplessness when ED responses did not result in improvements, or when consumers were discharged without their knowledge. Some carers provided accounts of where consumers were not adequately triaged, and where routine observations like temperature and blood pressure were not taken. Some contrasted their experience against times of supporting family members with other health crises (e.g. cardiac events), where they were automatically included in care and provided high quality clinical information. These experiences raise key questions about the quality of care offered to families and suggested that substantial work is required to improve workforce knowledge, skills and capacity in the BPD area. Workforce support and supervision is also required to improve service standards.

## ‘What I want you to know’: Information and support needs

Carers in the study reported the need for improvements in information and support offered to them during crisis, including information on the nature of BPD related distress, diagnosis and treatment options. As carers are often in extreme distress during crisis, they need guidance towards other organisations and groups where they can receive support and information. Many carers were not

aware of peer (carer) specialists in the public mental health system, or carer educational programs on BPD. Educational programs should include a component on the importance of providing high quality information and referral sources to families in crisis.

## Key findings and implications for emergency nursing

The research findings highlight many opportunities to improve the crisis management and care of a person with BPD. The involvement of carers in a crisis has been seen to improve outcomes for the person in crisis. Additionally, carers look to healthcare providers and nurses working in front line settings such as the ED for reliable and practical information on how to manage a crisis.

## Future research

The outcomes of this research align with other studies and industry reports on the common experiences of family carers in the BPD area. Future research should be targeted towards evaluating new models of care which are based on trauma informed and person-centred care principles, and family carer inclusion. It should also be directed to towards evaluation of nursing education and learning regarding BPD and effective care. South Australia has seen the establishment of the Centre of Excellence for BPD, which is in the early stages of developing a model of care in community mental health. The Centre also has a significant education and research role, and there is promise for research activities which evaluate both health professional education and treatment interventions. A focus which includes trialling innovative responses to crisis across both ED and community settings would be an important direction to pursue. From a carer's perspective, it is vital that effective responses are provided at the right time and place, as they are for other areas of health crisis.

More information about the BPD Centre of Excellence can be found on the [SA Health website](#).



## Background

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### Impacts of Borderline Personality Disorder

#### Prevalence

In Australia it is estimated that between 1% to 4 % of the population are living with BPD, with women three times more likely to have a diagnosis than men<sup>1</sup> (Lawn et al. 2015; National Health and Medical Research Council (NHMRC) 2012; BPD Foundation 2018).

#### Suicide and self-harm

BPD is a common mental illness which is accompanied by a higher than average incidence of suicide and self-harm due to a range of complex interactions and ongoing emotional and social difficulties that consumers experience (NHMRC 2012). The condition is also associated with high use of health care resources (SA Mental Health Commission (SAMHC) (2017). Self-harm is a concern and is most likely to first occur during adolescence, with 63% of people with the illness reporting their first self-harm event prior to age 18. Suicide rates amongst people with BPD are estimated to be between 3%-10%, higher than age standardised rates in the general population (Homan et al. 2017; NHMRC 2012). When a crisis arises, people with BPD struggle to regulate their emotions, and impulses, causing them distress which can then impact on family and others (NHMRC 2012).

### Family Carer

#### Caring for a loved one with BPD

Caring for a loved one or family member with BPD is known to be associated with stigma, medical discrimination and shame due to perceptions about difficult symptoms and experiences that consumers face (National Mental Health Consumer & Carer Forum (NMHCCF) (2017). These include reactions to chaotic thinking, emotional dysregulation and self-harming behaviours (NMHCCF 2017). In 2015, 4.5% of the Australian population reported living with a psychosocial disability, with 95.1% of that population requiring assistance with cognitive and emotional decision making, and activities of daily living (Australian Bureau of Statistics (ABS) (2017). Due to a shortage of appropriate specialist services, people with BPD frequently present to hospital EDs in a crisis (NHMRC) (2012). The caring role is most often assumed by a parent or spouse living with or nearby their loved one (Mind Australia 2015).

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<sup>1</sup> Bayes and Parker (2017) explore whether BPD prevalence in men is equal to that of women. They discuss literature indicating that the variation may be due to sampling bias, e.g., fewer men seek help in clinical settings, or forms of diagnostic bias. As aspect of bias is the possibility that men with BPD may be misdiagnosed with antisocial personality disorder, as men may display more externalized distress in the form of interpersonal aggression, anger and violence.

## Mental health carers

Mental health carers experience significant impacts due to the caring role. These include limits to the ability to engage in paid employment and education, with many receiving government payments (Mind Australia 2015; ABS 2017). Most of the mental health primary carers in Australia have been identified as women of working age who are not in the labour force and have lower education levels than other primary carer groups (Mind Australia 2015). The costs of caring for a person with a mental illness are extensive. In 2015, the estimated annual cost to the Australian Government to replace the support provided by primary mental health carers was \$13.2 billion (Mind Australia 2015). The economic value of carers to the Australian mental health system is therefore considerable, with carers providing support and assistance which would otherwise come at a substantial cost. Coordinating health care is noted as a central role for these carers (Mind Australia 2015).

One of the key drivers for increasing the burden and responsibility of carers and family members has been previous government policy. In Australia during the early 1980s, deinstitutionalisation of the mental health system was marked by the de-commissioning of purpose built and stand-alone mental health facilities. This resulted in increased numbers of mental health admissions to general hospital systems, and a noticeable increase of mental health presentations in EDs (Morphet et al. 2012). These changes have also brought changes to the way ED nursing practice unfolds and, simultaneously, carers and family members are expected to fill service gaps in providing care for someone with BPD (Morphet et al. 2012; Bailey et al. 2013). At the same time there is an accumulating body of literature discussing the barriers experienced by carers when trying to access support following a person's mental health crisis, self-harm or suicide attempt. Similarly, the impact on nurses providing care to people with BPD and the challenges they face has also been a focus (Lawn et al. 2015; Bailey et al. 2013). At present, research activity looking specifically at the perspectives of BPD carers' views on nursing practices in the ED has been largely overlooked.

## Emergency Department Nursing

Nurses, by the very nature of the work they do, are often the first point of contact at times of ED presentation or at times of accessing primary care. It is the nurses that carers, partners and significant others have contact with in assessment, management and overall engagement in consumer recovery. These support networks make a considerable contribution in developing a crisis plan and have potential to improve consumer outcomes (NHMRC 2012; Forde et al. 2016). In addition, the ED has an important role to play in the early identification and support of people with BPD, including prompt referral to specialist care and mental health supports to minimise the impact of the condition (NHMRC 2012). This process often begins with triage assessment in the ED.

## Trauma Informed Practice

Nurses are critical to the implementation and planning of advocacy and support to a person, their families, and caregivers (Taua, Hepworth & Neville 2012). However, there is much variation in nursing skills and the ability to effectively develop rapport and therapeutic communication with

consumers and their loved ones. In many settings, traditional practices of seclusion and restraint are still in regular use. Such practices can instigate and exacerbate distress and trauma and thus do harm (Beckett et al. 2017). Previous exposure to trauma and activation of the trauma experience is a critical consideration in the care of people with BPD (Beckett et al. 2017). In addition to this is the knowledge that past exposure to trauma impacts a person's ability to trust others and feel safe to express feelings. This can have collateral effects when working with health professionals and ensuring access appropriate services (Beckett et al. 2017). Nurses who are mindful of the ways in which past trauma influences a person's current thoughts, feelings and behaviours, as well as care and treatment, are said to be trauma informed. Trauma informed practice is essential in the care and treatment of people with BPD (Beckett et al. 2017).

## Stage 1: The literature review

The aim of conducting a literature review was to explore, locate and compile the literature regarding the perspectives of family carers for a person with borderline personality disorder in an emergency care setting with a focus on nursing practices.

The findings indicated that carers often perceive emergency departments as the only option for emergency care in a crisis. Carers require information about how to effectively manage a crisis with their loved one more effectively. Carers often perceive that nurses and health professionals have a lack understanding about the consumer's conceptualisation of distress and the nature of BPD, which becomes a barrier to effective crisis support and management. The literature often reported that a trusting and collaborative relationship between carers, nurses and health professionals demonstrated improved outcomes for the carer and consumer (Acres et al. 2018). For more details about the results of the literature review, see Acres et al. (2018).

