Shared Learning in Clinical Practice

Mental Health Practice Development Newsletter

Emergency department nursing for people with borderline personality disorder: Understanding the views and experiences of family carers.

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Introduction

Earlier this year, the South Australian Coroner published inquest findings into the suicide deaths of two young South Australian women diagnosed with borderline personality disorder (BPD). Each had sought help on multiple occasions from hospital emergency departments (ED) prior to their death. The coroner expressed concern that family members for each decedent was unable to locate specialist assessment, treatment and safety for their loved one prior to death (Courts Administration Authority of South Australia 2018). The coroner reported the mental health sector response had been inadequate. In addition to state-wide specialist services being unavailable, there is also a need for health professionals to receive education and training in ways to comfort and support people with BPD. More importantly, and central to this finding, appropriate care for people diagnosed with BPD must be inclusive of family carer engagement and perspective.

This edition of the *Shared Learning in Clinical Practice Newsletter* previews research currently underway in South Australia to examine the interface between family carer perspectives at the time of contact with ED nurses. A particular focus of this research will be on understanding the experiences of family carers who are supporting a loved one with BPD during times of crisis. Increased awareness of the ED interaction from the perspective of carers can shed light on key issues at the heart of person centred mental health care for people with BPD.

This research project has been conceived in partnership with the *Sanctuary Support Group* – a community based group focussed on the needs of carers of people with BPD. We would like to thank and acknowledge the members of Sanctuary for this collaboration and their sharing of key ideas and experiences. We also acknowledge the contributions of Sanctuary members: Judy Burke, Karen Bailey and Liz Hodgman in providing comments during the drafting of this article.

Impacts of Borderline Personality Disorder

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 diagnoses than men[1] (Lawn et al. 2015; National Health and Medical Research Council (NHMRC) 2012; BPD Foundation 2018). BPD is therefore a relatively common mental illness which is

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[1] 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.

accompanied by a higher than average incidence of suicide and self-harm due to range of complex interactions and ongoing emotional and social difficulties that consumers experience. The condition is also associated high use of health care resources (SA Mental Health Commission (SAMHC) (2017). Self-harm is a particular 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 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. These include reactions to chaotic thinking, emotional dysregulation and self-harming behaviours (National Mental Health Consumer & Carer Forum (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 (National Health and Medical Research Centre (NHMRC) (2012). The caring role is most often assumed by a parent or spouse living with or nearby their loved one (Mind Australia 2015).

Mental health carers in general experience impacts due to the role. These include limits to the ability to engage in paid employment and education, with many receiving government payments (Mind Australia 2015; ABS 2017). A majority of mental health primary carers 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 in particular a noticeable increase of mental health presentations in EDs (Morphet et al. 2012). These changes have also brought changes to the way of 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 a steadily 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, this includes the impact on nurses providing care to people with BPD and the challenges they face have been of focus (Lawn et al. 2015; Bailey et al. 2013). At present, research activity looking specifically at the perspectives of BPD carer's views on nursing practices in the ED has been largely overlooked.

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Emergency Department Nursing

This situation needs to change. 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 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.

In Australia, there are defined and clear process of triage pathways upon presentation to an ED. The triage process seeks to align an appropriate service response to the needs of the consumer. This initial assessment is often conducted by a Registered Nurse (RN) with clinical experience in emergency nursing (NSW Department of Health 2011). The distress and urgency of care is assessed within a designated triage category and guides necessary intervention to prevent threat to life, alleviate pain and suffering, and to improve consumer outcomes (NSW Department of Health 2011). The urgency triage criterion is based on observations and behaviours of a nursing assessment, which determine how long a consumer could wait to see a medical officer (NSW Department of Health 2011). The ED is often the initial starting place for conversations with family and carers on their perspective of loved ones' mental health or behavioural crisis. Implications for nurses in the triage setting when assessing mental health presentations have been identified as challenging (Kerrison & Chapman 2007). The level of training and competency in mental health assessments can result in discrepancies and inconsistencies of assessment, resulting in the level of urgency for review by a specialist as unpredictable. Taken in combination, this has potential to impact upon care received (or not received) and length of stay (NSW Department of Health 2011; Kerrison & Chapman 2007).

The care of a person with BPD is complex and resource-intensive due to the complex nature of need, including that associated with self-harm (Dickens et al 2015). ED nursing assessments for self-harm can be inconsistent, with documentation at triage minimal in content and descriptive about service involvement and consumer location. Where a re-presentation occurs, it is less likely to have a mental health assessment. Also of concern are the extended wait times to be reviewed by a specialist mental health clinician (Kuehl, Nelson & Collings 2012). The National Standards for Mental Health Services (2010) promote all levels of the mental health infrastructure as important in achieving optimal quality of life for people with mental illness. The role of the mental health liaison nurse (MHLN) was implemented as part of the integration of mental health services into mainstream medical services to provide specialist skills and knowledge to effectively bridge a gap in knowledge and skills from ED nursing. The engagement of a MHLN in the ED settings has brought significant positive outcomes for the consumers such as decreased length of stay (Wand 2004).

