‘I Need Help’

An Exploration of the PANDA - Perinatal Anxiety & Depression Australia National Helpline

Submitted by
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A thesis submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

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June 2018
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Statement of Authorship

This thesis consists primarily of work by the author that has been published or accepted for publication as described in the text. Except where reference is made in the text of the thesis, this thesis contains no other material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All work in this thesis was undertaken by myself, under the guidance of my supervisors, Professor Helen McLachlan, Professor of Midwifery, Judith Lumley Centre and School of Nursing and Midwifery, La Trobe University; Professor Della Forster, Professor of Midwifery and Maternity Services Research, Judith Lumley Centre, La Trobe University, and Royal Women's Hospital; Dr Touran Shafiei, Research Fellow, Judith Lumley Centre, La Trobe University; and Professor Pranee Liamputtong, Professor of Public Health, School of Science and Health, and Core Member Translational Health Research Institute, Western Sydney University.

Under the guidance of my supervisors I was responsible for all aspects of the thesis. This thesis is presented as a thesis with publication, consisting of four papers, of which I am the primary author for three and the second author for the fourth. I have made a substantial contribution to all papers, including the development, piloting and finalising of data collection tools, data collection, management and analysis throughout the study. Co-authors have contributed to the overall study design, intellectual input, drafting and editing of manuscripts.

All research procedures reported in the thesis were approved by the relevant Ethics Committees.

This work was supported by a La Trobe University Postgraduate Research Scholarship.
Details of papers published or under peer review included in this thesis are as follows:


Laura Biggs, 13th June 2018
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ASIST</td>
<td>Applied Suicide Intervention Skills Training</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
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<tr>
<td>DASS</td>
<td>Depression Anxiety Stress Scale</td>
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<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EPDS</td>
<td>Edinburgh Postnatal Depression Scale</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HM</td>
<td>Helen McLachlan</td>
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<tr>
<td>IPV</td>
<td>Intimate Partner Violence</td>
</tr>
<tr>
<td>JLC</td>
<td>Judith Lumley Centre</td>
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<tr>
<td>LB</td>
<td>Laura Biggs</td>
</tr>
<tr>
<td>LGBTIQ+</td>
<td>Lesbian, gay, trans*, intersex, queer/questioning, + other non-binary individuals</td>
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<tr>
<td>OCD</td>
<td>Obsessive Compulsive Disorder</td>
</tr>
<tr>
<td>PANDA</td>
<td>PANDA - Perinatal Anxiety &amp; Depression Australia (formerly PANDA Post and Antenatal Depression Association)</td>
</tr>
<tr>
<td>PHQ-2</td>
<td>Patient Health Questionnaire (two item scale)</td>
</tr>
<tr>
<td>PTSD</td>
<td>Post-Traumatic Stress Disorder</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>SANDS</td>
<td>Stillbirth and Newborn Death Support</td>
</tr>
<tr>
<td>SCID</td>
<td>Structured Clinical Interview for the DSM</td>
</tr>
<tr>
<td>SOS support</td>
<td>Source of Strength support</td>
</tr>
<tr>
<td>SSRI</td>
<td>Selective Serotonin Reuptake Inhibitor</td>
</tr>
<tr>
<td>TS</td>
<td>Touran Shafiei</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
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</table>

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1 An umbrella term covering a range of identities that transgress socially defined gender norms. Sam Killermann, [http://itspronouncedmetrosexual.com/](http://itspronouncedmetrosexual.com/)
## Helpline Definitions

PANDA - Perinatal Anxiety & Depression Australia runs the National Perinatal Anxiety & Depression Helpline, which is the focus of this thesis. The Helpline uses a number of key terms relating to Helpline service delivery, which are defined here:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Biopsychosocial assessment</strong></td>
<td>A comprehensive assessment conducted by Helpline staff that considers the biological, psychological, and social factors that may be contributing or relevant to a caller’s experiences.</td>
</tr>
<tr>
<td><strong>‘High needs’ caller</strong></td>
<td>Callers who are experiencing complex psychosocial factors, including drug and alcohol use, family violence, or acute mental health crisis. The category is used to help identify those callers who would likely benefit from additional proactive Helpline support.</td>
</tr>
<tr>
<td><strong>Initial call</strong></td>
<td>Term used to describe the first return call an individual receives from the Helpline, which includes a thorough biopsychosocial and risk assessment.</td>
</tr>
<tr>
<td><strong>Mental health status</strong></td>
<td>Term used to identify risk relating to a caller’s mental health status. An assessment of being ‘at risk’ due to mental health status is documented by PANDA staff when a caller is experiencing significant ‘moderate to severe’ symptoms of mental health decline which are impacting on their ability to care for themselves and/or their infant.</td>
</tr>
<tr>
<td><strong>New caller</strong></td>
<td>Term used to describe a caller who is new to the service.</td>
</tr>
<tr>
<td><strong>Re-engaging caller</strong></td>
<td>Term used to describe a caller who has had contact with the service in the past, and is re-engaging after a period of non-contact.</td>
</tr>
<tr>
<td><strong>Victorian Intensive</strong></td>
<td>An intensive counselling and service coordination program available for Victorian residents experiencing significant psychosocial complexity. The program has a focus on service coordination and advocacy to facilitate positive outcomes.</td>
</tr>
<tr>
<td><strong>Counselling and Service</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Coordination Program</strong></td>
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Abstract

Perinatal mental health is a major public health issue. Research to date has primarily focused on prevention strategies and treatments, however little research has been conducted with existing community-based perinatal mental health supports. PANDA - Perinatal Anxiety & Depression Australia, first founded in 1983, provides telephone support to anyone impacted by perinatal mental health issues via the National Perinatal Anxiety & Depression Helpline, which is staffed by professional counsellors and peer support volunteers.

This thesis used an exploratory, descriptive study design to evaluate the Australian National Perinatal Anxiety & Depression Helpline. The overall aim was to understand who calls the Helpline, their motivations for seeking help, the experiences of callers receiving support, and the experiences of volunteers providing peer support. The study comprises four Sub-studies.

Sub-study one describes the characteristics, health history and assessment of new callers to the Helpline from July 2010, when the Helpline became a national service, and October 2013. Routinely collected data showed that most women calling the Helpline for the first time were aged between 25 and 40, married or partnered, and having their first child. A high proportion of callers were assessed as experiencing significant biopsychosocial symptoms, social complexity or inadequate care and support – also known as ‘high needs’ callers. Over the study period there was a 70% increase in the number of initial calls to the Helpline.

Sub-study two considers the reasons why someone picks up the phone for the first time and asks PANDA for help. Helpline intake forms, completed when a new or re-engaging caller contacts the Helpline, were analysed to better understand help-seeking behaviours and factors which may have contributed to the callers’ emotional distress. Many callers described complex and interrelated psychosocial factors, such as social isolation, or difficult experiences in childhood. Close to a third of callers were identified as ‘at risk’, including a number who were experiencing thoughts of suicide and/or self-harm.

Sub-study three describes the views and experiences of callers to the Helpline who made their first contact with the service between 1st May and 30th September 2013. Most callers were women, and had contacted the Helpline concerned about their own mental health. Although PANDA is not a crisis service, over a third of callers were seeking crisis support and help. Overall callers reported that their contact with the service had been very positive, and
they described the Helpline as a safe space to be heard and receive support without judgement.

Sub-study four describes the experiences of volunteers providing peer support on the Helpline. An online survey and two focus groups were used to explore volunteers’ motivations for becoming a peer support volunteer, if the role had any impact on their own emotional wellbeing, what they saw as the positive and negative aspects of the role, and experiences of training and supervision. Volunteers described a strong desire to help parents experiencing emotional distress, and they felt that the Helpline played a really important, positive role supporting the community.

The PANDA Helpline provides a well utilised, specialised service which addresses barriers to support such as geographical isolation, stigma, and difficulty accessing face-to-face services. The PANDA telephone support model has been sustained over time and provides highly valued support to a complex population.
Acknowledgements

As with any thesis, this work would not have been possible without the generous support of a number of people. Firstly, I would like to thank my incredible supervision team. Helen, Della, and Touran – you have always been kind, patient, and responsive to my evolving needs and skills as a PhD student. I never sensed that you had any doubts in my ability to produce high quality work, and that confidence has been more helpful than you probably realised. If I had my time again I would honestly make the same decisions to undertake this study with the same supervision team, and I’m not sure that this is something many PhD Candidates would say upon submission. Thank you also to Pranee, who joined my supervision team in April 2015 – you have provided integral methodological and writing guidance, which has contributed significantly to the overall quality of this thesis.

To my mother Jenny, and my sister Merinda – thank you for your good humoured and consistent support throughout all my years of tertiary study. You have both had an enormous impact on my passion for health equity and social justice issues, without which I probably wouldn’t have undertaken this thesis. Thank you to Professor Melanie Birks, for being such a great listener and mentor as I have expanded my research knowledge. Thank you also to Jordan for his kindness in the final months of writing and editing; Ben for many years of friendship and whole-hearted support; Nathan for his helpful editorial comments on my final draft; and to Aryan and Sarah for their more than generous support in unexpected circumstances. A huge thank you to Sarah, my oldest friend, for never failing to remind me to laugh at myself, even from Switzerland.

Perhaps most importantly, I would like to thank my midwifery and Judith Lumley Centre family for all of their incredible support over the past few years. The most substantial assistance for this thesis has of course originated from my supervisors, but the unbelievably kind and supportive environment at the research centre is what has kept me afloat through all of the ups and downs that are an inevitable part of any PhD journey. I would like to thank some people individually: Rhian, for listening to my many and varied existential crises; Fiona and Anita, for being the best ‘roomies’ I could have asked for, and Kerryn, Heather, Fiona, Jess, and Ingrid for ensuring I never felt isolated. Thank you to Professor Rhonda Small, who was the chair of my progress panel, and has provided insightful and kind mentoring throughout my PhD journey, and Mandi, for always being available to help me develop new perspectives and insights. Thank you to my teaching colleagues at ACU: Jess Trubiano, for
sharing her lived experiences, and helping me to tackle the deeper questions; and Jane Morrow, who supervised my Honours degree, and suggested that the Judith Lumley Centre was where I should consider undertaking my PhD. You taught me that I didn’t need to remain passive in response to the issues I identified in clinical practice, and supported me to take an active role in research, teaching, and advocating for change for women and families.

There are a large number of people at PANDA - Perinatal Anxiety & Depression Australia that have helped to make this research possible. Thank you to Belinda Horton, former CEO, for engaging the Judith Lumley Centre to complete a service evaluation of the National Perinatal Anxiety & Depression Helpline, and for welcoming me onto the team as a PhD Candidate. Thank you to Jenni Richardson, former National Helpline and Programs Manager, for substantial support during the evaluation and further studies undertaken as part of this thesis. An enormous thank you to Terri Smith, CEO, and National Helpline and Programs Manager, Cathy Wyett, for ongoing support as I have completed this thesis and disseminated the study findings. You have all shown a great deal of trust in me by welcoming me to spend many hours in the Helpline data storage room, collecting and analysing data for this thesis, the significance of which is not lost on me. I will be forever grateful to have had the opportunity to work so closely with the organisation. Two of the studies in this thesis have relied on individuals sharing their very personal experiences with the research team. Without you this thesis would literally not have been possible. Thank you for trusting us with your stories.
I have been drawn to mental health research and practice for a long time. I grew up in country Victoria, where gender inequity and poor mental health were prominent community issues. At the age of 13, a school friend took her own life. What was striking about this event, beyond the enormous shock and growth required of us as young adolescents, was the responses of the adults in our lives. We experienced first-hand the stigma and fear associated with mental illness; our friend was framed by some as selfish and uncaring because of the hurt her actions had ‘caused’ others.

My exposure to unhelpful and harmful attitudes and social norms regarding mental illness has only continued; shame and stigma prevent many people from seeking help, and society still does not value emotional wellbeing in the same way that it values physical health. It could be said that this is particularly true of mental health in the perinatal period, given social expectations that this is a time in life characterised by joy and new life, not uncertainty, sadness, or fear.

When I moved to Melbourne in 2008 I joined a community-based mental health organisation as a peer support volunteer. I continued in this role for nine years, and I owe much of my understanding of what it is like to live day-to-day with a serious psychiatric illness to my trusting and generous peer.

Given all of this it is probably no surprise that I have found particular joy in caring for women who are experiencing challenges to their mental health in the perinatal period. One of my greatest joys as a midwife is caring for a woman facing complex psychosocial circumstances such as mental illness, abuse, or social isolation. Part of why I love this work so much is that I know many practitioners aren’t comfortable or confident providing this care, and how powerful respectful, holistic care can be in times of significant adversity. From this, one of my greatest passions as a midwifery lecturer is supporting the next generation of midwives to develop the skills and compassion they need to be present in these difficult times with women and families.
**Dissemination of Study Findings**

**Peer reviewed publications (as they appear in the thesis)**


**Conference presentations - oral**


**Conference presentations - poster (Appendix I and II)**


**Other presentations**

This thesis is an exploration of the National Perinatal Anxiety & Depression Helpline. It includes published work and ‘framing’ chapters, which explain how Part A and B, each with two Sub-studies, form the overall research study. **Chapter One** provides an introduction to the study, and **Chapter Two** introduces PANDA - Perinatal Anxiety & Depression Australia, and discusses the history of the organisation. **Chapter Three** presents a review of the literature, and **Chapter Four** provides a theoretical framework for the thesis. **Chapter Five** discusses the methodology of the thesis. **Chapter Six** presents the characteristics, health history and assessment of Helpline callers. **Chapter Seven** explores the reasons new and re-engaging callers make contact with the Helpline. **Chapter Eight** discusses the experiences of callers to the Helpline, and **Chapter Nine** explores the experiences of peer support volunteers. **Chapter Ten** is a discussion of the key findings from the study, and draws all of the Sub-study findings together to make a series of conclusions and recommendations for future research.