## Stage 2: The focus group study

This study sought and recruited participants living in South Australia. This was due to limitations in time with the project.



## Methodology

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Following consultation with a carer support group and receiving ethics approval by the University of South Australia (Ethics Protocol Number: 201320), four focus group interviews were conducted. A total of 13 participants took part in the study, which involved being asked questions in a semi-structured interview approach. Recruitment for the study involved promotion from across the networks of the Mental Health and Suicide Prevention Research Group and Sanctuary Carer Support Group. To be eligible for the study, participants needed to be primary carers of a person with BPD and have lived experience in accessing an ED in the carer role within the years of 2014 to 2018.

Prior to each interview, participants received a telephone call from a/the researcher (KA); this was done to discuss the nature of the study with participants and screen for inclusion. Participants had been informed of the potential for some emotional discomfort in participating in this study. Following telephone contact, each participant was emailed a copy of the consent form and participant information sheet which provided information about confidentiality and the potential for emotional discomfort and the available options for support.

All interviews occurred via semi-structured face to face focus group interviews. The researchers had an established relationship with Sanctuary BPD Carer Support group and consulted with Sanctuary leaders about the focus group questions and processes. Focus group interviews were designed to have a 60-90-minute duration.

Each focus group session opened with a statement from the facilitators (KA, ML, NP) discussing the areas of emotional safety, privacy, sharing and supports. Participants were thanked for their involvement and contribution. The conversation about emotional safety and potential discomfort was an important process in being trauma-informed during the research process. According to Procter et al. (2017, p. 8), the key components of trauma-informed practice include: collaboration, trust, safety, choice and empowerment. At all stages of the study each facilitator was mindful to maintain a trauma-informed approach for each participant. At the beginning of the groups, participants chose a pseudonym for themselves to enhance their privacy for the audio recordings and in reporting of findings. Participants were encouraged to use terms such as 'my son' or 'my brother' when referring to their loved one, or another pseudonym.

Group interviews explored the views of the carers, rather than focusing exclusively on the experience, allowing carers to generalise their association in this context. This approach is more favourable in group settings with sensitive subject matter (Schneider et al. 2013). The number of participants within each focus group was limited to a maximum of four participants due to the manageability and sensitivity of the topic. The interaction of the participants at the time of interview and their sharing of stories enhanced the quality of data through enabling multiple perspectives on the topic (Fusch & Ness 2015).

Several open-ended questions were applied in the interviews which were designed to help the researchers understand how participants had interacted with nurses and the potential impact it had. Participants were asked to describe the nature of the interactions they had had with nurses, how it

made a difference to the care of their loved one, and how it could be improved. Open ended questions were also used to explore and explicate the views and expectations of carers towards nursing practices and communication within the ED. Finally, open ended questions were used to assist carers to provide views on overcoming barriers to effective nursing care for consumers with BPD and for themselves in the caring role.

## Analysis

The data analysis was informed by Braun and Clarke’s (2006) thematic analysis to develop and generate emergent codes from the data set. This required six phases to develop and generate the findings: 1), familiarisation of the data, 2), generation of initial themes, 3), searching for themes, 4), revision of themes, 5), defining and naming and 6), producing a report. The thematic analysis was applied within a general qualitative descriptive approach.

The first stage of analysis involved analysing each transcript individually on a question-by-question basis to search for key ideas, meanings and experiences shared by participants from each focus group. Each response was then analysed from the sentence, phrase and paragraph level where key meanings were recorded as codes. A codebook consisting of 29 codes was developed. The second stage involved the analysis across each of the four transcripts and consolidation of the codes into four themes. Titles of the themes were generated from language used by participants.

## Results

A total of 13 people participated in the focus groups (see Table 1 for participants characteristics). Three focus groups contained three participants and one contained four participants.

**Table 1. Characteristics of study sample (N = 13)**

Characteristic	Indicator	Participants (n)
<b>Age range</b>	18-24	0
	25-34	1
	35-44	0
	45-54	4
	55-64	5
	65-74	2
	75+	1
<b>Number of years in caring role</b>	0-2	1
	3-4	3
	5-9	3
	10+	6
	<b>Total number of estimated ED presentations</b>	0-2
3-4		3
5-6		2
7+		8
<b>Number of estimated ED contacts per year</b>	0-5	1
	6-9	6
	10+	6

## Findings of the study

Four key themes were identified from the data: (1) ED is the gateway into crisis support; (2) Talk to us don't judge us; (3) A different level of care; (4) What I want you to know. A brief table of findings are presented below. Further discussions of the findings can be found on pages 17 to 29.

### Table of themes:

Themes	Key findings
<b>ED is the gateway into crisis support</b>	<ul style="list-style-type: none"> <li>• ED is viewed as one of the only options for crisis support and intervention and was considered the gateway into mental health services.</li> <li>• Levels of distress were one of the key reason carers present to the ED.</li> <li>• In many cases carers reported the GP had referred them and the consumer to the ED to receive crisis support.</li> <li>• Emergency services such as the South Australian Ambulance and South Australian Police were reported to escort consumers and carers to the ED to receive crisis support and intervention.</li> </ul>
<b>Talk to us don't judge us</b>	<ul style="list-style-type: none"> <li>• Communication with carers by the ED nurse was viewed as a barrier to effective care and treatment. Confidentiality is often referred to as a barrier for carers in being included in care.</li> <li>• Carers reported they have valuable information about the consumers mental state and can offer medical history and strategies in how to manage crisis situations, however they are often not included in discussions with ED staff.</li> <li>• The stigma of BPD was often viewed as a barrier by carers in why their loved one failed to receive appropriate care and compassion. The misconception that BPD is a behavioural issue becomes a barrier to carers and consumers engaging in appropriate supports.</li> </ul>
<b>A different level of care</b>	<ul style="list-style-type: none"> <li>• Carers perceive a lack of care and compassion by ED nurses when dealing with their loved one in distress. Nurses are viewed as having a significant role in minimising harm and distress; however, this often does not occur.</li> <li>• The medical management vs the mental health management was viewed to be in stark contrast. Carers reported that medical needs were often met, and carers were often included during this time. However, the mental health needs and responses were viewed as a complete opposite with carers often exclude and not involved.</li> </ul>

<p><b>What I want you to know</b></p>	<ul style="list-style-type: none"> <li>• Carers stated they are often in crisis. When responding to their loved one's crisis, they too are often frightened and experiencing trauma from the crisis.</li> <li>• Carers described that they want nurses to know that they expect them to remain professional and to provide education and support during crisis situations.</li> </ul>
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## Theme One: ED is the gateway for crisis support

Theme One refers to the pathways taken by carers to access crisis support and intervention for their loved one. This theme also related to the carers' understanding of the purpose of the ED in this respect. All participants talked about their distressing encounter when being faced with their child or loved one who was expressing suicidal ideation or had self-harmed. This finding reflected three sub themes.

### *Level of distress*

When asked about their experiences in supporting their family member in the ED, carers stated that the primary reason they presented to the ED was the immediate threat to life for the person they cared for and a fear of loss of life of their loved one. Suicidal distress was the predominant reason carers presented to the ED with an expectation of receiving crisis management and support for their loved ones' physical and mental health needs. Expressing suicidal ideation was viewed as the only way to access crisis support in the ED. Carers reported feeling helpless and not knowing how to respond to their loved ones' distress following a suicide or self-harm attempt which was the main reason for an ED presentation. The ED nurse was viewed as a gatekeeper into accessing crisis mental health services.

"If there is a threat, if he feels suicidal, like the case you pointed out, if he feels suicidal then we seem to get treatment and better care of him..."

(Anne)

"And yeah, when he's at threat of possibly doing it, they put him into the mental health ward or whatever."

(Anne)

"I call them the gate keepers. They are. They won't open the gate."