The Need for Deeper Understanding

This evidence is both a significant concern and key driver for deeper investigation of health care worker engagement with family carers for people with BPD. Additionally, we should highlight that the focus on carer engagement should not overlook the quality of engagement that consumers themselves experience in health care settings. Stigma, invalidation, and superficial health care responses will deeply affect the consumer at the centre of care. In practice, education and policy contexts, a focus on carer experience should always be considered alongside consumer perspectives and preferences.

The importance of improving ED health care responses is also understood when we consider the scale of increasing presentations in this area. Perera et al. (2018), conducted a retrospective study between 2010 and 2014 evaluating trends in mental health emergency department presentations in 115 New South Wales emergency departments, due to a 48.9% increase in mental health related ED presentations. This study identified women were 64% more likely to have a presenting diagnosis of self-harm and 71% more likely to present with intentional self-poisoning. Similarly, Hiscock et al. (2018), reported in a study conducted over a seven year period, there was a 52.8% increase of presentations for self-harm in Victorian EDs with adolescent girls presenting disproportionately higher than boys. Perera et al. (2018), reported similar findings that the presentation rate was significantly higher in the adolescent age group between 15- 19 years, with an 11.8 % increase of ED presentations and 13.8% increase between 10-14 year olds. Interestingly the report found that many of the ED presentations occurred after usual business hours, suggesting that the ED is the first point of accessing acute mental health care (Perera et al. 2018). Enhanced ED models of care are required to address service gaps. Triaging mental health presentations may place greater burden on EDs compared to physical illness and injury presentations, due to length of stay according to the National Emergency Access Target of being admitted or discharged within four hours (Hiscock et al. 2018).

The important point here is that the caring role for someone with a mental illness such as BPD is complex and involves ED staff. As seen through the preceding discussion and analysis, the family carer role may require managing and scheduling referral for follow-up medical appointments, facilitating transport and accommodation, providing advocacy and support to engage with services and helping with psychosocial care (Carer Gateway 2017). The caring role is not linear but rather can be episodic in accordance with the preferences and needs of the consumer. This means that carer work goes through ebbs and flows, simultaneously helping the person achieve their recovery goals (Carer Gateway 2017). In an acute mental health crisis, the caring role also incorporates advocacy and support and is significant in assisting nurses to recognise and respond early to the warning signs of consumer deterioration (Giacco et al. 2017). In this context carers are a vital resource for healthcare practitioners: they offer insights and knowledge into a consumer's history and coping strategies which may not otherwise be discussed. Carers often provide valuable perspectives to support recovery planning.

Trauma Informed Practice

Nurses are critical to the implementation and planning of advocacy and support to the patient, 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 carers. In many settings traditional practices of seclusion and restraint, are still in regular use. Such practices can exacerbate distress and therefore contribute to further 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 effectively 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 current through, feeling and behaviour, 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).

Study Aims

This study aims to bring further understanding of preferred nursing practices in the ED for people with BPD. Specifically, this research aims to bridge the gap in knowledge for preferred nursing practices in EDs from the perspectives of family carers. Acknowledging the complexities and challenges in engaging and supporting a person with BPD in crisis, an increased awareness of the ED interaction from a carer perspective will provide a greater understanding of issues at the heart of person and family centred mental health care (Morphet et al. 2012).

Carers have a unique experience of nursing care during a crisis. How nursing practice is framed and delivered with the carer is not only based on offering support to the family, but rather setting up a context of shared care which is necessary to support the consumer in their recovery (SAMHC 2017).

The specific aims of the study are:

1. What are the experiences of carers when they are supporting consumers with BPD to access ED based care?
2. What are the views and expectations of carers towards nursing practices and communication within the ED?
3. What ED nursing practices do carers see as effective and preferred?
4. What are carers' views on overcoming barriers to effective nursing care for consumers with BPD and for themselves in the caring role?

Contribution and Impact of the Research

The findings are expected to highlight individual and workplace factors that may be addressed by different levels of well-known workplace and practice development strategies (skill development in crisis intervention, person centred care and recovery orientation in mental health nursing). Findings will also inform the development of organisational learning for nurses, workplace policy guidelines and responses, as well as

important consumer processes for consideration in ED settings. It is also expected that these findings will become both a form of prevention (of feelings of marginalisation and stigma in family carers) as well as supporting consumers in their recovery and, for improving practice with future nursing encounters of with family carers.

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Information about Sanctuary

Sanctuary is an Adelaide-based support group for people caring for those affected by Borderline Personality Disorder (BPD). Sanctuary meets on the second Tuesday of each month from 4.00pm to 6.00pm= at the premises of Skylight (community mental health service), 5 Cooke Terrace, Wayville.

More information is available from http://bpd-carers-sanctuary.org/about-us/

The Shared Learning in Clinical Practice Philosophy

Shared Learning in Clinical Practice (SLICP) is a policy relevant and service delivery focussed collaboration to promote best practice in mental health and suicide prevention. The strategic purpose of the initiative is to demonstrate through research and practical example, how much consumers, carers, clinicians, policy makers and academic faculty can achieve working together. Deep discussion, deep connectivity and diffusion of the insights are central to its philosophy. With a nursing focus and multidisciplinary in composition, the aim of each publication, podcast, film, social media communication and symposium is to capture and spread new ideas and know-how in mental health practice and challenge traditional ways of thinking. Shared Learning in Clinical Practice updates are regularly posted on Twitter at @MHResearchUniSA.

Further information is available from:
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