**Chapter Six** is the published paper:


**Chapter Seven** is a paper currently under peer review:


**Chapter Eight** is the published paper:


**Chapter Nine** is the published paper:

“There is no time in the lifespan that the statement ‘there is no health without mental health’ rings truer than in the perinatal period.”

(Howard, Piot, & Stein, 2014)

Perinatal mental health is a critical public health issue, and poor perinatal mental health can have serious consequences for the entire family unit (Austin, Nicole, & Expert Working Group, 2017; Howard, Piot, & Stein, 2014; Stein et al., 2014). Specific estimates regarding the incidence and prevalence of perinatal mental illness, such as depression or anxiety, vary due to differences in data collection methods used, however, there is widespread agreement that these problems are common. A number of factors increase a woman’s chance of experiencing poor perinatal mental health, including a lack of partner support (Biaggi, Conroy, Pawlby, & Pariante, 2016; Lancaster et al., 2010); lack of social support (Biaggi, Conroy, Pawlby, & Pariante, 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); a history of abuse or domestic violence (Biaggi et al., 2016; Howard, Oram, Galley, Trevillion, & Feder, 2013; Lancaster et al., 2010; Leigh & Milgrom, 2008); a personal history of mental illness (Biaggi et al., 2016; Dennis, Falah-Hassani, Brown, & Vigod, 2016; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); unintended pregnancy (Biaggi et al., 2016; O’Hara & McCabe, 2013); adverse life events and high perceived stress (Biaggi et al., 2016; Dennis et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); past and present pregnancy complications (Biaggi et al., 2016; O’Hara & McCabe, 2013); and low self-esteem (Biaggi et al., 2016; O’Hara & McCabe, 2013).

Although these problems are common, many women do not seek help (Dennis & Chung-Lee, 2006; Gavin, Meltzer-Brody, Glover, & Gaynes, 2015; Woolhouse, Brown, Krastev, Perlen, & Gunn, 2009), and clinical recognition remains poor. It is estimated that up to three quarters of women with anxiety and/or depression in the perinatal period will not be identified by care providers (Coates, Schaefer, & Alexander, 2004; Spitzer, Williams, Kroenke, Hornyak, &
McMurray, 2000). Barriers to seeking help include stigma (Dennis & Chung-Lee, 2006; Galinsky, Schopler, & Abell, 1997); potential challenges such as lack of transportation to access face-to-face services; language and financial barriers (O’Mahony & Donnelly, 2010); poverty; discrimination (O’Mahony & Donnelly, 2013); and a lack of knowledge regarding available services and how to access them (Dennis & Chung-Lee, 2006).

One way of addressing some of the barriers to care is telephone support, including telephone peer support and counselling services (Dennis & Kingston, 2008; Galinsky et al., 1997; Lavender et al., 2013; Ugarriza & Schmidt, 2006). Despite the fact that the number of telephone support services for women during the perinatal period has increased, few of these services have been evaluated, and few studies have included volunteers’ experiences of providing peer support (Dennis & Kingston, 2008; Lavender et al., 2013).

PANDA - Perinatal Anxiety & Depression Australia offers support to anyone affected by mental health issues in the perinatal period. PANDA’s main support service is the National Perinatal Anxiety & Depression Helpline (the Helpline), which facilitates over 10,000 calls per year (Shafiei, Forster, McLachlan, Small, & Biggs, 2014). Callers to the Helpline are provided support by paid professional counselling staff, as well as peer support volunteers. All volunteers have a lived experience of a perinatal mental illness, or have supported someone who has. There has not been a comprehensive evaluation of the National Perinatal Anxiety & Depression Helpline since it was established in 2010, and in 2013, the Judith Lumley Centre was approached by PANDA to undertake an independent evaluation of the service (Shafiei et al., 2014).

This thesis is an exploration of the National Perinatal Anxiety & Depression Helpline, and includes some of the data collected in the evaluation (Chapters Six, Eight, and Nine), and a subsequent study that was developed in light of the findings of the original evaluation (Chapter Seven).
SCOPE OF THE THESIS

The overall aim of this thesis is to describe caller characteristics and help-seeking behaviour, callers’ experiences of receiving support, and the views and experiences of peer support volunteers. Specific aims of each Sub-study will be provided in detail in Chapter Five, and each of the papers. The majority of calls to the Helpline are from women concerned about their own mental health during pregnancy or the postnatal period, so the focus of this thesis has therefore remained on these women. It is, however, acknowledged that the mental health of fathers and non-birth mothers is of great importance, and has not gained as much attention in research or practice to date. Some of the information collected in the original evaluation, such as the views and experiences of PANDA counselling staff and key stakeholders, are not included in this thesis. These findings were less appropriate for publication, and have been provided to PANDA and the Federal Department of Health in an evaluation report published in 2014 (Shafiei et al., 2014).
I felt 'held' by PANDA and 'carried' when I couldn't pick myself up. I gained support to go into hospital to get further help. PANDA helped me to survive this mental illness. They supported me to be my own advocate and gain support and understanding from others. They helped me to identify my own destructive thought patterns. They listened without judgement...

33 year old woman. Participant in Sub-study three - quote continued at end of chapter
Chapter Two
PANDA - Perinatal Anxiety &
Depression Australia

INTRODUCTION
This chapter will address the study context and aims. PANDA - Perinatal Anxiety & Depression Australia will be discussed, including the history of the organisation, and Helpline practices at the time of data collection. Changes to Helpline practices since the time of data collection are described in footnotes.

HISTORY
PANDA was formed in 1983 in Melbourne, Australia, by two women who had both experienced postnatal depression\(^2\). They were introduced to each other by their Maternal and Child Health Nurse, and found it helpful to share their experiences. They continued to meet regularly, and soon found that more women were interested in sharing their personal experiences and found the mutual support to be beneficial. Collectively the women decided to establish a support group – this group was eventually known as PANDA Post and Antenatal Depression Association (referred to as PANDA hereafter).

At the time that PANDA was formed there was very little awareness of, or medical information about perinatal mood disorders. The group decided to approach a psychiatrist from the Royal Women’s Hospital in Melbourne who had a special interest in perinatal mental health to be a consultant and referral source for the group. The psychiatrist agreed, and an information session was held where the psychiatrist, a woman who had herself recovered

\(^2\) Information in this chapter regarding the history of PANDA was provided by PANDA CEO Terri Smith in August 2017.
from postnatal depression, and a man whose partner had experienced postnatal depression all spoke. Several hundred women and their families attended this first information session, demonstrating the desire for knowledge and to meet others experiencing similar challenges.

A Committee of Management was first formed in 1985, and the following year PANDA became an incorporated association. One of the first priorities for PANDA was to establish several support groups across Melbourne, and to publish a regular newsletter. PANDA’s early services were reliant on women who had recovered from postnatal depression training and committing to voluntary service either as a support group facilitator or a provider of telephone support. These telephone volunteers worked from their homes and received calls for support at any time during the day or night. During this stage, PANDA relied entirely on funds raised by volunteers.

As demand for the service grew, it became increasingly difficult for the volunteers to facilitate support groups, support unwell women and their families, and answer incoming support calls on the Helpline, which had remained a 24 hour service. At this time there was also a reduction in the number of volunteer resources within the community more broadly, as more women entered the paid workforce (Volunteering Australia, 2015). A service review was conducted in 1999-2000 which led to the development of a more sustainable model of operation with some minimal recurrent funding from the Federal Department of Human Services. The new model included the establishment of a telephone support helpline that was office-based and available during business hours, with answering machines providing information to support after-hours callers. PANDA also stopped facilitating support groups and instead developed a database of support groups run throughout Victoria by other facilitators that callers could be referred to. During this time paid professional counselling staff were first employed to provide helpline services alongside peer support volunteers.
PANDA has continued to grow and adapt since this time, and now provides a range of supports to the community, including two websites, education for health professionals and community members, and the National Perinatal Anxiety & Depression Helpline (the Helpline). One of the most significant changes to the service came in 2010, when the Federal Government provided PANDA with funding as part of the National Perinatal Depression Initiative to expand their Victorian Helpline to become a national service, providing support for Australian families in all states and territories. PANDA has also made deliberate efforts to expand its skillset and focus to include the mental health of fathers, refugee and migrant families, and LGBTIQ+ families.

NATIONAL PERINATAL ANXIETY & DEPRESSION HELPLINE

The National Perinatal Anxiety & Depression Helpline is free, and available to callers Monday-Friday, 10am-5pm. Each year over 10,000 calls are made to and from the Helpline (Shafiei et al., 2014), and these figures are likely to increase due to additional funding which resulted in increased hours of operation from July 1st 2017. The Helpline is staffed by paid professional counselling staff, and peer support volunteers who have lived experience of perinatal mental illness, or have supported someone who has. The Helpline provides reactive support when someone rings in, and with consent is able to provide proactive follow up calls.

The most common calls to the Helpline are from women who are concerned about their own emotional health, however calls are also received from friends and family members, health professionals, and partners concerned regarding their own and/or their partner’s wellbeing. Some callers to the Helpline may only have one or two contacts with the service, for example

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3 PANDA has a main website (https://www.panda.org.au), and also a website focusing on fathers’ mental health (http://www.howisdadgoing.org.au)

4 The National Perinatal Depression Initiative aimed to improve prevention, early detection, support and treatment for perinatal depression. A total of $85 million was allocated to the initiative over five years, until June 2013.

5 On July 1st, 2017, additional funding allowed Helpline hours to be extended to 9am-7.30pm
those seeking referral to a local support group. Other callers, particularly those impacted by issues of risk or complex psychosocial issues, or those who live in more rural or remote parts of Australia where access to face-to-face services can be difficult, may receive support from the service more regularly, in some instances for weeks or even months. Callers who are experiencing complex psychosocial factors and require this level of intensive support are referred to as ‘high needs’ callers.

High needs callers who reside in Victoria are cared for in the Victorian Intensive Counselling and Service Coordination Program. The program receives additional funding from the Victorian State Government, and is not available in other states. This program is provided by counselling staff with expertise in care coordination, and provides a case management and advocacy service for the most complex and ‘at risk’ callers to the service.

**PEER SUPPORT VOLUNTEERS**

PANDA recruits and trains volunteer peer support workers for the Helpline and also for home visiting and community education activities. Volunteers are recruited through word of mouth, the PANDA website and online volunteer opportunity websites. Volunteers have experienced, or have supported someone who has experienced, perinatal mental illness.

Individuals interested in volunteering with PANDA apply, then attend an information session to better understand what the role entails. Prospective volunteers also undergo an individual interview, and police and referee checks. Successful telephone support volunteer applicants then undertake a two stage training process; stage one involves 24 hours of group education

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6 In line with best recovery oriented mental health practice, this term has been replaced with ‘callers needing intensive support’

7 An Intensive Counselling and Service Coordination service is now offered in an Adelaide Primary Health Network catchment area

8 Home visiting services are no longer offered

9 No longer part of volunteer recruitment
delivered over an eight week\(^{10}\) period, and stage two includes observing experienced volunteers and/or counsellors on the Helpline until the individual volunteer displays readiness to conduct their first phone call. The education provided to volunteers focuses on perinatal mental health, loss and grief, transition to parenthood, family of origin, attachment theory, the Helpline systems and processes, counselling skills, risk assessment, organisational values, and strategies for self-care. All volunteers on the Helpline are required to complete a two day Applied Suicide Intervention Skills training (ASIST)\(^{11}\). A volunteer coordinator is present to support volunteers on the Helpline at all times.

PROFESSIONAL COUNSELLING STAFF

Professionally trained counsellors are also employed by PANDA to provide telephone counselling as part of the Helpline services, and have qualifications in psychology, counselling, social work or similar. All counselling staff undergo police and referee checks, and complete a two day Applied Suicide Intervention Skills Training (ASIST)\(^{12}\).

At the time of the study there were a total of 40 telephone support volunteers and 12 telephone counsellors working on the Helpline.

HELPLINE CALL PROCESS

When an individual phones the Helpline for the first time (or re-engages after a period of non-contact) a member of staff completes a hard copy caller intake form (Figure 1). This form includes details such as: the caller’s name and contact details (although a caller may choose to remain anonymous); gender; state of residence; if the caller is pregnant and/or has children; mental health history; if the caller is already linked with mental health services or

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\(^{10}\) Now 6 weeks

\(^{11}\) No longer a requirement for volunteers – counsellors still undertake this training

\(^{12}\) Core training has now been extended to include more information relating to trauma-informed practice and family violence
supports; risk of harm to self or others; and the reason/s for the call. The form includes a combination of checkbox and free text data, and aims to identify callers who may be at high or immediate risk and require crisis assistance; facilitate an understanding of what made the caller ‘pick up the phone’ and seek assistance; and help to prioritise service delivery. In most instances the caller will receive a call back from PANDA the same day to conduct an ‘initial call’, which includes a full biopsychosocial and risk assessment. If, however, the caller is identified as being at high or immediate risk of harm to themselves or others at this first point of contact, the call is immediately taken by a senior counsellor.

All calls to and from the Helpline, with the exception of caller intake forms, are documented in the Helpline database by counsellors and volunteers. This enables both quantitative and qualitative call data to be recorded. Data are recorded using checkboxes in the quantitative database, which are used to record the caller’s demographic characteristics; psychosocial and risk assessments; existing support and interventions; and any interventions and referrals made by PANDA. At the same time, a more detailed record of the caller’s ‘story’ and the assessment and planning process are entered onto the qualitative part of the database.

THESIS AIMS

The Perinatal Anxiety & Depression Helpline has not been evaluated since it was first launched in 2010. The aim of this thesis is to conduct an exploratory, descriptive study of the Helpline, including: identification of caller demand and characteristics over time; reasons for contacting the service; caller experiences of receiving Helpline support; and volunteers’ experiences of providing peer support. These aims will be discussed further in Chapter Five.