(Deb)

Data indicated that carers require compassionate and kind communication which is free of stigma, judgement and blame. Carers reported feeling scared, lonely and isolated. They look to the ED nurse as the gateway to knowledge, support and understanding on how to help them and their loved one in a crisis. Despite all the challenges faced by carers, carers were able to conceptualise what they

saw and heard through a trauma informed framework and acknowledge empathy for ED nurses. Carers further conceptualised poor communication and lack of carer involvement as an emotional response to how nurses themselves cope when working with a person with BPD and witnessing traumatic experiences themselves.



### *GP referral pathway*

Carers reported that their GP were often the first healthcare professional they had engaged with prior to presenting to the ED. Carers often presented to the ED by referral from their GP who had expressed that ED was the only option for crisis management. By seeking medical advice prior to ED admission, carers felt that the level of urgency for their loved ones physical and mental state would be taken seriously, however this was often not the case.

“And I think sometimes if you had a letter from the doctor or the doctors told you to go in, there’s an expectation that something is going to happen because you’ve actually got the letter, or the doctor said go in, and I think that’s the thing as well because we haven’t just gone in there because we think the child’s not well, the GP and we have a very supportive GP as well every time and they were wonderful and they were very supportive. No, you need to go in now and then you get in there and you come home again.”

(Anne)

### *Emergency services*

The entry into ED often involved first responders such as police and/or ambulance services. The level of urgency for specialist physical and mental health care was often shared by first responders and the carer. Carers described feeling validated and respected during a crisis situation by police and ambulance, and they expected the same level of care and management in the ED setting, however this was often not the case.

“I think, she’s been to emergency four or five (times), about, I can’t even remember actually, because so many incidents or, like, maybe seven times or maybe more, but several times by the ambulance because my daughter’s friends called the ambulance because she was threatening to (harm herself), you know, communicating with friends through the Facebook, so they tried to help and called the ambulance ,and police officers came.”

(Amy)

In summary, participants highlighted that the ED was the only perceived option for crisis support and that when a presentation to ED occurred it was related to a situational crisis and the level of distress had caused concern for their loved one’s welfare. The level of urgency for crisis intervention to alleviate the threat of suicide was often shared with emergency services and general practitioners but they were often met with rejection in the ED. Carers reported frequent rejection and invalidation by ED nurses when in crisis. According to participant descriptions the ED is one of the few options available when crisis arises.

## Theme Two: Talk to us don’t judge us

This theme refers to the lack of collaboration, information sharing, and stigmatised practices experienced by carers in the ED. The lack of communication was shared by all participants, and the lack of effective communication was viewed as a barrier to effective care and treatment as carers often have vital information about their loved one’s current mental state. All participants in the study recalled a time where they felt they were or their loved one was judged or dismissed by the ED nurse.

### *Communication and confidentiality*

Communication issues were viewed as a significant barrier to providing effective care and treatment for the person with BPD and the carer in crisis. Communication was multidimensional with implications for all facets of ED nursing practice. Carers described that on arrival to ED, the person they cared for would be triaged by a nurse in a public waiting room. Consumers would be asked sensitive and personal questions about their mental state and suicidal distress in a common space shared by other people. Carers expressed that there is often no consideration of privacy, resulting in a loss of dignity and respect for their loved one. The lack of confidentiality has been described by carers to increase levels of anxiety for the consumer which has led to the carer trying to mitigate between their distressed loved one and the triage nurse.

“The worst part was going to the triage nurse that was my first impact of, are you the next of kin? Yes, I am. Okay, and I’m trying to shield Isabella from this



atmosphere I guess and the crisis, and trying to shelter her from that and saying, and protect her and advocate for her but then they just started basically asking her what she'd done to herself and, oh, you've done it before and just the whole belittling and making her, and it was flu season, there were sick kids everywhere, and they're making her show in the middle of the emergency room, 'let me see what you've done to yourself, what have you done?' No privacy at all, and then I stepped up and said, 'that's not on, you're doing that, that's not okay' so, yeah, I was very, very hurt by the lack of consideration and that they just thought this was another kid self-harming."

(Jane)

"There is nothing confidential about a nurse saying to me, 'Your daughter is extremely unwell at the moment. We're going to give her, we're going to do, we're going to keep her in or we're going to send you home'."

(Deb)

Participants described confidentiality as a barrier to care:

"When they stick to the letter of that confidentiality rule it really blocks us out."

(Cathy)

"It's where the confidentiality can actually become harmful."

(Lynn)

In participants' experiences, confidentiality protocols appeared contradictory, from the absence of a right to confidentiality and an expectation for the carer and the consumer to publicly share their mental health history in the triage setting, to confidentiality being applied by the nurse as a reason for not sharing information with the carer. Carers described a lack of information and communication sharing by ED nurses when they asked about their loved one. What carers most wanted was for information about BPD to be provided to them and how to manage their loved one; despite this, carers reported being frequently excluded or denied communication based on the grounds of confidentiality. One participant said, "*the nurses aren't giving you any information... everybody leaves you alone*" (Cathy). Carers need nurses to help them conceptualise and understand what is happening to their loved one. Nurses are viewed as the interface of healthcare services and the gateway into mental health services. When in crisis carers need the nurse to help them understand what BPD is, how they can respond to the situation and how they access treatment and support.

“I need something to name it (a diagnosis); what was it? Why did they keep writing down Group B (personality disorder diagnostic cluster) and not-telling me, I used to be at the hospital all the time...”

(Johanna)

“...I felt very unconnected in the emergency department, very little communication.... We sat for 24-48 hours in emergency in the reception area not knowing what was going on..... No one talking to us at all.”

(Ann)

In summary, poor communication and confidentiality can become a barrier for effective care and management for carers and consumers. Lack of information sharing, and carer involvement was also viewed as a barrier to providing person centred care.

### *We have valuable information*

Carers often felt overlooked in the ED setting despite their ability to help ED nurses in understanding their perspective of the consumer’s mental health, strengths and preferences surrounding personal recovery. Carers described feeling well placed to provide valuable information on emotional regulation techniques and how to help soothe their loved one. They can offer previous medical and mental health history which can help the nurse to perform a detailed nursing assessment and gain insight and a different perspective of their loved one’s presentation. However, this is often not the case; carers often felt excluded from discussions with nurses in the care and management of their loved one due to fears of breaches in confidentiality.

“They never talk to us. We have the information. We can tell you what behaviour or what they’ve been doing.”

(Drew)

“I know her better than anyone else knows her, and my last part was, I’m invaluable to nursing staff and the doctors about making informed decisions about her treatment.”

(Johanna)

There were occasions during psychiatric assessment where carers experienced being included in discussions with health care professionals. These practices were viewed as favourable and contributed to positive outcomes for the carer and the person in crisis.

“The social worker was there and the psychiatrist was there, they had a chat with her and a chat with me, and they asked me what I thought and then they asked her what she thought..... It made a huge difference. It calmed the situation down.” (Deb)

### *Stigmatising practices*

Stigmatising and judgemental attitudes were described as barriers to the consumer effectively engaging in treatment. Even when practices of kindness and empathy are shown, the therapeutic relationship could be lost very quickly if judgemental practices were demonstrated. Some carers have been informed to accept the potentially fatal behaviour of their loved one, with nurses expressing thoughts to the carer that there was no hope for the consumer. These views are internalised that the very health professionals which are in the position to be caring and offer support have no compassion for their loved one and that there is no hope for the person or for recovery. One participant said, *"I was frequently not treated with respect"* (Jane). Patronising and judgemental practices have been used to describe the ED nurse, with many carers reporting experiences or the nurse lecturing their loved one and that they have no reason to self-harm or to feel the way they do. Often the consumer is referred to as *"just a naughty girl"* (Sarah), *"a naughty child"* (Johanna) despite being of adult age. The frequent invalidation of the consumer's distress and minimising the seriousness of the crisis further reinforces rejection to the person in crisis and their carer and can have serious adverse outcomes.

"He was really agitated, and a nice nurse came over and shut the door so he couldn't get out, speaking to him. Calmed him down and convinced him to wait for treatment and another nurse came up and said, 'Oh, bloody hell. What's he doing back here?' At which point Mike turned round and decided he was going to leave. And they said, 'What are you going to do?' And he said, 'Go home (and hurt myself).' So, they let him go."

(Sue)

"I was crying I was so angry. And they're sitting there going, 'You know what? You can't control.' The same thing. 'You can't control what he's doing, it's part of his illness so there's nothing more we can do for him.' And he's like, yeah, I said, 'Well how are you going to feel if he turns up dead tomorrow?' 'Oh, well, there's nothing we can do about it.'

(Ann)

"I'm guessing her self-harm or in terms of her, don't worry you're not going to kill yourself because you're ticking all of the boxes, so for us she's low-risk but for us we're going crazy, but to a mental health person and even its demeaning it's just like, oh, no, there's much worse out there."

(Jane)

"One nurse, a male nurse came to her and asked her why did you do that? Because she tried to (harm herself), and on that occasion my daughter's old friend (died by) suicide actually in the week before, yeah, and she was really

depressed about it and she was really sad, and really down, so she mentioned to the nurse that my friend (died by) suicide three weeks ago and then the nurse started to, lecture again, like, why did you do that? Your friend (died by) suicide so that's why you are doing that. Why would you do that?

Like, again, you have parents to support you and you have friends, why would you do that?"

(Amy)

### Theme 3: A different level of care

#### *Lack of care and compassion*

Many participants felt that there was a lack of care and compassion for them and their loved one. This was described as leaving the carer feeling helpless and abandoned and not knowing how to respond to a crisis. Participants spoke about implications when discharging their loved one, with many recalling times when their loved one was discharged without notifying the carer. This was viewed as demonstrating a lack of care and compassion for the wellbeing of the person with BPD. When a person has presented to the ED in a crisis state and has either expressed or engaged in the act of suicidal or self-harm behaviours, participants felt that ED nurses had a role and a duty to ensure the person in crisis has access to support and crisis planning. Discharging a person without supports and crisis planning, with only as much as a taxi voucher was viewed as a significant lack of compassion.

"We're not validated. Okay, you're going through a traumatic experience. I really see that. So just a bit of compassion would be, you know. I haven't experienced it really. I feel like they've just gone, okay, here we go again."

(Drew)

"We were just abandoned and left to deal with it on our own ...we had no idea what we were really dealing with which was really distressing."

(Jane)

"Other times they've just given her a taxi voucher and sent her on her way. She's suicidal and they gave her a taxi voucher and I get there and say, 'where's my daughter?' 'Oh, we gave her a taxi voucher.'"

(Sarah)

#### *Medical management vs mental health management*

Carers discussed the medical management of their loved one was often appropriate, professional and timely. However, this was in stark contrast with responses to their loved one's mental health

needs. Many carers reported that medical and mental health needs did not occur in parallel with each other. Loved ones were required to be 'medically cleared' before mental health intervention. Carers felt this was often counterproductive as the presenting reason of their loved one's mental state placed them in a situation which was viewed as critical to alleviate the threat to life.

"Like what ever happened to EDs, they're lifesaving and an emergency department is a lifesaving department, they're there to save lives."

(Jane)

"I felt like I had health authorities who were just treating the burn, nothing else; they weren't looking at her mental health state."

(Jayne)

"Basically, they'd fixed the wound and there were times when my daughter's cuts were not stitched; she was released without stitching."

(Lynn)

Carers highlighted that upon presentation to triage across multiple occasions, there were noticeable differences in triage processes and medical management of their loved one. The absence of a basic nursing assessment in triage was viewed as not caring or valid of medical attention. A judgement was made about the consumer in a busy waiting room and that their needs were different to any other person; therefore, they did not require any medical intervention. For example, the act of taking of a blood pressure (BP) and triaging the consumer like any other person was viewed as the ED nurse demonstrating compassion and care, to the carer that their loved one. This clinical assessment is routine practice in the triage setting; however, in the absence of taking a BP in the ED, this strongly reinforced the idea that mental health presentations did not belong in the ED setting:

"You go to your GP and you're really sick and he takes your blood pressure, he checks your temperature...What's the difference when your daughter rolls into the ED? It's no different."

(John)

"They didn't even check his blood pressure and I was thinking he was sitting there for nearly an hour... But they didn't check anything."

(Drew)

In summary, this theme identified that carers perceived a lack of care and compassion when they presented with their loved one in crisis. There was a perceived noticeable difference in the medical management of their loved one compared to their mental health management. Often, these practices this did not occur in parallel, with management viewed to be considerably inconsistent in the triage area.

## Theme four: What I want you to know

This theme describes carers' feelings of hopelessness and helplessness. When their loved one is in crisis, the carer is in crisis too. Carers have knowledge of key issues and triggers and what is helpful for the person in crisis. These skills can assist nurses in helping to calm and regulate their loved one's emotions. The lack of carer involvement in trying to gain insight into how to best help the person is seen as counterproductive. Nurses are always expected to have generalist knowledge about BPD and to maintain professionalism.

### *Where do I go? I'm in crisis too!*

Due to the nature of BPD, carers experience significant levels of grief compared to other disorders. Carers described they require nursing and health professionals to engage and communicate with them about what is happening and to provide information about BPD. The implication of not providing this information is that carers are not aware of crisis planning and supports available. This can have serious adverse outcomes for the consumer and the carer. The gathering of knowledge and information was also based on a trusting relationship, and when trust is lacking, carers felt that nursing and health professionals hold judgement and stigmatised views which become a barrier for the consumer and carer to positively engage in treatment and support.

Some carers described how they go to considerable lengths to shield their loved one, other children or family members from the extremity and nature of the self-harm, which can isolate carers further from critical support networks. The level of care and unconditional love provided was described as carers are keeping their child or loved one alive. Carers discussed the extreme lengths they go to, to understand their loved one's level of emotion and distress daily. Feeling helpless and hopeless was expressed by carers, stating they are living with a constant feeling they would lose their child or loved one to suicide. Parental responsibility to respond and manage a crisis was expressed, however carers did not know how to protect the life of their loved one. Carers view their loved one's thoughts and behaviours in a crisis as a true and genuine threat to life. However, when a presentation to ED occurs, there appears to be a real disconnect in the understanding of the persons conceptualisation of distress and how this impacts their quality of life. Moreover, there is a deep worry regarding a potentially fatal outcome. ED is viewed as the only place to respond to a crisis and has the infrastructure to alleviate the threat to life. When a crisis arises for the person with BPD, the carer is also in a state of crisis. It is important for nurses to understand the complexity of BPD is not only for the consumer but extends to the families and carers of those who support them each day.

"It's pretty sad as a mother, like, at the time where with that discharge, you get to the stage where its, I know I'm going to lose him to suicide. I know he is going to (die by suicide). But I'm going to make it effing hard for him. But your mindset is, it's inevitable. It's going to happen. We shouldn't be thinking like that, but that's what's created this situation..."

(Anne)

“I want the nurses to understand that I’ve been trying to keep my daughter alive, it’s been on many occasions where I’m on edge because she has gone to (harm) herself.”

(Johanna)

“You can be quite lonely in there. If you’re waiting to hear if your son’s going to live or not, and you’re sitting there by yourself.”

(Anne)

“Yeah, I’ve been in a situation where she doesn’t answer the phone for two hours and we freaked out, we would absolute freak out thinking is today the day, is it D-Day?”

(John)

### *Expectations*

Carers expected ED nurses to have knowledge about BPD and to impart their knowledge of the disorder to the carer. Carers reported that they understood that their loved one’s distress was not attention seeking, but a true and genuine disorder which can have a serious threat to life. There was an expectation that nurses are professional, non-judgemental and gather the facts. Nurses were expected to be “*intelligent*” (Deb) in their information sharing and treat BPD as a true and genuine disorder. They are expected to not re-traumatise their loved one. One participant said, “*I expect them to look after her...Don’t make her feel more abandoned*” (Sarah). A further perspective included:

“As a carer I expect nurses to just be professional, just collect the facts and then communicate with the doctors and then, yeah, see what they can do to help my daughter, I don’t want any of those health professionals to give the judgement to her, or to me.”