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13 There have been substantial changes to the initial call process since the time of data collection, which is detailed further in Chapter Ten.
FIGURE 1: HELPLINE CALL PROCESS

Individual calls PANDA Helpline
Call received by Intake Worker
Basic information collected and initial risk assessment

Mild-moderate needs
(no identified risk)

- Absence of
  - suicide plan or intent
  - acute mental health crisis
  - family violence
  - drug or alcohol use
  - self-harm
  - child safety concerns

* eligible for PANDA initiated follow up

Moderate-severe needs
(low-medium risk)

- Risk identified in one or all areas of risk/complexity, including
  - social isolation
  - culturally and linguistically diverse (CALD)
  - limited support
  - suicide risk
  - self-harm risk
  - acute mental health crisis
  - child safety concerns
  - drug and alcohol use
  - family violence
  - inadequate care

* moderate-severe needs callers residing outside Victoria are not eligible for PANDA initiated follow up although they may proactively maintain contact with the Helpline

Moderate-severe needs
(high/immediate risk)

- Risk of harm to self or others assessed as high or immediate

Call is taken immediately by a senior counsellor

*once high/immediate risk of harm has resolved caller will move to a mild-moderate or moderate-severe pathway

Return phone call made, most commonly by a counsellor, although sometimes by a volunteer depending on the requirements of the caller and the competency of the volunteer

Biopsychosocial and risk assessment undertaken and referrals made as appropriate

Follow up calls made as necessary

Low-moderate needs calls made by volunteers
Moderate-severe needs calls made by counsellors

*Callers may change pathways depending on what is happening for them at that time, e.g. a risk of self-harm may present for the first time
... She has saved my life. She's helped me stay focused, be kind to myself, accepting of the journey (and its corners!) and has shown me that I know what to do.... PANDA have always provided me with the validation I needed to work through the complexities of birth trauma and childhood trauma in conjunction with my GP, psychologist and psychiatrist.

33 year old woman. Participant in Sub-study three - quote concluded from beginning of chapter
Chapter Three
Review of the Literature

This chapter aims to provide a broad context for the thesis. An overview of relevant literature is presented that highlights the limitations of current knowledge in the areas the thesis aims to address. Further discussion of the literature can be found in each of the publications included in the thesis.

Perinatal Mental Health

Mental disorders are one of the most common morbidities women experience in pregnancy and the year following birth, with a range of mental health difficulties occurring in the perinatal period (Howard, Molyneaux, et al., 2014). Although disorders across the diagnostic spectrum can occur, for a long time focus in research and practice has remained on postnatal depression, with far less attention paid to mental health during pregnancy, and the importance of other mood disorders such as anxiety (Howard, Molyneaux, et al., 2014; Wenzel, 2011). There thus remains much more known about postnatal depression than any other mental disorder in the perinatal period, although this is beginning to change (Wenzel, 2011), with increasing evidence to demonstrate significant morbidity relating to other mental health disorders in the perinatal period (Howard, Molyneaux, et al., 2014).

Anxiety and depression are the most commonly occurring mental disorders in the perinatal period (Howard, Molyneaux, et al., 2014), and are often co-occurring (Austin et al., 2010; Falah-Hassani, Shiri, & Dennis, 2017). Depressive disorders are characterised by features such as depressed or persistent low mood, loss of interest or pleasure in activities, and low energy (American Psychiatric Association, 2013; World Health Organization, 1992). Anxiety disorders appear just as common, if not more so, than depressive disorders, and are characterised by features such as excessive worry and fear (American Psychiatric Association, 2013; World Health Organization, 1992).
Health Organization, 1992). Although less common than anxiety and depression, women may also experience eating disorders, post-traumatic stress disorder (PTSD), personality disorders (Howard, Molyneaux, et al., 2014), or severe mental illness including bipolar disorder, schizophrenia, and affective psychosis (Jones, Chandra, Dazzan, & Howard, 2014), with research indicating that most women with schizophrenia and bipolar disorder do have children (Howard, Kumar, & Thornicroft, 2001).

PREVALENCE OF PERINATAL MENTAL DISORDERS

Although specific estimates regarding the incidence and prevalence of perinatal mood disorders vary, there is wide agreement that these problems are common, and are critical public health issues (Austin, Hightet, & Expert Working Group, 2017; Howard, Piot, & Stein, 2014; Stein et al., 2014). Estimates vary due to large differences in data collection methods used, such as differences in screening tools, whether a diagnostic interview was completed, variation in cut-off points, and the use of point or period prevalence. There has also been inconsistent definitions of perinatal depression and anxiety used by both researchers and clinicians, adding to this confusion (Gaynes et al., 2005).

A highly cited systematic review found a period prevalence of major and minor depression in pregnancy of 18.4%, and 19.2% in the first three months postpartum (Gavin et al., 2005). This is similar to an Australian population based survey of 4,366 women, which found (using the DASS-21 [21 item] Depression Anxiety Stress Scale) that at six months postpartum, 17.4% of women screened positive for depression symptomatology, 12.7% for anxiety, and 8.1% for comorbid depression and anxiety (Yelland, Sutherland, & Brown, 2010).

A recent British study identified a higher population prevalence of perinatal mood disorders in early pregnancy than has been found in previous studies (Howard et al., 2018). This study aimed to investigate the prevalence of mental health disorders in early pregnancy, as well as the diagnostic accuracy of two screening tools; the Edinburgh Postnatal Depression Scale
(EPDS) (Cox, Holden, & Sagovsky, 1987) and the Patient Health Questionnaire 2 (PHQ-2[Whooley]) (Whooley, Avins, & Browner, 1997). The study has two strengths that are not common in population-based studies of perinatal mental health; all women recruited to the study (regardless of screen negative or positive) underwent a Structured Clinical Interview DSM-IV (SCID) (First, Spitzer, Sickel, Gibbon, & Williams, 2002; Zanarini, Frankenburg, Sickel, & Yong, 1996), and women who did not speak English were able to be included in the research through the use of interpreters. The study included 545 women, and the weighted estimation indicated a population prevalence of any disorder identified by the SCID interview to be 27%. Overall, 11% were diagnosed with depression; 15% an anxiety disorder; 2% obsessive-compulsive disorder; 2% eating disorders; 0.3% bipolar disorder I; 0.3% bipolar disorder II; and 0.7% borderline personality disorder. The study found that one in four women at midwifery ‘booking’ appointment met diagnostic criteria for a mental health disorder, a higher prevalence than previous studies have identified, however the study only included one maternity site in inner city London.

Although less common than other disorders, the perinatal period is associated with an increased risk of severe mental disorders, such as bipolar disorder, schizophrenia, or affective psychosis (Jones et al., 2014; Wisner et al., 2013). These disorders may occur as a continuation of an existing illness, or new onset soon after birth (Jones et al., 2014). Research reviewing the rate of postnatal psychiatric hospital admission indicates that one to two women per 1000 giving birth will experience postpartum psychosis (Kendell, Chalmers, & Platz, 1987; Munk-Olsen, Laursen, Pedersen, Mors, & Mortensen, 2006; Terp & Mortensen, 1998), however there is some uncertainty relating to these figures, as some women with postpartum psychosis may be treated at home, especially if a joint mother baby admission is not possible (Jones et al., 2014).
Although the perinatal period is considered to include pregnancy and the first 12 months following birth, a literature review by Goodman (2005) reports that a significant number of women continue to experience depression well beyond the first 12 months postpartum. This review suggests depressive symptoms that persist beyond the first months after birth will often remain throughout the first year, and in some cases into the second year. Factors associated with depression from six months to two years postpartum included maternal health problems, lower socioeconomic status, poor social support, life stress, depression during pregnancy, and partner relationship difficulties.

Longer term impacts of perinatal depression are also supported by the Maternal Health Study, a more recent Australian, prospective longitudinal cohort study of 1507 nulliparous women (Woolhouse, Gartland, Mensah, & Brown, 2014). Participants were recruited to the study during their pregnancy and completed questionnaires at three, six, 12 and 18 months postpartum, and again at four years postpartum. Using an EPDS score of $\geq 13$, 31% of women reported depressive symptoms at some point during the study period, with 22% reporting symptoms during pregnancy and/or the first 12 months following birth. The highest prevalence of depressive symptoms was identified at four years postpartum, with 14% of women reporting symptoms. Women were more likely to report depressive symptoms at four years if they had previously reported symptoms in pregnancy or the first 12 months after birth, experienced stressful life or social events, were aged 18-24 years at recruitment, experienced intimate partner violence, or had a low income.

These findings challenge the assumption that the most ‘at risk’ time for a woman’s mental health is during pregnancy and the first 12 months postpartum, and contribute to the evidence suggesting women may not overcome mental health challenges if their experiences of social adversity are not also addressed (Yelland et al., 2010).
A range of psychosocial factors have been identified as contributing to poor mental health in the perinatal period, including a lack of partner support (Biaggi et al., 2016; Lancaster et al., 2010); a lack of social support (Biaggi, Conroy, Pawlby, & Pariante, 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); a history of abuse or domestic violence (Biaggi et al., 2016; Howard, Oram, Galley, Trevillion, & Feder, 2013; Lancaster et al., 2010; Leigh & Milgrom, 2008); a personal history of mental illness (Biaggi et al., 2016; Dennis, Falah-Hassani, Brown, & Vigod, 2016; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); unintended pregnancy (Biaggi et al., 2016; O’Hara & McCabe, 2013); adverse life events and high perceived stress (Biaggi et al., 2016; Dennis et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); past and present pregnancy complications (Biaggi et al., 2016; O’Hara & McCabe, 2013); and low self-esteem (Biaggi et al., 2016; O’Hara & McCabe, 2013).

A history of mental illness has been found to be one of the strongest predictors of poor mental health in the perinatal period (Biaggi, Conroy, Pawlby, & Pariante, 2016; Dennis, Falah-Hassani, Brown, & Vigod, 2016; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013). The Victorian Intergenerational Health Cohort Study (VIHCS), a 20 year prospective cohort study, was able to assess the relationship between mental health problems in adolescence, early adulthood, and perinatal depression (Patton et al., 2015). Three-hundred and eighty four women with 564 pregnancies were included in the analysis, of whom 253 (66%) had a history of mental health problems at some time in adolescence, young adulthood, or both. Women with a history of mental health problems were far more likely to report symptoms of perinatal depression (EPDS score >10); of the 109 pregnancies where depressive symptoms were reported, 85% had a history of mental health problems prior to pregnancy.
Stressful life events and poor social health are also common in the perinatal period, and women who report three or more social health issues are far more likely to experience postnatal anxiety or depression when compared to women who do not report this number of issues (Yelland et al., 2010). Nearly half of the 4,366 women in an Australian population-based survey reported stressful life events or social health issues in the six months following birth (Yelland et al., 2010). The authors caution that traditional approaches to treating perinatal mental health issues may be ineffective if concurrent social health issues are not properly addressed.

A past or current history of abuse is known to be another important risk factor for poor mental health in the perinatal period. A systematic review identified that women who experience childhood abuse are more likely to develop anxiety and depression during pregnancy, beyond the increased life-time risk of mental disorders resulting from childhood abuse (Biaggi et al., 2016). The same review identified that experiencing past or current intimate partner violence (IPV), as well as past or current emotional, physical, or sexual abuse, all increased the risk of a woman developing anxiety or depression during her pregnancy.

Research indicates up to 20% of women experience intimate partner violence in the perinatal period (Devries et al., 2010; Gazmararian et al., 1996; Walsh, 2008), and in addition to poorer mental health outcomes this can also have a negative impact on the woman’s experiences of early motherhood (Hooker, Samaraweera, Agius, & Taft, 2016). Another systematic review exploring the relationship between domestic violence and perinatal mood disorders found that women who had experienced domestic violence were more likely to experience high levels of depressive, anxiety, and PTSD symptoms both in pregnancy and following birth (Howard et al., 2013).

These findings are supported by a Melbourne longitudinal study of 1507 nulliparous women published after the systematic review by Howard et al. (Gartland et al., 2016). Childhood
abuse was reported by 41% of the women in this study. A total of 28% of women reported experiencing IPV, 25% depression, and 32% anxiety in the first four years following birth. The study found that women who had experienced childhood sexual abuse were more than twice as likely to experience IPV in their pregnancy and the early postpartum period, and women who experienced any childhood abuse were more likely to report poor mental health than women who had not experienced maltreatment.

IMPACT ON WOMEN AND FAMILIES

There is increasing recognition of the impact perinatal mental health may have on the entire family unit, including increasing the chance of paternal depression (Paulson & Bazemore, 2010; Wee, Skouteris, Pier, Richardson, & Milgrom, 2011), and psychological and developmental issues in children (Stein et al., 2014). Most evidence relating to the impact of maternal mental health and child outcomes is specific to anxiety and depression, with far less research exploring less common disorders such as bipolar or personality disorders (Stein et al., 2014).

Perinatal depression and anxiety have been linked with premature birth and low birthweight (Ding et al., 2014); impaired maternal-infant interactions; cognitive, attention and expressive language problems (Field, 2010), and negative maternal perceptions of infant behaviour (Stein et al., 2014). Women with postpartum depression are less likely to be sensitive to their infant’s needs, use harsh punishments, and experience thoughts of harming their child (Field, 2010). Negative impacts on children are, however, not inevitable; Stein et al. (2014) note that available research shows moderate or small effect sizes for associations between parental mood disorders and child outcomes, and that risk of harm to children is greatest when other factors are present, such as low socioeconomic status and absence of social support.

Perinatal mental disorders are also associated with other, but less common, adverse outcomes, such as self-harm (Wisner et al., 2013), suicide (Gavin, Tabb, Melville, Guo, &
Katon, 2011; Humphrey, 2016; Onah, Field, Bantjes, & Honikman, 2017; Thornton, Schmied, Dennis, Barnett, & Dahlen, 2013), and risk of harm to children (Field, 2010; Stein et al., 2014).

There is limited information available on suicidality and self-harm in the perinatal period. A study conducted in the United States of America (USA) screened 10,000 women by telephone four to six weeks following birth using the EPDS (Wisner et al., 2013). Overall 14% screened positive (EPDS score $\geq 10$), who were then offered home visit psychiatric diagnostic assessment using SCID DSM-IV. Of the overall sample, 3.2% disclosed thoughts of self-harm, with 84.6% of these women also screening positive on the EPDS. Women who completed a diagnostic interview were most likely to be diagnosed with a unipolar depressive disorder (68.5%), however the authors describe their finding of 22.6% of women having a bipolar disorder as ‘striking’ (Wisner et al., 2013, p. 490), a further demonstration that more serious mental illnesses are not uncommon in the perinatal period.