(Amy)

### *What helps?*

Carers in this study were able to identify what helps them in their caring role. Practices of kindness and the act of showing the carer where the parent’s room is so they were able to recharge was viewed as helpful. Participants also spoke about the ED nurse providing information about the Mental Health Triage service and explaining what the service was and how it could help the carer and consumer in a crisis. When carers feel there is “*acknowledgement*” (Anne), a “*professional response*” (Amy) and nursing practices are “*not judgemental*” (Amy), they feel supported and valued in a crisis. This is particularly important as a trusting and collaborative relationship with carers, consumers and nurses leads to better outcomes and demonstrates a person-centred approach.

“.... A nurse was saying, “Here’s the parent’s room, just go make yourself a cup of coffee.” So that was helpful.”

(Sue)

“One nurse came in and gave her... Or us the number for either triage numbers and ways to contact and you know where I can ask for help if she is really suicidal.”

(Amy)

“We got a lovely little young nurse, I guess, she looked younger, but seemed very new and young and she actually put us in a private, kind of, lounge room which was lovely, and we could sit away from everyone.”

(Jayne)

“The carer consultant took me aside and probably spent half-an-hour with me just chatting and validating, saying, ‘Oh, it must be really hard for you.’”

(Cathy)

In summary, this theme discusses the level of distress experienced by the carer participants. Participants expressed that they were in crisis as well as their loved one. It is at this point where participants expect nurses to remain professional and free from judgment as these practices help them when responding to their loved one’s crisis and their own emotional state. This report has presented four key themes of the carer perspective. These represent a significant range of key experiences, meanings and preferences in how carers see the work of nurses in responding to consumers and carers in the ED context

## Discussion

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The core aim of this study was to explore carer's perspectives of a person with BPD on ED nursing practices: what were their experiences, expectations, preferred practices and ways to overcome barriers? Each of these will now be considered in four broad sections. The first section, 'carers view of the ED nursing role', summarises the perception carers have about the role and care provided in ED and triage setting. 'Communication and carer involvement' are the next section presented which reports on the different types of communication carers experience and the implications this can have. The third section presents 'perception of care and what is needed', an overview of the preferences of carers and what services they require. This discusses previous experiences of care and the perceived differences and what level of care is recommended. The final section discusses 'preferences and understanding us', which provides an overview of what carers would prefer and what they want service providers to know.

### Carers' views of the ED nursing role

All participants stated that the main reason for presenting with their loved one to an ED was the threat of death by suicide or self-harm. Participants perceived ED as the only service which had the infrastructure and resources to alleviate the threat to life and respond to the crisis which they were seeking help for. This is important to note as the rates of death by suicide for those with BPD are between 3-10%, a rate higher than the general population (Homan et al. 2017; NHMRC 2012). The ED is viewed as a frontline service which has the capacity to link with other specialist supports. One participant (Anne) referred to the ED nursing role as the "*gate keepers*" to specialist mental health services. This was often reinforced by other healthcare professionals i.e. GP referral to the ED or presentation via ambulance or police. This is critical to understand as suicide is one of the most common forms of mortality among children and young people between the ages of 5-17 (Perera et al. 2018).

Carers often felt as though the potential risk to life and reason for presentation was not taken seriously by ED staff resulting in triage ratings not reflecting the true level of urgency. The Australian triage process aims to alleviate the threat to life; on presentation to ED a nurse will perform an assessment and categorise each person based on the urgency for review by a medical officer (NSW Department of Health 2011). Despite the level of urgency all participants reported waiting excessively long periods for review by a mental health practitioner, if it occurred at all. Accounts such as (Ann's) highlight that carers and consumers can be "*waiting 24-48 hours in emergency in the reception area*", for specialist care. These practices sit in stark contrast to the Australasian triage standards which highlight that assessment and management of a person in the ED should occur within a four-hour timeframe. In a report commissioned by the Australasian College for Emergency Medicine (2018), mental health presentations to the ED have considerably longer wait times compared to medical presentations, with 90 percent of people left in the ED within seven hours of initial presentation. South Australia had the poorest wait times in the ED with many people waiting as long as 16.5 hours for a review (Australasian College for Emergency Medicine 2018). This data suggests our health system is failing to meet the needs of those who live with a mental illness and

their families. In Victoria, similar trends have prompted a call for a Royal Commission into this States mental health system (Orygen 2018).

The finding of this study is that many carers report ED experiences which do not meet their needs and, in many cases, lead to more difficulties and distress. This is a finding that needs to be considered alongside information about consumer experiences of ED and performance data on health outcomes from ED contacts and treatment. The finding indicates that substantial improvements need to occur in the model of care offered to families when requiring crisis-based emergency care.

## Communication and carer involvement

Carers are a significant resource to both the consumer and to the nursing staff, as the carer holds vital information on the consumer's history, present state of mind, and most importantly through the identification of trends and patterns in the consumers mental health that warrant the need for emergency intervention. Furthermore, the carer is also able to contribute to service outcomes and identify gaps in the system. By working collaboratively with health professionals, the need for repeat ED presentations can be minimised leading to improved outcomes (Bailey & Grenyer 2013; SAMHC 2017). Carer inclusion also improves outcome in therapeutic work in the community setting (Project Air 2015).

Despite the demonstrated ability of carers to contribute to positive outcomes; there is evidence that carers are not consulted with on a routine basis or informed on how to best support and manage their loved one (Giffin 2008). This finding is supported by the present study with carer's statements suggesting a similar lack of engagement such as: *"they never talk to us"*. *"We have the information"* (Drew) and *"I was frequently not treated with respect"* (Jane). This is concerning as carers are often relied upon to make care related decisions despite a lack of information (Lawn et al 2015; Dunne & Rogers 2013).

This research demonstrates that carers have not always been considered as a significant resource. The lack of carer voices in clinical practice can result in less than optimal care arrangements (NHMRC 2012). Without reliable information on crisis management adverse outcomes can occur. Carers recognition legislation at the state and commonwealth level (Australian Government 2010), identify carers as a valuable resource, their needs are important, and they should be recognised and treated with dignity and respect. Providing information on how to manage self-harm and suicidal distress is one-way nurses can communicate with and involve the carer. The benefits of carer involvement go beyond the ED and are more than simply emotional, as carers are estimated to save the Australian Government \$13.2 billion each year in associated care and support (Mind 2015). The study's findings around carer inclusion and preferred nurse –carer communication align with the *SA Action Plan for people living with Borderline Personality Disorder 2017-2020* (SAMHC 2017). Significant education needs to occur in health care workforces regarding skills and capacities for meeting the needs of families supporting consumers with this diagnosis.

## Perception of care and what is needed

Evidence has shown that nurses can have a lack of understanding of a person's conceptualisation of distress. This then becomes a barrier to the effective care and management of a person in crisis (Australian Borderline Foundation 2018; Dunne et al 2013). Such barriers are evident by participants' accounts of being in an ED setting and receiving different levels of care or nursing interventions. This variation in care has been demonstrated in the present study with some participants stating that their loved ones had been "*neglected*" (Sue) and "*not had routine observations administered*" (John) by ED nurses after triaging. The lack of observational procedure was viewed by carers as deliberate, with their loved one's crisis not warranting the same level of care. In other accounts, carers spoke of being excluded from any contribution in the ED such as "*getting rejected*" (Jane) or "*they either won't tell me anything, or they don't know anything*" (Sue).

The findings suggest that carers have experienced gaps in care quality as well as communication and inclusion. Experiences of poor service and unmet expectations can lead to carers feeling overwhelmingly frustrated, disappointed and angry about quality of care. This can set up a process where carers respond by becoming more vigilant and focused on negative aspects of care, which in turn reinforces critical views. Jurgens et al (2012) have studied carer experience in dementia care and termed this phenomenon the 'cycle of discontent'. A range of staff responses to this cycle, including wariness about including carers, or withdrawal, can exacerbate already stressed relationships.