The World Health Organization World Mental Health surveys identified a lifetime prevalence of suicidal ideation to be 9.2%; with 3.1% having made a plan, and 2.7% having attempted suicide (Nock et al., 2008). It was previously thought that pregnancy and the early postpartum period acted as protective factors against suicidality, however this is no longer thought to be the case (Gavin, Tabb, Melville, Guo, & Katon, 2011). A longitudinal study of 2,159 women conducted in the USA found 2.7% had experienced thoughts of suicide in pregnancy (Gavin et al., 2011). Of the women reporting suicidal ideation, 52.5% screened positive for probable antenatal depression, and 15.7% for probable antenatal panic disorder. Assessment of psychosocial factors indicated that women were more likely to report thoughts of suicide and screen positive for antenatal major depression and panic disorder if they had less years of education, smoked, reported a high number of chronic health conditions, a high level of psychosocial stress, and domestic violence (Gavin et al., 2011).
Another smaller USA cross-sectional study of 166 women explored the relationship between antenatal suicidality and experiences of intimate partner violence (Alhusen, Frohman, & Purcell, 2015). The women in the study were mostly single, low-income earners, and African-American. A high rate of intimate partner violence was identified, almost 20%, and 23% of the sample reported suicidal ideation during their current pregnancy. Both and EPDS score >12 and experience of IPV were found to be significant predictors of suicidality; women were more than nine times more likely to report suicidal ideation if they were experiencing IPV, and more than 17 times more likely if they had an EPDS score > 12.

Maternal mortality has decreased over time in Australia, however deaths due to psychosocial causes have increased, with most attributed to suicide (Humphrey, 2016). In 2006 to 2010, ‘psychosocial morbidity’ was the second highest cause of indirect maternal death in Australia, defined as a psychiatric condition contributing to the cause of death, and includes wider issues such as domestic violence and substance misuse (Johnson, Bonello, Li, Hilder, & Sullivan, 2014). A New South Wales data linkage study identified that 31% of maternal deaths in the year following birth during the study period (1 July 2000 to 31 December 2007) were caused by suicide. Of the women who died as a result of non-medical causes, 67% had a documented history of substance abuse and/or a mental health diagnosis (Thornton et al., 2013). Seventy three percent of the women in this study who committed suicide did so by violent means, such as jumping from a high place, suffocation, or gunshot, a feature which, although uncharacteristic of female suicide at other times, has been identified in other Australian (Austin, Kildea, & Sullivan, 2007; Johnson, Bonello, Li, Hilder, & Sullivan, 2014) and international studies reporting on maternal suicide (Centre for Maternal and Child Enquiries (CMACE), 2011).
IDENTIFICATION AND HELP-SEEKING

Although anxiety and depression are common in the perinatal period (Gavin et al., 2005; O’Hara & Wisner, 2014; O’Hara & Swain, 1996), clinical recognition and treatment of perinatal mood disorders remains poor, with research indicating up to three quarters of women with anxiety and/or depression are not identified by health care providers (Coates et al., 2004; Spitzer et al., 2000). Many women do not seek help (Dennis & Chung-Lee, 2006; Gavin, Meltzer-Brody, Glover, & Gaynes, 2015; Woolhouse, Brown, Krastev, Perlen, & Gunn, 2009). Of the women in the Victorian Maternal Health Study, only half of those who reported symptoms of anxiety and/or depression had sought help from a health professional (Woolhouse, Brown, Krastev, Perlen, & Gunn, 2009). The study highlighted under-reporting of anxiety symptoms in particular; only 25% of women reporting just anxiety symptoms had sought help from a health professional, in contrast to 46% of women reporting symptoms of depression, or 64% of women reporting co-occurring symptoms of anxiety and depression.

Women reported different reasons for not seeking help, with the most common being a belief that they could deal with their difficulties themselves; being too busy; feeling too embarrassed; or not having anyone with whom they would be comfortable to discuss their experiences. The authors hypothesised that historical emphasis on depression may also help to explain why women appear less likely to seek help for anxiety (Woolhouse et al., 2009).

Other barriers to help-seeking have been identified in the literature, including difficulties related to attending appointments; a lack of awareness of postpartum depression; a perceived lack of time; stigma; being worried about being perceived as unable to cope (Dennis & Chung-Lee, 2006); practical challenges such as lack of transportation; language barriers; financial difficulties (O’Mahony & Donnelly, 2010); poverty; discrimination (O’Mahony & Donnelly, 2013); and a lack of knowledge about what services are available and how to access them (Dennis & Chung-Lee, 2006).
The attitudes of health care providers can also act as a barrier to help-seeking (Dennis & Chung-Lee, 2006). A population-based postal survey of 4,366 recent mothers in Victoria and South Australia identified that only 46% recalled being asked by care providers during pregnancy if they had ever been depressed, and 50% if they were anxious or worried about things in their life (Yelland & Brown, 2014). Even less women recalled being asked about violence in their home (14%), housing problems (13%), or financial worries (17%). Despite this, one in five women in the study (18%) reported significant social adversity (defined by the authors as three or more issues, such as family-related grief or financial adversity). Since 2007 when the data for this study were collected there have been changes in Australian health policy, which now advocates that every woman should be screened for mental health issues and psychosocial risk factors in pregnancy (Austin et al., 2017). It is unclear if these changes in policy have led to more women being asked about their psychosocial health in pregnancy, or an improvement in outcomes. An evaluation of the impact of the National Perinatal Depression Initiative did not identify a statistically significant increase in the number of women accessing publicly-funded (Medicare\(^{14}\)) psychology and psychiatry services between 2006 and 2010, even though the initiative recommended all perinatal health providers begin universal screening for perinatal mood disorders in 2008 (Chambers et al., 2016).

**INTERVENTIONS TO IMPROVE PERINATAL MENTAL HEALTH**

A wide range of interventions have been aimed at the prevention and treatment of perinatal mood disorders. A systematic review of 28 trials identified that psychosocial and psychological interventions, such as interpersonal psychotherapy, individualised postnatal home visits, or peer support, significantly reduce the number of women who develop

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\(^{14}\) Medicare is Australia’s universal health scheme. The program is funded by the Australian government and ensures all Australian citizens, and some overseas visitors, access to a range of health services at little or no cost.
postnatal depression (Dennis & Dowswell, 2013). Much less research has been conducted relating to the prevention of perinatal anxiety (Howard, Molyneaux, et al., 2014). Existing evidence includes support for the use of a brief antenatal cognitive thought behavioural therapy intervention to help reduce postnatal anxiety and depression (Austin et al., 2008), and an antenatal self-guided workbook and weekly telephone support (Milgrom, Schembri, Ericksen, Ross, & Gemmill, 2011).

Psychosocial and psychological interventions have also been found to be effective in treating perinatal mood disorders, however, far more is known about the treatment of depression in the postnatal period than during pregnancy, and even less is known about anxiety and other disorders (Howard, Molyneaux, et al., 2014). All studies included in the Cochrane review of psychosocial and psychological treatments for postnatal depression demonstrated reductions in depressive symptomatology when compared with standard care, and included peer support, interpersonal therapy, and cognitive behavioural therapy (Dennis & Hodnett, 2007).

There is also some evidence to support the use of pharmacological interventions, especially for severe cases. Antidepressants are most commonly used, particularly selective serotonin reuptake inhibitors (SSRI) (Howard, Molyneaux, et al., 2014). However, due to concerns regarding randomised trials involving pharmacological interventions in pregnancy, the only trials conducted to date have been in the postnatal period. The latest relevant Cochrane review includes only six trials, and indicates response to, and remission with SSRIs was significantly better than placebo, however the authors stress that the evidence was very limited and of low quality (Molyneaux, Howard, McGeown, Karia, & Trevillion, 2014).

It is not uncommon for women who have been taking antidepressants prior to conception to discontinue these early in pregnancy, however, this is associated with an increased risk of relapse of depression and suicidal ideation (Cohen et al., 2006; Einarson, Selby, & Koren, 2001), and significant economic costs (O’Brien, Laporte, & Koren, 2009).
It is important to understand women’s individual treatment preferences. Dennis and Chung-Lee (2006) conducted a qualitative systematic review exploring the help-seeking barriers and facilitators for women with postnatal depression, as well as their treatment preferences. From the 40 included studies, the authors found that women preferred non-pharmacological treatment options, and were reluctant to take antidepressant medications due to concerns including side effects, possible addiction and transmission to their baby via breast milk. The authors also found that many women wanted ‘to be given permission to talk in-depth about their feelings, including ambivalent and difficult feelings... to talk with a nonjudgmental person who would spend time listening to them, take them seriously, and understand and accept them for who they are, and... recognition that there was a problem and reassurance that other mothers experience similar feelings and that they would get better’ (Dennis & Chung-Lee, 2006, p. 327). Women expressed the need to feel that the person they were talking to had an understanding of their problem for this reassurance to be effective.

Participants in the Maternal Health Study who had sought help for their mental health most commonly reported emotional support as helpful, particularly as compared to practical support, medication or counselling (Woolhouse et al., 2009). An earlier Victorian study of women’s experiences of depression following childbirth asked women what advice they would give to others having a similar experience, with the most common suggestion being to find someone to talk to (Small, Brown, Lumley, & Astbury, 1994).

**PEER SUPPORT**

There is evidence to suggest peer support can help prevent women from developing depression in the perinatal period (Dennis et al., 2009), and can provide valuable support to women experiencing mental health difficulties (Biggs, McLachlan, Shafiei, Small, & Forster, 2018; Biggs, Shafiei, Forster, Small, & McLachlan, 2015; Dennis & Kingston, 2008; Lavender et
Peer support within mental health services originated from the consumer and recovery mental health movements (Pound, Judd, & Gough, 2011). Driven by principles of social justice and human rights, these movements advocated for change in mental health care, and sought to end the ‘social suppression of difference and [the treatment of] differences through psychiatric diagnosis’ (Mead & MacNeil, 2006, p. 134).

Although there is no universally acknowledged definition of what peer support is, it is generally accepted that a peer is a created source of support internal to a community who shares important similarities with the ‘target population’, such as age, health concern, or stressor (Dale, Caramlau, Lindenmeyer, & Williams, 2008). This peer has developed knowledge through lived experience which allows them to provide support to someone considered an equal (Dale et al., 2008; Dennis, 2003), and may mean they are able to understand the target populations’ experiences or situations in a way that an individual’s established social networks may not (Dennis, 2003).

Dennis goes on to define peer support within the healthcare context as including emotional, informational, and appraisal support as key defining attributes (Dennis, 2003). Emotional support is considered to include attentive listening, reflection, encouragement and expressions of caring, and can act to counteract threats to the self-esteem of the peer receiving support. Informational support includes advice, suggestions, and other factual input to assist the individual overcoming difficulties. This may include help accessing resources, or alternative courses of action. Encouraging the individual to persist, and reassurance that efforts will lead to a positive outcome is considered appraisal support, also known as affirmational support. This component is important as many life stressors are not immediately or easily overcome, so this form of support can help to generate positive future expectations (Dennis, 2003).
Peer volunteers have been included in a number of health interventions and services, including supporting people with chronic pain (Arnstein, Vidal, Wells-Federman, Morgan, & Caudill, 2002); supporting refugee women (Liamputtong, Koh, Wollersheim, & Walker, 2016); breastfeeding women (Dennis, 2002; Dennis, Hodnett, Gallop, & Chalmers, 2002; Forster et al., 2014); supporting mothers who are disadvantaged (McLeish & Redshaw, 2017); or HIV positive (McLeish & Redshaw, 2016, 2017); and for the prevention (Dennis et al., 2009) and treatment of perinatal mental health issues (Caramlau, Barlow, Sembi, McKenzie-Mcharg, & McCabe, 2011; Dennis et al., 2009).

It is important that peer support interventions for mental health are evaluated, and that peer volunteers are included in this evaluation process (Dennis, 2013; Salzer & Shear, 2002). This is important as there is not the same distinction between care provider and service recipient that there is in more traditional forms of mental health care (Salzer & Shear, 2002), and the success of any peer delivered service depends on dedicated and adequately supported peer support volunteers (Dennis, 2013). It has also been suggested that the ongoing support and supervision offered to peer support volunteers may be just as important as their initial training. Ongoing support may help volunteers to cope with some of the challenges of their role, including emotional distress, and help to protect them from potential harmful or negative aspects of volunteering (Fisher et al., 2014).

Despite this, there have been very few studies to date that have explored the views and experiences of volunteers providing peer support in the perinatal period. Available studies report a high level of peer volunteer satisfaction (Boyle, Mutch, Barber, Carroll, & Dean, 2015; Dennis, 2013; McLeish & Redshaw, 2015). An Australian cross-sectional study explored the experiences of 24 telephone peer supporters providing parents with support following pregnancy loss with SANDS (Stillbirth and Newborn Death Support), a 24 hour support service run mostly by volunteers (Boyle et al., 2015). The study found that peer supporters were
motivated to volunteer by personal experiences of perinatal loss, and a desire to ensure all parents experiencing perinatal loss have access to timely and responsive support. Along with high levels of satisfaction, volunteers reported that it was sometimes difficult to balance their voluntary role with other commitments, such as paid work and parenting, as well as a strong desire for additional training (Boyle et al., 2015).

A Canadian RCT exploring the effects of individualised proactive telephone peer support included an evaluation of the peer volunteers’ experiences (Dennis et al., 2009). The volunteers reported high levels of satisfaction, that they felt adequately prepared for the role, and that providing peer support had allowed them to grow as an individual (Dennis, 2013). Personal growth resulting from providing volunteer peer support was also highlighted by SANDS volunteers, who reported that their role had helped them to give further meaning to their personal experiences of perinatal loss (Boyle et al., 2015).