Despite the challenges experienced by carers when responding to a crisis, there was an opportunity for reflection on what practices are needed in a crisis. Acknowledgement, a non-judgemental approach and professionalism were featured by many participants on the practice which is preferred and expected by nurses. These practices have previously been documented. The Carer Gateway (2018), highlight that carers require a person-centred approach which values the person, their values, interests and culture. There is an understanding that each person's needs are unique, irrespective of diagnostic label. On the contrary, when person-centred care is absent, practices of stigma, judgement, and lack of care and compassion can be seen (Carer Gateway 2018). This can have a negative impact on the carer and consumer and often reinforce past traumatic experiences and impede the development of a therapeutic relationship with nursing staff (Procter et al. 2017). A trauma-informed approach acknowledges the complexity of trauma and its influence on recovery for the consumer and the carer and seeks to avoid re-traumatisation (Australian Institute of Family Services 2014). By being trauma informed, the principals of beneficence can be seen. This is important as the *Code of Ethics for Nurses in Australia* (Nursing and Midwifery Board of Australia 2005, p.1) states that; "*the nursing profession recognises the universal human rights of people and the moral responsibility to safeguard the inherent dignity and equal worth of everyone*". The current findings highlight multiple issues which need to be addressed. These include involving carers in the ED, providing information and education on how to manage a crisis, and providing a safe and non-judgemental environment. These are important topics for educational practice.

## Preferences and understanding us

Carers highlight that the significance of BPD and the potential for adverse outcomes were not always taken seriously by ED nurses. Furthermore, carers felt disempowered and marginalised in their role, further adding to the trauma and stress of the situational crisis. Carers reflected on what they would like nurses to know about the role of the carer and the emotional significance of harmonious interaction and communication. Many carers spoke of the trauma with which they were living and the constant fear of losing their loved one to suicide. Research conducted by Dunne & Rogers (2012) reinforces the significance of “stress” experienced by carers on an ongoing basis. However, the NHMRC (2012) argues that there remains a lack of evidence-based recommendations directed at interventions for carers. In a study conducted by Nicholls et al. (2011) the role of a mental health nurse practitioner in the ED proved to bridge a gap in knowledge of ED staff. A reduction in negative attitudes were seen and contributed to positive outcomes for people (Nicholls et al. 2011). The need for improved inclusion and understanding of carer needs indicates that similar capacity building roles need to be considered in the BDP crisis context. Nursing specialists in the BPD and self-harm area could play a significant role in improving levels of service for consumers, inclusion and education for families and carers, and links with other providers. Peer specialists (carer and consumer) could also play a supportive role in this context (Halpin & Gallagher 2016).

## Limitations

This study has several limitations which need to be considered when considering the representativeness of the sample, and application of the findings to the field. In terms of the sample of carers involved in the study, there remains a potential in having a biased sample group due to purposive sampling, where participants self-selected their involvement in the study (Sargeant 2012). Additionally, the findings are drawn on a sample size of 13 participants who were involved in four discussion groups. ‘Member checks’ – involving participants reviewing their own data were not possible for a focus group design. These ways of designing the study reflected the nature of restricted resources available for the honours level research project. Including a higher number of participants may have broadened the representativeness of the sample. And using individual interviews may have resulted in different levels of data regarding views and experiences and lessened any group influences in discussion.

A further limitation is apparent in that the study was promoted via one specific carer network. It could be argued that recruited participants were primarily drawn from one group bound with a common interest, rather than wider representation of carers generally. In this context it is important to highlight that not all participants were derived from this network, and that some participants came to the study via other more general promotion methods (e.g., via general information about the study in mental health networks). The limitation needs to also be considered in light of Sanctuary being a specialist support group for carers of people with BPD, and that this pathway of recruitment enabled participation of carers with extensive experience of emergency department contact in the role. Many carers had experienced over 6 contacts with EDs and were able to provide in depth information about their perspectives and related experiences. As common

to many qualitative research projects, this range of limitations mean that the views and findings of the study cannot be attributed to views of all carers of people living with BPD, or that the nursing care issues identified are indicative of nursing care in all instances, or across different ED settings. Consideration of the limitations of the study needs to be balanced with the significant concerns raised by the participating carers.

## Directions for future research

Prior to the current study, the perceptions of carers on ED nursing practices had not been extensively studied. A key observation on the findings is that carers have reported negative experiences on their ED contact and that these have significantly outweighed the range of positive experiences reported. These findings need to be seen in the context of recent changes to South Australian ED services. Further studies may yield a different range of perspectives which point to improved levels of inclusion and care.

The study indicates that educational interventions for ED nurses and BPD carer inclusion are a priority. There are a significant range of topics within the findings which can inform research based educational initiatives. These include ways of managing confidentiality and family inclusion, care and discharge planning, carer education, and links to BPD support and education resources for families

The carers in this study have reported very distressing experiences in their contact with EDs. An implication of these reports is to question whether local ED nurses, including mental health liaison services, have the capacity and skills base to offer a consistent level of care for consumers and carers facing BPD related crisis situations. Research development is required towards an improved model of care supporting nurses to effectively engage and work with carers in crisis, alongside their work in assisting consumers (where appropriate). Such a model would need to be based on trauma-informed approaches and could be comparable to other speciality nursing/ medicine models of emergency care.

## Reference List

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Acres, K, Loughhead, M, Procter, N, 2018, 'Carer Perspectives of people diagnosed with borderline personality disorder: A scoping review of emergency care responses', *Australasian Emergency Care Journal*, vol.22, pp. 34-41.

Australasian College for Emergency Medicine 2018, *The long wait: An analysis of mental health presentations to Australian emergency departments*, viewed 02 November 2018, <[https://acem.org.au/getmedia/60763b10-1bf5-4fbc-a7e2-9fd58620d2cf/ACEM\\_report\\_41018](https://acem.org.au/getmedia/60763b10-1bf5-4fbc-a7e2-9fd58620d2cf/ACEM_report_41018)>.

Australian BPD Foundation 2018, *What is Borderline Personality Disorder?* Viewed 5<sup>th</sup> April 2018, <<https://bpdfoundation.org.au/what-is-bpd.php>>.

Australian Bureau of Statistics 2017, *Psychosocial Disability*, Australian Bureau of Statistics, viewed 02 April 2018, <[http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features902015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view="](http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features902015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=)>.

Australian Government 2010, *National standards for mental health services 2010*, Department of Health, viewed 19<sup>th</sup> August 2018 <<http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-servst10>>.

Australian Government, 2010, *Carer Recognition Act 2010*, Australian Government, viewed 14<sup>th</sup> May 2018, <<https://www.legislation.gov.au/Details/C2010A00123>>.

Australian Institute of Health and Welfare 2016, *Nursing and Midwifery Workforce 2015*, AIHW, viewed 02 May 2018, <<https://www.aihw.gov.au/reports/workforce/nursing-and-midwifery-workforce-2015/contents/who-are-nurses-and-midwives>>.

Australian Institute of Health and Welfare 2017, *Mental Health Services Provided in Emergency Departments, 2017*, AIHW, viewed 28 May 2018, <<https://www.aihw.gov.au/getmedia/1ffc85db-f620-48e8-8d94-57a375e132fe/Mental-health-services-provided-in-emergency-departments.pdf.aspx>>.

Aviram, RB, Brodsky, BS & Stanley, B 2006, 'Borderline Personality Disorder, Stigma, and Treatment Implications', *Harvard Review of Psychiatry*, 2006, Vol.14(5), p.249-256, vol. 14, no. 5, pp. 249-256.

Bailey R & Grenyer B 2013, 'Burden and support needs of carers of persons with borderline personality disorder: A systematic review', *Harvard Review of Psychiatry*, 21. 248-58. 10.1097/HRP.0b013e3182a75c2c. Viewed 03 March 2018, <[https://www.researchgate.net/publication/260997476\\_Burden\\_and\\_support\\_needs\\_of\\_carers\\_of\\_persons\\_with\\_borderline\\_personality\\_disorder\\_A\\_systematic\\_review](https://www.researchgate.net/publication/260997476_Burden_and_support_needs_of_carers_of_persons_with_borderline_personality_disorder_A_systematic_review)>.