TELEPHONE INTERVENTIONS

Peer support can be provided in a range of settings through varying modes of interaction, such as home visiting services, support groups, or telephone-based support (Dennis, 2003). Many telephone-based interventions are used in maternity care (Lavender et al., 2013), including volunteer peer support telephone helplines for breastfeeding and perinatal mental health support (Dale et al., 2008), with predictions that global resource shortages are likely to further encourage their use (Lavender et al., 2013). Telephone support may be ‘passive’, in which support is only available when requested or initiated, or it may also be offered proactively (Lavender et al., 2013).

Telephone-based health support has been identified as a way to overcome barriers to care such as geographical isolation (Lavender et al., 2013; Ugarriza & Schmidt, 2006) as it may be more accessible and available than face-to-face support (Dale et al., 2008). Some women
may, however, find it difficult to access telephone support, such as those with language barriers (Dennis & Kingston, 2008).

A small number of studies have explored the effectiveness of telephone supports, including peer support, to prevent or treat maternal postnatal depression and anxiety. A multisite randomised controlled trial (RCT) by Dennis et al. (2009) explored the effect of proactive individualised telephone peer support on the prevention of postnatal depression among women identified as being at high risk of developing postnatal depression; 14% of women in the intervention group had an EPDS score >12 at 12 weeks postpartum, compared with 25% of women in the control group. Maternal satisfaction with the intervention was also high, with 92% reporting that they liked their peer, and 83% stating that they would recommend the support to a friend. Milgrom et al (2011) conducted an RCT to examine the effectiveness of an antenatal intervention aiming to reduce postnatal symptoms of depression and anxiety and parenting difficulties. The intervention included a nine-unit self-guided workbook and weekly telephone support sessions conducted by a psychologist or trainee psychologist in which the content of that week’s module would be discussed. Women in the intervention group had significantly lower levels of depression and anxiety post treatment. Due to the nature of the intervention it is not possible to assess the effectiveness of the telephone intervention separately from the self-guided workbook.

RATIONALE FOR THIS STUDY

The use of telephone supports in the perinatal period, including telephone peer support, has been increasing, however there have been limited studies conducted with community based consumer led telephone support services, such as PANDA. The Perinatal Anxiety & Depression Helpline has not been evaluated since it was first launched in 2010, presenting an important opportunity to better understand Helpline service provision, patterns in service demand, and the characteristics of callers to the Helpline. It has been argued that it is important to conduct
research with community organisations, as this thesis has done, as it begins to address knowledge gaps relating to the real world application of public health knowledge (Israel, Schulz, Parker, & Becker, 1998).

SUMMARY

A significant number of women will experience mental health issues in the perinatal period. Depression and anxiety are the most common disorders, however many women with a more serious mental illness will become mothers. A number of psychosocial factors have been found to increase the likelihood of a woman developing a psychiatric condition in the perinatal period, including past or current experiences of abuse or family violence, social isolation, limited partner support, and a negative or traumatic birth experience. Telephone peer support and counselling is a promising intervention to improve women’s mental health in the perinatal period. Telephone support is flexible, and may help to overcome barriers to care including stigma, geographical isolation, and limited financial resources. To date, very little research has been conducted with existing community based perinatal mental health services, and few evaluations of peer support interventions have included the experiences of those providing peer support.
I felt ashamed...
I still haven't told many of my friends what I went through
Chapter Four
Theoretical Perspectives

The purpose of this chapter is to provide a theoretical framework for the thesis. These theories will be drawn on in Chapter Ten to help facilitate discussion of the key study findings and conclusions.

INTRODUCTION

There are a number of social theories relevant to women’s mental health, peer support, and the provision of support to individuals experiencing emotional distress and adversity. This chapter will discuss some of these theories, namely Feeney and Collins’ *Thriving Through Relationships* (Collins & Feeney, 2000; Feeney & Collins, 2015a, 2015b), Batson’s *Empathy-Altruism Hypothesis* (Batson, 1991; Batson et al., 1991; Batson, Ahmad, Lishner, & Tsang, 2002), and Riessman’s *Helper Therapy Principle* (Riessman, 1965). These theories explore concepts relating to human thriving in circumstances with and without adversity, the role of empathy and altruism in human behaviour, and how helping others may facilitate personal wellbeing and growth.

SOCIAL RELATIONSHIPS AND WELLBEING

Access to caring relationships is associated with health and wellbeing across the life span (Feeney & Collins, 2015a). A systematic review of 70 prospective studies found social isolation and loneliness increases the likelihood of mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015), and a lack of social support is known to increase a woman’s chance of developing perinatal anxiety and depression (Biaggi et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013).
Although there is considerable knowledge relating to social support and mental and physical health outcomes, very little is known about how relationships actually contribute to positive health outcomes (Feeney & Collins, 2015a; Uchino, Bowen, Carlisle, & Birmingham, 2012). To attempt to address this gap, Feeney and Collins (2015a, 2015b) have developed a theoretical model to explain the behaviours and interaction patterns that can help or hinder individual wellbeing. Based on attachment theory’s understanding of a safe haven and secure base support (Bowlby, 1988), the model aims to understand how relationship support during stressful and non-stressful times in a person’s life can contribute to wellbeing (Feeney & Collins, 2015a, 2015b). The model builds on three literatures; the positive wellbeing literature, social support literature, and close relationship literature. The majority of social support literature to date has focused on the provision of social support for the purposes of buffering stress during times of adversity, however, the model argues that support-providers can achieve a lot more than just assisting someone to return to ‘baseline levels of functioning’ (Feeney & Collins, 2015a, p. 118).

The concept of ‘thriving’ is used to explain the end point of support, which is a holistic understanding of wellbeing that includes more than just the absence of illness (Feeney & Collins, 2015a). The authors use five components to describe thriving: Hedonic wellbeing, which includes happiness, life satisfaction, and subjective wellbeing; Eudaimonic wellbeing, such as having purpose and meaning in life, autonomy and self-determination; psychological wellbeing, which includes positive self-regard and self-acceptance, and the absence or reduction in mental health symptoms or disorders; social wellbeing, which can include deep and meaningful human connection, high perceived social support, and; physical wellbeing, which includes an absence or reduction in illness and disease, and physical fitness. This multidimensional model allows for an understanding of thriving as a continuum which is relative to the individual’s unique circumstances, rather than an ‘all or none’ state.
Thriving in situations with and without adversity

Thriving in situations of adversity is more than simply surviving or avoiding potentially negative consequences of the adversity; it involves a process of growth and development, leading to the individual emerging from the experience as a ‘stronger and more knowledgeable person’ (Feeney & Collins, 2015a, p. 115). Through this process of growth and development, individuals who experience adversity are therefore able to develop something useful and constructive from the experience, which in turn improves their wellbeing. In situations without adversity, an individual thrives by making a meaningful contribution to community and society, through the ability to fully participate in fulfilling opportunities such as work, socialising, discovery, hobbies, creating, and learning. For an individual to be ‘maximally thriving’, they would thrive well in both the absence and presence of adversity (Feeney & Collins, 2015a, p. 116).

Relational support in times of adversity

Relationships are central to Feeney and Collins’ model, which argues that well-functioning and responsive close relationships facilitate thriving by helping an individual successfully cope with adversity, and take advantage of opportunities for growth and fulfilment in situations without adversity (Feeney & Collins, 2015a). Provision of support during times of adversity, defined as Source of Strength (SOS) support, includes four support functions. The first is to provide a safe haven, a concept first developed by Bowlby (1988) within attachment theory. This involves facilitating a safe refuge and relief from experiences and burdens relating to the adversity (Bowlby, 1988; Collins & Feeney, 2000), which includes providing an environment where the person is comfortable to express negative emotion (Spiegel & Kimerling, 2001), and responding to those expressions with emotional comfort, reassurance, understanding, and instrumental aid (Feeney & Collins, 2015a). Thriving, rather than simply coping or surviving adversity, is achieved through a process of fortification focused on developing the
individual’s strengths and abilities related to responding to the adversity. Importantly, this may include simply pointing out existing strengths that the individual may not have been able to recognise, or helping to build new strengths. Following the fortification process, SOS support assists with the reconstruction process, a process of motivation aimed at helping the individual to use their strengths for positive action focused on rebuilding. This rebuilding process requires the adversity to be reframed or redefined, which is the final support function involved in SOS support. This support helps the individual to see the adversity in a new light, so that it can be seen as less threatening and able to be overcome, laying the foundations for the possibility of thriving through the experience, rather than simply surviving (Feeney & Collins, 2015a).

Provision of SOS support therefore assists someone to grow or thrive through their experiences of adversity, which is a broader understanding of relational support through times of adversity than has been offered by social support theories historically, which have instead focused on buffering the negative effects of adversity (Feeney & Collins, 2015a). Feeney and Collins’ model also helps to explain the role of social isolation in poor perinatal mental health. Poor quality or a lack of SOS support may extend the period of time someone is distressed, reduce resilience, and prevent growth from experiences of adversity, leading to a failure to thrive due to social isolation or poor quality relational support (Feeney & Collins, 2015a).

There are a number of immediate outcomes predicted as a result of SOS support: changes to emotional state, such as a decrease in fear, anxiety, and despair; altered self-evaluations and self-perceptions, such as increased self-acceptance and self-compassion; altered appraisals of the adversity, including the belief that it can be dealt with successfully; improved motivational state, such as a motivation to make changes and begin rebuilding; improvements in coping strategies, self-regulation and problem solving; altered expectations and attitudes, such as
feelings of trust and of feeling accepted and cared for; altered neural activation and physiological functioning associated with a reduction in stress responses, such as adaptive immune, endocrine and cardiovascular functioning, and; improved health and lifestyle behaviours, such as better self-care, nutrition, and sleep quality (Feeney & Collins, 2015a, 2015b).

APPLICATION TO THIS THESIS

Feeney and Collins’ theory of Thriving Through Relationships is relevant to this thesis in a number of ways. Firstly, it provides a deeper understanding of how social isolation and poor quality partner relationship may contribute to poor emotional health in the perinatal period, since access to responsive, close relationships and the provision of SOS support is important for someone to thrive in the face of adversity.

The model also provides insights relating to callers’ descriptions of the support they receive when they call the Helpline, discussed further in Chapter Eight, including feeling that PANDA volunteers and counsellors were kind and non-judgemental, created a safe space for callers to discuss their experiences, helped them to reframe their understandings, and feel more able to overcome difficulties. Callers to the PANDA Helpline may only speak with a particular volunteer or counsellor once, therefore often there is no opportunity for the development of an ongoing relationship. Feeney and Collins’ (2015a, 2015b) model was developed to explain the role of close ongoing relationships on an individual’s thriving (i.e. partner, close friends and family), however, the authors stress that supporting another’s thriving does not necessarily require a large investment of time and energy, and that many of the key behaviours involved, such as communicating availability and providing encouragement, are simple to provide (Feeney & Collins, 2015a). In this way, the model remains very relevant to this study.
In addition to this, the model’s explanation of thriving in situations of adversity is applicable to both callers and volunteers providing peer support on the National Perinatal Anxiety & Depression Helpline, which is discussed further in Chapters Four, Eight and Nine. Volunteers in this context are a powerful example of individuals who have managed to thrive through personal experiences of perinatal mental illness, and have become stronger and more knowledgeable individuals, constructing something useful from their experience which they have decided to use to support others.

EMPATHY, ALTRUISM, AND RESPONSIVE BEHAVIOUR

Successful peer support interventions are reliant on dedicated and capable volunteers, so it is important to understand what motivates individuals to volunteer to provide this kind of support. The Empathy-Altruism Hypothesis attempts to answer the question of why we help others (Batson, 1991). The majority view in Western philosophy and psychology, known as universal egoism, is that everything we do, even if it benefits others, is done with the ultimate goal of benefiting ourselves (Batson, 1991). In contrast to this, the Empathy-Altruism Hypothesis proposes that some people, at least at times and under certain circumstances, are capable of a form of motivation with the ultimate goal of benefiting someone else (Batson et al., 2002). The hypothesis acknowledges that a person may benefit from helping another, however the motivation for this helping would still be considered altruistic if these self-benefits are an unintended consequence rather than the ultimate goal (Batson & Shaw, 1991).

The hypothesis describes empathic emotion as a source for altruistic motivation; that is, motivation with the ultimate goal of helping another. Batson and colleagues define empathy as ‘an other-oriented emotional response elicited by and congruent with the perceived welfare of someone else’ (Batson et al., 2002, p.486). They go on to suggest that if the other is considered to be in need, empathic emotions including sympathy, compassion, and
tenderness are experienced. The greater the empathic emotion experienced, the greater the altruistic motivation. It is possible however for altruistic and egoistic motives to coexist, as an individual may have more than one goal at any given time, and therefore more than one motive (Batson & Shaw, 1991).

Building on Batson’s work, Winczewski and colleagues (2016) explore the concepts of empathic concern and empathic accuracy. Their study tests the assumption that someone is able to be more caring and responsive to someone in need when they accurately understand the individual’s thoughts, feelings and needs. Empathic accuracy provides someone with knowledge regarding how to be responsive to another’s needs, in contrast to empathic concern, which motivates people to want to be responsive. The study identified that the effect of empathic accuracy on an individual’s behaviour was dependent on the presence of compassionate motivation; ‘empathic accuracy can facilitate responsive behaviour, but only when perceivers are motivated to use their insight for benevolent goals. In the absence of empathic concern, empathic accuracy may be unhelpful (or even harmful)’ (Winczewski et al., 2016, p. 401).