Bland, AR & Rossen, EK 2005, 'Clinical Supervision of Nurses working with Patients with Borderline Personality', *Issues in Mental Health Nursing*, 2005, Vol.26(5), p.507-517, vol. 26, no. 5, pp. 507-517.

Bramer, W, Rethlefsen, M, Kleijnen, J, Franco, O & Rotterdam, EM 2017, 'Optimal database combinations for literature searches in systematic reviews: A prospective exploratory study', *Systematic Reviews*, vol. 6, no. 1, pp. 245.

Braun, V & Clarke, V 2006, 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77-101.

Carer Gateway 2018, Person-centred caring, Australian Government, viewed 02 October 2018, <<https://www.carergateway.gov.au/person-centred-caring>>. Cypress, SB 2017, 'Rigour or Reliability and Validity in Qualitative Research: Perspectives, Strategies, Reconceptualization, and Recommendations', *Dimensions of Critical Care Nursing*, vol. 36, no. 4, pp. 253-263.

Dickens, GL, Hallett, N & Lamont, E 2016, 'Interventions to improve mental health nurses' skills, attitudes, and knowledge related to people with a diagnosis of borderline personality disorder: Systematic review', *International Journal of Nursing Studies*, vol. 56, no1, pp. 114-127.

Dunne, E & Rogers, B 2013, "'It's Us That Have to Deal with it Seven Days a Week": Carers and Borderline Personality Disorder', *Community Mental Health Journal*, vol. 49, no. 6, pp. 643-648.

Fonagy, P, Speranza, M, Luyten, P, Kaess, M, Hessel, C & Bohus, M 2015, 'ESCAP Expert Article: Borderline personality disorder in adolescence: An expert research review with implications for clinical practice', *European Child & Adolescent Psychiatry*, vol. 24, no. 11, pp. 1307-1320.

Forde, R, Norvoll, R, Hem, M & Pedersen, R 2016, 'Next of kins experiences of involvement during involuntary hospitalisation and coercion', *BMC Medical Ethics*, vol. 17, no. 1, pp. 1-9.

Fusch, P & Ness, L 2015, 'Are We There Yet? Data Saturation in Qualitative Research', *The Qualitative Report*, vol. 20, no. 9, pp. 1408-1416.

Gardner, G, Duffield, C, Doubrovsky, A & Adams, M 2016, 'Identifying advanced practice: A national survey of a nursing workforce', *International Journal of Nursing Studies*, vol. 55, pp. 60-70.

Giacco, D, Dirik, A, Kaselionyte, J & Priebe, S 2017, 'How to make carer involvement in mental health inpatient units happen: a focus group study with patients, carers and clinicians', *BMC psychiatry*, vol. 17, no. 1, pp. 101.

Giffin, J 2008, 'Family Experience of Borderline Personality Disorder', *Australian and New Zealand Journal of Family Therapy*, vol. 29, no. 3, pp. 133-138.

Gillespie, H, Kelly, M, Duggan, S & Dornan, T 2017, 'How do patients experience caring? Scoping review', *Patient Education and Counseling*, vol. 100, no. 9, pp. 1622-1633.

Guest G, Namey E & McKenna K 2016, 'How many focus groups are enough? Building evidence base for nonprobability sample sizes', *Sage Journals*, vol. 29, no.1 pp. 3-22.

Halpin, MA & Gallagher, C 2016, *Lived Experience Workforce in SA Public Mental Health Services*, Government of South Australia, SA Health, Adelaide South Australia.

Hauck, J 2012, 'Psychiatric Nurses' Attitudes Toward Hospitalized Patients Diagnosed With Borderline Personality Disorder Experiencing Self-Harm Issues and Implications in Clinical Nursing Practice', *Journal Of The American Psychiatric Nurses Association*, vol. 18, no. 1, pp. 44-44.

Hauck, J, Harrison, B & Montecalvo, A 2013, 'Psychiatric Nurses' Attitudes Toward Patients with Borderline Personality Disorder Experiencing Deliberate Self-Harm', *Journal of Psychosocial Nursing And Mental Health Services*, vol. 51, no. 1, pp. 20-29.

Hiscock, H, Neely, RJ, Lei, S & Freed, G 2018, 'Paediatric mental and physical health presentations to emergency departments, Victoria, 2008-15', *The Medical Journal of Australia*, vol. 208 no. 8, pp. 343-347.

Homan, KJ, Sim, LA, Fargo, JD, Twohig, MP & Widiger, TA 2017, 'Five-Year Prospective Investigation of Self-Harm/Suicide-Related Behaviors in the Development of Borderline Personality Disorder', *Personality Disorders: Theory, Research, and Treatment*, vol. 8, no. 2, pp. 183-188.

Hooley, JM & Hoffman, PD 1999, 'Expressed Emotion and Clinical Outcome in Borderline Personality Disorder', *American Journal of Psychiatry*, vol. 156, no. 10, pp. 1557-1562.

International Council of Nurses 2018, *Nursing Definitions*, International Council of Nurses, viewed 28 October 2018 <<https://www.icn.ch/nursing-policy/nursing-definitions>>.

Jurgens, FJ, Clissett, P, Gladman, JR and Harwood, RH, 2012, 'Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study', *BMC geriatrics*, vol. 12, no. 1, p.57.

Katsikitis, M, Lane, BR, Ozols, I & Statham, D 2017, 'Consumer and carer perspectives in the development of a mental health research, treatment and teaching facility: A thematic analysis', *Journal of Psychiatric and Mental Health Nursing*, vol. 24, no. 7, pp. 534-544.

Kerrison, SA & Chapman, R 2007, 'What general emergency nurses want to know about mental health patients presenting to their emergency department', *Accident & Emergency Nursing*, vol. 15, no. 1, pp. 48-55.

Koehne, K & Sands, N 2008, 'Borderline personality disorder - an overview for emergency clinicians', *Australasian Emergency Nursing Journal*, vol. 11, no. 4, pp. 173- 177.

Kuehl, S, Nelson, K & Collings, S 2012, 'Back so soon: rapid re-presentations to the emergency department following intentional self-harm', *The New Zealand Medical Journal (Online)*, vol. 125, no. 1367, pp. 70-9.

Lawn, S & McMahon, J 2015, 'Experiences of care by Australians with a diagnosis of borderline personality disorder', *Journal of Psychiatric and Mental Health Nursing*, vol. 22, no. 7, pp. 510-521.

Levac, D, Colquhoun, H & O'brien, KK 2010, 'Scoping studies: advancing the methodology', *Implementation science*, vol. 5 no. 69.

Lieb, K, Zanarini, MC, Schmahl, C, Linehan, MM & Bohus, M 2004, 'Borderline Personality Disorder', *The Lancet*, vol. 364, no. 9432, pp. 453-461.

Marynowski-Traczyk, D, Moxham, L & Broadbent, M 2017, 'Emergency Department Registered Nurses' conceptualisation of recovery for people experiencing mental illness', *Australasian Emergency Nursing Journal*, vol. 20, no. 2, pp. 75-81.

Mcauliffe, D, Andriske, L, Moller, E, O'Brien, M, Breslin, P & Hickey, P 2009, 'who cares?' An exploratory study of carer needs in adult mental health', *Australian e-Journal for the Advancement of Mental Health*, vol. 8, no. 1, pp. 57-68.

Mccann, T, Clark, E, Mcconnachie, S & Harvey, I 2006, 'Accident and emergency nurses' attitudes towards patients who self-harm', *Accident and Emergency Nursing*, vol. 14, no. 1, pp. 4.

Menon, V 2014, 'Silverman revisited: A relook at some of the pitfalls and challenges in suicide nomenclature and few suggestions', *Industrial Psychiatry Journal*, vol. 23, no. 1, pp. 73-74.

Mental Health Australia 2014, *Why is Australia afraid of Borderline Personality Disorder?*, viewed 17<sup>th</sup> May 2018, <<https://mhaustralia.org/general/why-australia-afraid-borderline-personality-disorder>>.

Mind Australia 2015, Implications for family carers when people with a psychosocial disability have individualised funding packages- a literature review, viewed 26 April 2018, <[https://www.mindaustralia.org.au/sites/default/files/publications/Implications\\_for\\_family\\_carers\\_literature\\_review.pdf](https://www.mindaustralia.org.au/sites/default/files/publications/Implications_for_family_carers_literature_review.pdf)>

Mind Australia 2015, Implications for family carers when people with a psychosocial disability have individualised funding packages- a literature review, viewed 26 April 2018, <[https://www.mindaustralia.org.au/sites/default/files/publications/Implications\\_for\\_family\\_carers\\_literature\\_review.pdf](https://www.mindaustralia.org.au/sites/default/files/publications/Implications_for_family_carers_literature_review.pdf)>

Morphet, J, Innes, K, Munro, I, O'Brien, A, Gaskin, CJ, Reed, F et al. 2012, 'Managing people with mental health presentations in emergency departments—A service exploration of the issues surrounding responsiveness from a mental health care consumer and carer perspective', *Australasian Emergency Nursing Journal*, vol. 15, no. 3, pp. 148-155.

National Health and Medical Research Council 2012, *Clinical Practice Guidelines for the Management of Borderline Personality Disorder*, viewed 14 March 2018, <<https://www.nhmrc.gov.au/guidelines-publications/mh25>>.

National Mental Health Consumer & Carer Forum 2017, *Borderline Personality Disorder*, viewed 01 May 2018, <<https://nmhccf.org.au/publication/borderline-personality-disorder>>.

Ng, F, Bourke, M & Grenyer, B 2016, 'Recovery from Borderline Personality Disorder: A Systematic Review of the Perspectives of Consumers, Clinicians, Family and Carers', *Plos One*, vol. 11, no. 8, pp. e0160515-e0160515.

Nicholls, D, Gaynor, N, Shafiei, T, Bosanac, P & Farrell, G 2011, 'Mental health nursing in emergency departments: the case for a nurse practitioner role', *Journal of clinical nursing*, vol. 20, no. 3-4, pp. 530.

NSW Department of Health 2011, *Australian Triage Process Review*, NSW Department of Health, PricewaterhouseCoopers, Viewed 05 April 2018, <<https://www.health.gov.au/internet/main/publishing.nsf/.../Triage%20Workbook.pdf>>.

Nursing and Midwifery Board of Australia 2008, *Code of Ethics for Nurses in Australia*, viewed 15<sup>th</sup> May 2018, <[file:///C:/Users/Kristy%20PC/Downloads/5 New-Code-of-Ethics-for-Nurses-August-2008%20\(9\).PDF](file:///C:/Users/Kristy%20PC/Downloads/5%20New-Code-of-Ethics-for-Nurses-August-2008%20(9).PDF)>.

Olasoji, M, Maude, P & Mccauley, K 2017, 'Not sick enough: Experiences of carers of people with mental illness negotiating care for their relatives with mental health services', *Journal of Psychiatric and Mental Health Nursing*, vol. 24, no. 6, pp. 403.

Orygen 2018, Orygen welcomes Victorian Government's pledge of a royal commission into mental health, viewed 30<sup>th</sup> October 2018, <<https://www.orygen.org.au/About/News-And-Events/2018/Royal-commission-mental-health>>.

Perera, J, Wand, T, Bein, KJ, Chalkley, D, Ivers, R, Steinbeck, KS, et al. 2018, 'Presentations to NSW emergency departments with self-harm, suicidal ideation, or intentional poisoning, 2010-2014', *The Medical journal of Australia*, vol. 208, no. 8, pp.349-353.

Pham, MT, Rajić, A, Greig, JD, Sargeant, JM, Papadopoulos, A & Mcewen, SA 2014, 'A scoping review of scoping reviews: advancing the approach and enhancing the consistency', *Research Synthesis Methods*, vol. 5, no. 4, pp. 371- 385.

Polit, DF & Beck, CT 2017, *Nursing research: generating and assessing evidence for nursing practice*, 10th edn, Wolters Kluwer, Philadelphia.

Procter N, Ayling B, Croft L, Degaris P, Devine M, Dimanic A, Di Fiore L, Eaton H, Edwards M, Ferguson M, Lang S, Rebellato A, Shaw K and Sullivan R 2017, *Trauma-informed approaches in mental health: A practical resource for health professionals*, University of South Australia, SA Health, Adelaide.

Project Air 2015, *Project Air Strategy Treatment Guidelines for Personality Disorders*, Project Air, viewed 02 November 2018, <<https://www.projectairstrategy.org/guidelines/index.html>>.

Purves, D & Sands, N 2009, 'Crisis and Triage Clinicians' Attitudes Toward Working With People With Personality Disorder', *Perspectives in Psychiatric Care*, vol. 45, no. 3, pp. 208-215.

Robinson, OC 2014, 'Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide', *Qualitative Research in Psychology*, vol. 11, no. 1, pp. 25-41.

SA Health 2016, *Clinical services capability framework, 'Emergency'*, Government of South Australia, viewed 19<sup>th</sup> August 2018, <<https://www.sahealth.sa.gov.au/wps/wcm/connect/34f033804e49e9a88fd7dfc09343dd7f/15137.2-11+Emergency-WebSec.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-34f033804e49e9a88fd7dfc09343dd7f-m08cp4g>>.

SA Mental Health Commission 2017, *South Australian Action Plan for people living with Borderline Personality Disorder 2017-2020*, Government of South Australia, viewed 02 May 2018, <<http://samentalhealthcommission.com.au/what-we-do/borderline-personality-disorder/>>.

Sargeant, J 2012, 'Qualitative Research Part II: Participants, Analysis, and Quality Assurance', *Journal of graduate medical education*, vol. 4, no. 1, pp. 1.

Schneider, Z, Whitehead, D, Lobiondo-Wood, G & Haber, J 2013, *Nursing and midwifery research : methods and appraisal for evidence-based practice*, 4th edn, Mosby/Elsevier, Sydney.

Silverman, MM, Berman, AL, Sanddal, ND, O', PW & Joiner, TE 2007, 'Rebuilding the Tower of Babel: A Revised Nomenclature for the Study of Suicide and Suicidal Behaviors Part 2: Suicide-Related Ideations, Communications, and Behaviors', *Suicide and Life-Threatening Behavior*, vol. 37, no. 3, pp. 264-277.

Sledge, WH, Lawless, M, Sells, D, Wieland, M, O'connell, MJ & Davidson, L 2011, 'Effectiveness of Peer Support in Reducing Readmissions of Persons With Multiple Psychiatric Hospitalizations', *Psychiatric Services*, vol. 62, no. 5, pp. 541-544.

Stringer, B, Meijel, B, Karman, P, Koekkoek, B, Hoogendoorn, AW, Kerkhof, FM et al 2015, 'Collaborative Care for Patients With Severe Personality Disorders: Preliminary Results and Active Ingredients From a Pilot Study (Part I)', *Perspectives in Psychiatric Care*, vol. 51, no. 3, pp. 180-189.

Taua, C, Hepworth, J & Neville, C 2012, 'Nurses' role in caring for people with a comorbidity of mental illness and intellectual disability: A literature review', *International Journal of Mental Health Nursing*, vol. 21, no. 2, pp. 163-174.

Tong, A, Flemming, K, McInnes, E, Oliver, S & Craig, J 2012, 'Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ', *BMC medical research methodology*, vol. 12, pp. 181.

Torio, CM, Encinosa, W, Berdahl, T, McCormick, MC & Simpson, LA 2015, 'Annual Report on Health Care for Children and Youth in the United States: National Estimates of Cost, Utilization and Expenditures for Children With Mental Health Conditions', *Academic Pediatrics*, vol. 15, no. 1, pp. 19-35.

Wlodarczyk, J & Lawn, S 2017, 'The Developmental Trajectory of Borderline Personality Disorder and Peer Victimization: Australian Family Carers' Perspectives', *Emotional & Behavioural Difficulties*, vol. 22, no. 2, pp. 98-110.