APPLICATION TO THIS THESIS

Batson’s Empathy Altruism Hypothesis provides a useful framework to understand peer support volunteers motivations to join PANDA, and, along with the concept of empathic accuracy, the potential role of lived experience in helping those receiving peer support to feel understood and heard. Feeney and Collins also hypothesise that support providers are most effective when motivated by altruistic concerns, rather than egoistic motivations (2015a), an argument supported by Batson and colleagues (Batson, 1991; Batson et al., 2002; Batson, Bruce, Ackerman, Buckley, & Birch, 1981; Batson & Shaw, 1991), which is relevant to both peer support volunteers and paid professional staff working on the Helpline.
THE HELPER THERAPY PRINCIPLE

Although small in number, past studies of volunteers providing peer support in the perinatal period have reported high levels of satisfaction (Boyle et al., 2015; Dennis, 2013; McLeish & Redshaw, 2015), and in some instances personal growth and development resulting from volunteer experiences (Boyle et al., 2015; Dennis, 2013). Salzer and Shear (2002) identify five theories that could be used to explain the benefits of providing peer support: social comparison theory; social learning theory; social support theories; experiential knowledge; and the Helper Therapy Principle (2002). The Helper Therapy Principle was developed in an attempt to begin to understand the benefits identified for individuals who were helping others (Riessman, 1965). It is noted that helping can be particularly beneficial for individuals with similar problems to those they are helping (Salzer & Shear, 2002). These benefits have been described as: an increased feeling of interpersonal competence due to impacting another’s life; developing a sense of equality in giving and taking between self and others; developing new personally relevant knowledge while helping others; and receiving social approval from the people they help (Skovholt, 1974).

APPLICATION TO THIS THESIS

The Helper Therapy Principle is used to understand the experiences of volunteers providing peer support on the Helpline. Feeney and Collins’ theory of Thriving Through Relationships is also relevant to this discussion, in particular their argument that thriving in situations without adversity is achieved by making meaningful and fulfilling contributions to society, through activities like providing peer support to those in need.
“...I have been not coping for nearly 2 years, on and off. I am not like what I was before this hit me. I have been to the doctor, seen a [counsellor], rang [another helpline] numerous times and it wasn't until I spoke to PANDA that I felt like I was getting anywhere. The fact that PANDA specialises in [perinatal] conditions seems to have made all the difference...Before I rang PANDA I felt like I would have had to be falling completely apart for anyone to listen. I am extremely lucky PANDA listened before I got there.”
Chapter Five
Methodology

This chapter will discuss the philosophical foundations underpinning the mixed methods approach adopted in this study, as well as the rationale for this design choice. The chapter will also discuss the overall study design, which includes two parts, each with two Sub-studies.

MIXED METHODS RESEARCH

Qualitative and quantitative research have been considered by some as incompatible, originating from separate paradigms with vastly different philosophical, epistemological and ontological origins and assumptions (Biesta, 2010; Gorard, 2010; Howe, 1988; Meixner & Hathcoat, 2018; Teddlie & Tashakkori, 2009). This was the basis for the so called ‘paradigm wars’, which positioned the two research traditions as dichotomous and fundamentally incompatible (Biesta, 2010; Meixner & Hathcoat, 2018; Teddlie & Tashakkori, 2009), referred to by some as the ‘incompatibility thesis’ (Howe, 1988). Discussions regarding the supposed incompatibility of qualitative and quantitative research methods have focused on issues of epistemological questions relating to the objectivity or subjectivity of knowledge, and ontological questions regarding the nature of social phenomena (Biesta, 2010; Howe, 1988; Meixner & Hathcoat, 2018).

These arguments have been described as being based on pervasive and faulty assumptions that the terms qualitative research and quantitative research stand for more than simply the kind of data being used, and include ideas about ‘the nature of reality, the limits of knowledge, or the purpose and politics of research’ (Biesta, 2010, p. 100), a sentiment echoed by Gorard, who refers to these assumptions as a divisive ‘sign of scientific immaturity’ (2010, p. 247). The incompatibility thesis rests on the assumption that research of a particular kind, for example research using numbers and statistics, will always be conducted from an
objectivist epistemology, and research using narrative and text will be conducted from a subjectivist epistemology (Biesta, 2010; Howe, 1988). These assumptions have therefore been used to argue against the combination of qualitative and quantitative research methods, since these two epistemological foundations truly are incompatible. Biesta (2010) however, warns that assumptions such as these are both wrong and unhelpful, and encourage oppositions and create ‘quasiproblems’, and scenarios where researchers addressing similar issues from similar philosophical positions may actually think they have nothing to share simply because one is using numbers and the other is using text.

Gorard (2010) advocates a different way of presenting research logic that does not involve the unhelpful and counterproductive dichotomies generated by paradigms, and avoids defining mixed methods as a research design in and of itself, or as a new paradigm. He argues that mixed methods is a logical and ethical response to social science research questions, ensuring the research methods used are driven by the research question itself, which is in turn driven by the research purpose (Gorard, 2010). Research in social sciences should be designed to maximise the chances of generating evidence relating to the research aims, and is responsive to the research context, including the program being evaluated, the data collected, and groups of interest (Gorard, 2010).

**PRAGMATISM AS A PHILOSOPHICAL FOUNDATION TO MIXED METHODS RESEARCH**

It is generally recognised that the rationale for adopting a mixed methods approach to research is a pragmatic one, driven by the particular research questions the research is seeking to answer (Biesta, 2010). Biesta notes that this is an example of *everyday* pragmatism, just as one ‘*would argue that a screwdriver is generally a better tool for fixing a screw than a hammer*’ (Biesta, 2010, p. 96). Building on this foundation, philosophical
pragmatism can be used to help solve potential problems in mixed methods research, including criticisms that qualitative and quantitative methods are incompatible.

Knowledge and truth

Biesta (2010) uses John Dewey’s Theory of Knowledge to demonstrate the contribution pragmatism can make to the mixed methods discussion. Dewey’s pragmatism argues that knowing is always a result of our actions, a human construction concerned with the relationship between actions and consequences, since ‘our intervention, our action, is a crucial, necessary, and constitutive part of knowledge’ (Biesta, 2010, p. 120). The other crucial component for knowledge development, according to Dewey, is reflection; it is the combination of action and reflection that leads to knowledge. This means that it is not possible to obtain objective ‘once-and-for-all’ truths about the world independent from lived experience. From this, Dewey argues that knowledge can only ever offer possibilities, and not certainty, because knowledge is related to a particular context or ‘transactional situation’; what is possible in one situation may not be possible in another (Biesta, 2010).

Based on careful observation and control, we are able to make ‘warranted assertions’ about the consequences of our actions in the particular situation in which they were produced (Biesta, 2010). Dewey advocated referring to the outcomes of research and inquiry as ‘warranted assertions’, rather than truth, as these assertions are only warranted specific to the situation in which they were produced, and should not be referred to as ‘truth’ as this suggests they will be warranted for all time and in all situations. This reflects the idea that there are different knowledges which are the result of different ways that we have engaged with the world; the consequences of different actions. This means that knowledge claims need to be judged pragmatically; that is, with acknowledgement of the particular methods and methodologies used to generate those claims.
Dewey’s pragmatism is particularly useful in defending the use of multiple research methods, as it deconstructs the dichotomous epistemological assumptions regarding the either/or of objectivism and subjectivism (Biesta, 2010) which have been the basis for much of the ‘paradigm wars’ (Howe, 1988)

A MIXED METHODS STUDY OF THE NATIONAL PERINATAL ANXIETY & DEPRESSION HELPLINE

A mixed methods study of the National Perinatal Anxiety & Depression Helpline has been undertaken, using pragmatism as a philosophical foundation (Figure 2). Mixed methods has been defined as ‘research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry’ (Tashakkori & Creswell, 2007, p. 4). This approach has been utilised in this study, as the use of both numerical and narrative information provided the best opportunity to answer the research questions developed at the beginning of the study.
FIGURE 2: RESEARCH DESIGN

Paradigm
Pragmatism

Research purpose
To explore the National Perinatal Anxiety & Depression Helpline

Methodology
Mixed methods

Descriptive quantitative
Routinely collected Helpline data
Surveys

Design frameworks

Descriptive qualitative
Routinely collected Helpline data
Surveys
Focus groups

Methods of data collection
THESIS AIMS

This study is the first time the Australian National Perinatal Anxiety & Depression Helpline has been evaluated. Given this, an exploratory, descriptive study design has been used. The overall aim is to understand who calls the Helpline, their motivations for seeking help, the experiences of callers receiving support, and the experiences of volunteers providing peer support. The study comprises two parts, each with two Sub-studies (Figure 3). Part A aimed to identify who called the Helpline (Sub-study one), and why they called (Sub-study two). Part B aimed to explore the views and experiences of service users (Sub-study three), and volunteers providing peer support on the Helpline (Sub-study four).

The two study parts are described below, along with each of the four Sub-studies. Some detail of the methods is provided for each, with further detail provided in the relevant papers, presented later in the thesis.

**FIGURE 3: THESIS OVERVIEW**
PART A: CHARACTERISTICS OF HELPLINE CALLERS AND REASONS FOR SEEKING HELP

Study Part A aimed to describe the characteristics of callers to the National Perinatal Anxiety & Depression Helpline (the Helpline), changes in service demand over time, and callers’ reasons for seeking help from the service. Both Sub-studies in Part A utilise retrospective routinely collected Helpline data, or secondary data (Boslaugh, 2007), which were collected for the purpose of service provision, rather than research. Use of secondary data for research is an example of what has been referred to as ‘unobtrusive methods’, which draw on nonliving data such as text or artefacts (Liamputtong, 2013; Patton, 2015). Use of documents that have not been developed for the purpose of research provide an opportunity to better understand a program or organisation being studied from a ‘behind the scenes’ perspective (Patton, 2015). In this instance, use of routinely collected Helpline data provided an opportunity to review patterns of service demand and caller profile over time. The data sources for Part A, relative to Helpline call processes, are illustrated in Figure 4.

There are a number of potential advantages and disadvantages to the use of secondary data. Use of secondary data is economical, as it does not require the same time and money as primary data collection (Boslaugh, 2007; Powell, Davies, & Thomson, 2003). This was particularly true in the case of Sub-study one, where multiple years of Helpline data for the entire caller population were able to be utilised in a short period of time. Secondary data can also present an opportunity to conduct population-based studies with datasets that include a wide range of information (Boslaugh, 2007; Powell et al., 2003). An inherent disadvantage to the use of secondary data is that because it was not collected for the purposes of research, or the particular research questions for which it is being used, all the specific information required may not have been collected, or may not have been collected in a way that increases its applicability to the research questions (Boslaugh, 2007). Use of routinely collected data
may also raise issues relating to data quality and reliability (Powell et al., 2003). As data is collected by Helpline staff and volunteers as part of routine service delivery, it is possible that during periods of high service demand data collection or recording activities may have conflicted with immediate service provision needs. Data could also be affected by issues of consistency between individual staff and volunteers (Powell et al., 2003).

*More detailed information regarding Helpline call processes can be found in Figure 1.*
This Sub-study has been published:


A more detailed discussion of the methods used in this Sub-study can be found in Chapter Six.

AIMS

To describe the profile and characteristics of callers’ at the time of their initial call to the Helpline, including: the number of initial callers to the Helpline; caller demographic characteristics; health assessment, history, and risk factors; number of callers assessed as high needs; and supports and interventions provided.

RESEARCH QUESTIONS

- What is the profile, health history, mental health presentation, and assessed risk of callers to the National Perinatal Anxiety & Depression Helpline?
- What changes, if any, have there been over time in service demand and caller profile to the National Perinatal Anxiety & Depression Helpline?

DESIGN

A cross-sectional design was used, using routinely collected de-identified Helpline data from 1st July 2010 to 31st October 2013 (Figure 4). This data range was selected as July 1st is when the Helpline became a national service, and the initial evaluation study was conducted in October 2013. Only records documenting initial calls from women calling regarding their own mental health (as opposed to health professionals or family members) were included. Calls to
and from the Helpline are documented in the PANDA database by counsellors and volunteers, which includes both qualitative and quantitative data. This study used quantitative checkbox data, which is used to record the caller’s demographic characteristics; psychosocial and risk assessments; existing support and interventions; and any interventions and referrals made by PANDA.

DATA COLLECTION

Helpline data for the study period was extracted into an Excel spreadsheet by the database developer, and provided to the research team.

DATA ANALYSIS

Data analysis was undertaken using descriptive statistics (Pierson, 2013) in STATA version 14 (StataCorp, 2015).

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SUB-STUDY TWO

REASONS NEW AND RE-ENGAGING CALLERS CONTACT THE PANDA PERINATAL ANXIETY & DEPRESSION HELPLINE

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This Sub-study is currently under peer review:


A more detailed discussion of the methods used in this Sub-study can be found in Chapter Seven.

AIMS

This Sub-study aimed to explore the reasons callers themselves gave for making their first contact with the service, as well as callers’ mental health presentation, history, and assessed risk at point of first contact with the Helpline.
RESEARCH QUESTIONS

- Why do callers make their first contact with the National Perinatal Anxiety & Depression Helpline?
- What is the health history, mental health presentation, and assessed risk of callers making their first contact with the National Perinatal Anxiety & Depression Helpline?

DESIGN

A retrospective descriptive design was used, using routinely collected intake forms which included checkboxes and open-ended questions (Figure 4). When a caller contacts the Helpline for the first time, or after a significant period of non-contact, an intake form is completed, which details the individual’s reason for contacting the service, as well as key demographic features. By using these intake forms it was possible to gain insight into how callers’ describe their situation and motivations to call the Helpline at this very first point of contact, meaning these descriptions of seeking help were not impacted by issues of recall bias or changed understanding of their experience, as might be the case if callers’ were asked to recall these details at a later date. These forms are not entered into the electronic Helpline database, therefore these data are not part of Sub-study one; they describe the point in time when the callers decides ‘I need help’ and makes their first call to PANDA.

DATA COLLECTION

All PANDA intake forms from the middle month of each season in 2014 were collected and assessed for eligibility by LB (January, April, July and October). Intake forms recording the details of new or re-engaging callers who had called regarding their own mental health were included. Forms were ineligible for inclusion if they documented calls from someone who had contacted the service regarding someone else’s mental health (listed as third-party caller), or from existing callers who were already in contact with the Helpline. A decision was made to
focus the study on callers who contacted the service regarding their own mental health, as these individuals are the largest caller group to the Helpline. Eligible forms were entered into a database by LB.

DATA ANALYSIS

For quantitative data, analysis involved descriptive statistics (Pierson, 2013) undertaken using STATA 14 (StataCorp, 2015). Free text data were analysed using qualitative content analysis by LB and HM. Unlike quantitative content analysis, which seeks to apply pre-existing codes to the data, qualitative content analysis is a reflexive process that generates codes from the data itself (Leung & Chung, 2018; Sandelowski, 2000, 2010), and can be used to answer questions relating to a phenomenon, including what is happening?, and what might the consequences be? (Sandelowski, 2000). Free text data were coded by hand using In Vivo coding, also known as literal or verbatim coding, and a code book developed that included descriptions of each code, and examples from the data (Saldaña, 2013). Codes were organised into categories, based on commonalities in the data (Sandelowski, 2000, 2010; Teddlie & Tashakkori, 2009).

PART B: THE EXPERIENCES OF CALLERS AND PEER SUPPORT VOLUNTEERS

Study Part B aimed to explore the views and experiences of Helpline callers, and peer support volunteers. This was undertaken using a number of data collection methods, including online surveys and focus groups. The data collection for both Sub-studies was undertaken during the evaluation study in 2013, meaning that the data needed to be collected over a relatively short period of time, as explained in further detail in Chapters Eight and Nine.
This Sub-study has been published:


A more detailed discussion of the methods used in this Sub-study can be found in Chapter Eight.

AIMS

Explore the views and experiences of callers to the Helpline, including: callers’ experiences of communication with PANDA; why callers’ contacted the Helpline; what callers’ felt they had gained from their contact with the service; how the Helpline differed, if at all, from other services they had accessed, and; if there were things that could be improved within the service.

RESEARCH QUESTION

- What are the views and experiences of callers accessing support from the National Perinatal Anxiety & Depression Helpline?

DESIGN

A cross-sectional survey was used for a number of reasons. The survey allowed for the collection of a range of information about callers, including personal characteristics, reasons for contacting the service, and experiences of receiving Helpline support in a relatively short period of time, from a geographically diverse sample (Schofield & Forrester-Knauss, 2017). It was also possible to gain a larger number of responses than would have been possible using
face-to-face or telephone interviews, and use of a survey allowed respondents to remain anonymous.

All new callers to PANDA, from 1st May to 30th September 2013 were invited to participate in the survey four to eight weeks after their initial contact with the service. This timeframe was selected as it was anticipated that most would no longer be in contact with PANDA, and that the contact with the service was recent enough to reduce possible issues with accurate recall of information.

SURVEY INSTRUMENT

The survey was adapted from a previous survey of PANDA callers conducted in 2012 as part of a Master’s study (Pliszka, 2012) (Appendix XI), and was piloted with experienced maternity clinicians and perinatal researchers who reviewed the survey for content, flow, face and content validity (Schofield & Forrester-Knauss, 2017). The survey consisted of 23 questions, and collected demographic information, as well as a range of closed and open-ended questions, and a number of statements with Likert-type scale response options, i.e., ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’, or ‘strongly disagree’. The questions explored how callers had heard of PANDA, number of contacts they had with the service, overall experiences with the Helpline, call content, views regarding organisational features, referrals to other supports, and suggestions for changes to the Helpline.

DATA COLLECTION

Callers’ contact details, such as an email or postal address, were obtained by PANDA staff and/or volunteers during their first call as part of ‘usual care’ on the Helpline. Surveys were sent by PANDA to all new callers within the study period, by email if those details were available (Appendix V), or by hard copy with a return envelope (Appendix VI). A detailed letter was sent with an invitation to participate in the survey explaining the purpose of the study, and reassuring participants that all responses would remain anonymous. The letter also
detailed that all responses would be returned directly to the research team, and that the contents of any response, or a decision not to participate, would not impact on any current or future contact with PANDA. Return of the survey was taken as consent to participate.

Callers were sent two reminders (Appendix VII and VIII) using the same method that they had initially been contacted with two and four weeks after their initial invitation to participate. As the surveys were sent by PANDA, then received by the research team, it was not possible to send reminders to only those who had not yet responded, and so a note thanking those who had already participated was sent with these reminders.

DATAS MANAGEMENT ANALYSIS

Data were managed within the secure web-based application Research Electronic Data Capture (REDCap) (Harris et al., 2009). Online survey respondents completed surveys directly in REDCap, and hard-copy surveys entered directly into the application by one of the research team. Data were transferred to STATA11 (StataCorp, 2009) for data cleaning, including range and logic checks, and analysis. Descriptive statistics were used (Pierson, 2017), and presented mostly as numbers and percentages. Responses to open-ended questions were analysed thematically, a common means for analysing qualitative data (Braun, Clarke, Hayfield, & Terry, 2018; Liamputtong & Serry, 2017) by LB and HM. The analysis is presented as a thematic network, which presents the key themes and the relationships between them (Attride-Stirling, 2001).
This Sub-study has been published:


A more detailed discussion of the methods used in this Sub-study can be found in Chapter Nine.

AIMS
To explore the views and experiences of Helpline peer support volunteers, including:
motivations to volunteer at PANDA; volunteers’ descriptions of positive and challenging aspects of their role; to describe the impact, if any, for volunteers with personal experience of a perinatal mood disorder; volunteers’ experiences of training, support, and supervision; and experiences of the PANDA workplace culture and environment.

RESEARCH QUESTION
- What are the views and experiences of volunteers providing peer support on the National Perinatal Anxiety & Depression Australia Helpline?

DESIGN
The study utilised a mixed methods design, incorporating two focus groups and an online survey. Focus groups were used as they provided an opportunity to generate data through social interaction, which would provide an understanding of the diversity of experiences amongst the volunteers, and also provide the research team with an opportunity to observe the peers interact with each other (Davidson, Halcomb, & Gholizadeh, 2017; M. Q. Patton, 2015). It has been hypothesised that focus groups can also reduce individual vulnerability, since the data are obtained collectively, rather than individually (Patton, 2015).
It was however acknowledged that some volunteers may not be comfortable to share all of their views or experiences in a focus group with their peers (Patton, 2015), and so the online survey was developed to ensure volunteers were able to participate anonymously if they preferred. Surveys allow for the collection of information relating to a range of issues, including individual’s attitudes, experiences, and satisfaction, and prioritises the respondents themselves as the best source of accurate information (Schofield & Forrester-Knauss, 2017).

SURVEY INSTRUMENT

The survey was designed specifically for the purpose of the evaluation and was piloted with experienced researchers to assess content and flow, as well as face and content validity (Appendix XIII) (Schofield & Forrester-Knauss, 2017). As all the volunteers were going to be invited to participate in the study, the survey was not piloted with this group. The survey consisted of 16 questions, and included a range of demographic, closed and open-ended questions, and a number of statements with Likert-type scale response options, i.e., ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’, or ‘strongly disagree’. The survey questions explored a range of issues, including their experiences of support and supervision, positive and negative aspects of their role, and experiences of the PANDA workplace culture and environment.

FOCUS GROUP SCHEDULE

A semi-structured focus group schedule was developed specifically for the study, which explored volunteers’ experiences of providing peer support on the Helpline, including positive and negative aspects of the role, and their experiences of training, support, and supervision (Appendix XII). The focus group schedule aimed to keep the group discussion focused to the key research aims, while also allowing enough freedom for participants to share their views and experiences (Patton, 2015).
DATA COLLECTION

All volunteers working on the Helpline at the time of the evaluation were sent an email in October 2013 by the PANDA Helpline Manager inviting them to participate in a focus group, complete the online survey, or both (Appendix IX and X). Volunteers were assured that they were under no obligation to participate, and that all survey responses would remain anonymous and be returned directly to the research team.

Focus groups were held at PANDA by two members of the research staff who were not known to the peer support volunteers, and were audio recorded with participants’ consent.

DATA MANAGEMENT AND ANALYSIS

Data were collected and managed within the secure web-based application Research Electronic Data Capture (REDCap) (Harris et al., 2009). Data were transferred to STATA13 (StataCorp, 2013) for data cleaning, including range and logic checks, and analysis. Descriptive statistics were used (Pierson, 2017), and presented mostly as numbers and percentages.

Focus group recordings were transcribed verbatim using Audacity 2.1.0 (Audacity Team, 2015). Focus group transcripts and responses to open-ended survey questions were analysed thematically, a common means for analysing qualitative data (Braun et al., 2018; Liamputtong & Serry, 2017).

ETHICAL CONSIDERATIONS

Ethics approval for this research was obtained from the La Trobe University Human Research Ethics Committee (FHEC 11/032 and FHEC11/057) (Appendix III and IV).

A number of steps were taken to protect research participants.
Informed consent

Participants were provided with a detailed information sheet when invited to participate in the study, which included a description of the purpose of the study, how their information would be managed, and that they were free to withdraw from the study at any time (Appendix V, VI, IX, and X). Participants attending a focus group were asked to sign a written consent form (Sub-study four).

Protection of participant anonymity and confidentiality

Data provided for the purposes of Sub-study one were de-identified, and had a specific study ID allocated to differentiate individual records.

The surveys (Sub-study three) were sent to callers by PANDA, meaning that the research team had no knowledge of the caller’s identity. All responses were received by the research team, which meant PANDA had no knowledge of who had responded to the survey, and what those responses were. A detailed letter was sent at the time callers were invited to participate, which included reassurance that all responses would remain anonymous, would be sent directly to the research team, and would not impact on any current of future relationship with PANDA.

All volunteers (Sub-study four) were assured that they did not have to participate in the study, that all survey responses would be returned anonymously to the research team, and that participation or the nature of their responses would not impact their ongoing relationship with the organisation. Focus groups were run by members of the research team, and no members of PANDA senior staff were present.
Data management

All hard copy data was held in a locked cabinet in a locked room at La Trobe University. All consent forms were kept separate from transcripts and identifiable information able to be re-identified by study ID only. Electronic data were kept on University servers, and password protected. Care was taken to ensure no quotes or other information used in presentations or publications could be used to identify any of the research participants.

SYNTHESIS

The findings of each Sub-study are considered together in the thesis discussion and conclusion (Chapter Ten), in order to address the overall aims of the study.
Part A

Characteristics of Helpline callers and reasons for seeking help
“...Because you need help when you NEED help and in my recent experience it can be difficult to get the help when you need it... [they gave] me encouragement to keep trying when I was so exhausted and ready to just give up... a touch of human kindness in a scary and lonely place.”

34 year old woman. Participant in Sub-study three.
This paper describes the characteristics, health history and assessment of new callers to the Helpline from July 2010, when the Helpline became a national service, and October 2013. Routinely collected data shows that most women calling the Helpline for the first time are aged between 25 and 40, married or partnered, and having their first child. A high proportion of callers were assessed as experiencing significant biopsychosocial symptoms, social complexity or inadequate care and support – also known as ‘high needs’ callers. Over the study period there was a 70% increase in the number of initial calls to the Helpline.

CONTRIBUTION TO THE PAPER

I declare that I have made substantial contribution to this paper, including study design, data analysis, and drafting the paper. My supervisors all contributed to the study design, intellectual input, and editing the manuscript.

Laura Biggs

I declare that Laura Biggs made a substantial contribution to this paper. She contributed to all aspects of the study and drafted this paper.

Helen McLachlan
Characteristics of women calling the PANDA Perinatal Anxiety & Depression Australia National Helpline: a cross-sectional study

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Received: 2 January 2018 / Accepted: 24 May 2018 © Springer-Verlag GmbH Austria, part of Springer Nature 2018

Abstract
The PANDA Perinatal Anxiety & Depression Australia National Helpline provides support for people affected by perinatal mental health issues. To describe the characteristics of women contacting the Helpline, specifically callers’ health, past history and assessed risk factors. Analysis of routinely collected de-identified data of women making initial calls between July 2010 and October 2013. Five thousand eight hundred eighteen women made an initial call to the Helpline. Most were between 25 and 40 years old (79%) and married/partnered (94%); 52% were having or had their first child; and 23% were pregnant. Over half had no prior mental health diagnosis at the time of their initial call, and 40% were assessed as ‘high needs’—experiencing significant bio-psychosocial symptoms, complex situations and/or inadequate care and support. There was a 70% increase in calls to PANDA over the data collection period. Concerns recorded by PANDA staff from the initial risk assessment included inadequate treatment for a mental health condition (31%), women not feeling connected to their baby (31%), low functioning (26%) and general thoughts of suicide (18%). The Helpline experienced a significant increase in demand during the study period, and a substantial proportion of callers had complex mental health needs. PANDA plays a major role in providing support to a large number of women experiencing perinatal mental health problems.

Keywords Helpline · Perinatal · Anxiety · Depression · Caller

Introduction
Perinatal mental illness is a major public health issue, with potential serious adverse consequences for a woman’s health and that of her infant and family (Howard et al. 2014). Estimates of the rates of perinatal mental illness vary due to different study designs, tools used, assessment times and sample populations (O’Hara and Wisner 2014). A systematic review including 28 studies reported period prevalence of depression as 18% during pregnancy and 19% in the first 12 weeks postpartum (Gavin et al. 2005). Anxiety disorders are also common during the perinatal period (Austin et al. 2010; Ross and McLean 2006) and commonly co-occur with depression (Austin et al. 2010; Howard et al. 2014). A recent systematic review of 102 studies from 34 countries reported prevalences of 18, 15 and 15% for any anxiety disorder in the first, second and third trimester of pregnancy, respectively (Dennis et al. 2017). The prevalence of anxiety disorder within the first year postpartum ranges from 9 to 10% (Dennis et al. 2017).

An Australian study found that at 6 months postpartum, 17% of mothers experience depressive symptomatology, 13% experience anxiety, and 8% experience both (22% experience anxiety and/or depression) (Yelland et al. 2010). This is even higher if the period prevalence is used (Austin et al. 2010; Wynter et al. 2013). Given over 300,000 women giving birth annually in Australia (Australian Institute of Health and Welfare 2017), an estimated 66,000 Australian women are affected each year.

Risk factors associated with anxiety and depression in the perinatal period include low self-esteem, stressful life events, poor partner relationship, lack of social support (Lancaster et
al. 2010; O'Hara and McCabe 2013), history of abuse or domestic violence, unintended pregnancy, current or past pregnancy complications including pregnancy loss (Biaggi et al. 2016) and a history of mental illness (Biaggi et al. 2016; Dennis et al. 2016).

Treatments for perinatal mental illness may include pharmacological, psychosocial and/or psychological options (O'Hara and Wisner 2014). Non-pharmacological treatments such as peer support and counselling have become increasingly popular given concerns about the potential side effects of medication during pregnancy and breastfeeding (Battle et al. 2013; Goodman 2009). A qualitative systematic review exploring the help seeking barriers and treatment preferences of women with postnatal depression found that many women preferred ‘talking therapies’ with a non-judgmental person rather than pharmacological treatments (Dennis and Chung-Lee 2006).

Women often do not seek help from health professionals for mental health issues in pregnancy and postpartum (Dennis and Chung-Lee 2006; Woolhouse et al. 2009) and are often reluctant to disclose an issue that may be associated with social stigma; some do not know where to seek assistance or what support or treatment is available (Dennis and Chung-Lee 2006). Identification of perinatal anxiety and depression in clinical practice is often poor (Gavin et al. 2005). An Australian study identified that less than half of the women surveyed remembered being asked about depression or feeling anxious during their pregnancy care (Yelland and Brown 2014).

Telephone-based interventions are increasingly used to deliver and enable access to a range of health services (Dale et al. 2008). Advantages include greater accessibility than face-to-face contact and a more private, flexible and non-stigmatising service (Dennis and Kingston 2008), not affected by transportation or geography, and allowing access to personal support when required (Dale et al. 2008; Lavender et al. 2013). While there is growing evidence of improved health outcomes, sufficient evidence of efficacy of telephone support is limited, mostly due to limitations in the methods of existing studies (Dale et al. 2008; Lavender et al. 2013). Some studies of telephone-based interventions conducted in the perinatal period suggest encouraging findings and improvement in participant outcomes (Dennis and Kingston 2008; Efrat et al. 2015; Ngai et al. 2015). A Cochrane systematic review of 27 randomised controlled trials of telephone support during pregnancy and postpartum also showed some evidences that telephone support might be a promising intervention to improve health outcomes, though the findings were inconsistent and inconclusive (Lavender et al. 2013).

**PANDA Perinatal Anxiety & Depression Australia**

In Australia, there are telephone-based organisations where women can seek help anonymously. The PANDA Perinatal Anxiety & Depression Australia Helpline (the Helpline) is the only national specialist perinatal mental health helpline providing confidential information, support and referral to anyone affected by perinatal mental health problems. During the period of this study, the Helpline was available to callers free of charge Monday to Friday, from 10 am to 5 pm.

PANDA Perinatal Anxiety & Depression Australia (formerly PANDA Post and Antenatal Depression Association) began as a peer support organisation in Victoria, Australia in the 1980s and expanded to become a national service in July 2010 (Post and Antenatal Depression Association 2012). PANDA is funded by the Australian Government Department of Health, and Victorian State Government Department of Health and Human Services. PANDA provides support to the Australian community in multiple ways, including online fact sheets, two websites and a National Helpline. The service works collaboratively with health professionals, providing professional training, and assists in the establishment of community support groups for families experiencing perinatal mental illness. PANDA also recruits and trains peer support, and community education volunteers to provide services within the organisation. These volunteers have themselves experienced perinatal mental illness or supported someone who has, and all undergo a 6- to 8-week training program, followed by role play assessments to ensure competency, before commencing as a volunteer on the Helpline. Professional staff are also employed to provide counselling services on the Helpline. Telephone Counsellors are paid professional staff with a range of professional qualifications, such as social work, counselling, occupational therapy, psychology and nursing. All receive ‘on the job’ training, including perinatal-specific content updates and observation shifts where they partner with an experienced staff member. All counsellors and volunteers also receive training in using PANDA’s database, with a focus on data consistency and reliability. Senior Helpline staff monitor all Helpline activities and are able to provide support and feedback to counsellors and volunteers regarding service provision and data collection quality.

**PANDA Helpline call management**

Call processes and risk assessment for callers to the Helpline are presented in Fig. 1. At the time of this study, all incoming calls to the Helpline were received by a senior clinical intake worker who conducted an initial triage process, which included securing caller details if possible (callers could choose to remain anonymous if they wished). In most instances, a return phone call was made later the same day by a PANDA counsellor to undertake a full assessment, except in instances where it was considered that the caller was in crisis and required immediate assistance. When a caller received the first return phone call, caller data were entered as an ‘initial call’. If a caller re-engaged with the service after a period of non-
contact (i.e. they had sought support from the service during a previous pregnancy or had not made contact for several months), a new ‘initial call’ was recorded in light of the need to assess their current circumstances and emotional health.

At the time of this study, there had been limited research about consumer-led telephone-based support programs, and no systematic evaluation of PANDA’s Helpline had been undertaken since its inception. To improve the service and explore its effectiveness, an evaluation was commissioned to understand demand for the service, as well as caller characteristics and their views of the service.

In January 2013, a team from the La Trobe University was engaged to conduct an independent evaluation of the Helpline (Shafiei et al. 2014). The evaluation included a description of the PANDA callers’ profiles and demand and referral pathways; an exploration of the views and experiences of callers (Biggs et al. 2015), including interviews with ‘high needs’ callers; and consultations with PANDA staff/volunteers (Biggs et al. 2018) and key stakeholders. This paper presents findings of a key study aim to describe the characteristics of callers at their ‘initial call’ to the Helpline, including the assessment of callers’ health, past history and assessed risk factors. The specific aims were to explore the number of women making their initial calls to PANDA compared to total callers; their demographic characteristics; their health assessment, history and risk factors; number of high needs callers; and supports and interventions provided.

**Methods**

A cross-sectional design was used. Routinely collected de-identified data from the PANDA database from 1 July 2010 (chosen because in July 2010 PANDA expanded its telephone-based service to provide support nationally) to 31 October 2013 (when the evaluation was conducted) were included.

All calls to and from the Helpline are documented in the PANDA database by counsellors and volunteers. This enables both quantitative and qualitative call data to be recorded. Data are recorded using checkboxes in the quantitative database. Checkboxes are used to record the caller’s demographic characteristics; psychosocial and risk assessments; existing support and interventions; and any interventions and referrals made by PANDA. At the same time, a more detailed record of the caller’s ‘story’ and the assessment and planning process are entered onto the qualitative part of the database. For this paper, just quantitative data are presented (in-depth qualitative data will be presented separately).

**Inclusion criteria**

Consumers (i.e. those calling regarding their own emotional health) are the most common callers to the Helpline. Other types of callers include those from agencies/services such as hospitals, doctors and maternal and child health nurses,
partners, family/friends and students (Shafiei et al. 2014). Women make up 97% of callers to the Helpline (Shafiei et al. 2014). For this reason, data analyses for this paper included only women calling about themselves (i.e. consumers) and making their initial call to the Helpline.

At the time of the evaluation, all initial and follow-up calls were entered as a separate call entry, that is, they were not continued from a previous call. All call entries were therefore unidentifiable, and further follow-up calls were not linked to an individual within the database (although all call records were printed and linked to individuals in a hard copy of the caller file). The database included a variable, ‘call type’, identifying categories of ‘initial’ and ‘follow-up’ calls. As it is possible that the same caller may be described in the data more than once, analyses were conducted using only ‘initial’ calls (as described above) in order to obtain a more accurate overview of callers making contact with the Helpline. It is therefore possible that callers in this dataset had more than one initial call completed during the study period, although it is considered that this number would be relatively low.

Data management and analysis

Data were extracted from the PANDA database into Excel spreadsheets by the database developer. Data analysis was undertaken using descriptive statistics, with STATA version 14 (StataCorp 2015). Due to the varied number of responses to different questions, the denominators may vary for each category.

Results

In total, there were 35,853 calls recorded in the PANDA database between 1 July 2010 and 31 October 2013, including both ‘initial’ (22%) and ‘follow-up’ calls (78%) (Fig. 2). Of the ‘initial’ calls, 6021 were from individuals who had contacted the service regarding their own emotional health, and 5818 of these were women. This is the sample on which analyses were undertaken for this paper.

The number of women calling the Helpline increased substantially over the study period. As data had been collected between July 2010 and October 2013, data on the total number of women who had called the Helpline were not available for all the complete years in that time period. For this reason, only data from complete financial years were used to explore the trend in the number of calls, that is, data from 1 July to October 2013 were excluded. There were 1299 initial calls in the financial year 2010–2011, 1816 calls in 2011–2012, and 2220 calls in 2012–2013—a 70% overall increase.

The majority of women calling the Helpline were 25–40 years old (79%), married/partnered (94%) and living in Victoria (54%) (Table 1). More than half (52%) were pregnant with, or had given birth to, their first child, and 23% were pregnant at the time of their call. Of those with a child, over half had a child aged less than 6 months (55%).

Initial presentation and risk assessment

Table 2 describes what was recorded by PANDA staff in terms of callers’ ‘initial presentation’. One third of callers were recorded as crying when they called PANDA and 14% as agitated (NB: more than one option could be recorded for the ‘initial presentation’ variable). In terms of the documented ‘reason for call’, the majority were calling for ‘support’ (98%), with a smaller number seeking information about postnatal depression (30%). In 20% of cases, women had been referred to the Helpline. Similar to ‘initial presentation’, multiple options were able to be recorded for the ‘reason for call’.

The most common condition as categorised by the PANDA staff, based either on a previous diagnosis the woman had received, or the woman’s own personal story at the time of her initial call, was postnatal depression and/or anxiety (36%), followed by parenting transition difficulties (16%), with a significant number categorised as having an ‘unknown condition’ (34%). A large number of callers were also recorded as ‘high needs’ (40%), indicating they were experiencing significant symptoms of perinatal depression and anxiety, and/or complex social circumstances such as social isolation and limited supports, and/or inadequate care and support (Table 2). The proportion of high needs callers increased almost three-fold over the study period (by financial year), from 18% (240/1299) in 2010–2011 to 52% (1165/2220) in 2012–2013.
The initial call process includes a full risk assessment. The recorded data for initial risk assessment indicated that the majority of callers had been assessed as at ‘no risk’ of self-harm (92%), suicide (82%), of harming their baby (86%) or experiencing family violence (96%) (Table 3). Other categories noted from the callers’ risk assessment were concerns including receiving inadequate treatment for a mental health condition (31%), not feeling connected to their baby (31%), low functioning (26%) and experiencing general thoughts of suicide (18%).

At the initial risk assessment, PANDA staff collect information on a caller’s existing diagnosis of mental health problems prior to their call to PANDA. Over half of the women (59%) were recorded as having no existing diagnosis at the time of the initial call. Of those with an existing diagnosis, ‘postnatal depression’ was the most common (67%) (Table 4). This diagnosis was most likely to have been made by a general practitioner (61%) or psychiatrist (17%).

### Symptoms and contributing factors

*Symptoms* that women were experiencing at the time of their call to the Helpline as well as *contributing* factors are presented in Tables 5 and 6. In each table, the overarching category is shown, with the denominator being all women for whom the question was answered, then in both tables the sub-categories selected are shown, with the denominator being the number who responded ‘yes’ to the main category. The *symptoms* most commonly recorded for callers were emotional (97%; e.g. feeling overwhelmed, anxious), physical (80%; e.g. poor sleep, exhaustion), cognitive (66%; e.g. negative thinking, loss of sense of self) and social (46%; e.g. isolated, social withdrawal) symptoms (Table 5). Counsellors also documented factors which they or the woman identified as *contributing* to the caller’s condition, with the most common including mental health history (57%; e.g. previous depression, family history), physical issues (55%; e.g. sleep deprivation, difficult birth), emotional issues (54%; e.g. expectations of parenthood, low self-esteem), social issues

<table>
<thead>
<tr>
<th>Table 1 Participant characteristics</th>
<th>n</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td><strong>Age (n = 1092)</strong></td>
<td></td>
<td></td>
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<tr>
<td>&lt; 25 years</td>
<td>133</td>
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<tr>
<td>25–30 years</td>
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</tr>
<tr>
<td>31–40 years</td>
<td>538</td>
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<tr>
<td>41–45 years</td>
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<tr>
<td>&gt; 45 years</td>
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<tr>
<td><strong>Relationship status (n = 3178)</strong></td>
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<tr>
<td>Married</td>
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<tr>
<td>Living with partner</td>
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<td>13.1</td>
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<td>Separated/single/widow</td>
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<td>Had or having subsequent child</td>
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<td>53.2</td>
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<tr>
<td><strong>Ages of youngest child (n = 3167)</strong></td>
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<tr>
<td>&lt; 4 months</td>
<td>1168</td>
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<td>4–6 months</td>
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<td>&gt; 1 year</td>
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<td><strong>State of origin (n = 5818)</strong></td>
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<table>
<thead>
<tr>
<th>Table 2 Profile of participants</th>
<th>n</th>
<th>%</th>
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<tr>
<td><strong>Initial presentation a on phone (n = 3143)</strong></td>
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<td></td>
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<tr>
<td>Calm</td>
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<td>61.6</td>
</tr>
<tr>
<td>Crying</td>
<td>1032</td>
<td>32.8</td>
</tr>
<tr>
<td>Agitated</td>
<td>450</td>
<td>14.3</td>
</tr>
<tr>
<td>Other</td>
<td>347</td>
<td>11.0</td>
</tr>
<tr>
<td><strong>Reason for call (n = 5389)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>5295</td>
<td>98.3</td>
</tr>
<tr>
<td>Postnatal depression information</td>
<td>1596</td>
<td>29.6</td>
</tr>
<tr>
<td>Referral</td>
<td>1062</td>
<td>19.7</td>
</tr>
<tr>
<td>Find out about PANDA</td>
<td>561</td>
<td>10.4</td>
</tr>
<tr>
<td>Antenatal depression information</td>
<td>323</td>
<td>6.0</td>
</tr>
<tr>
<td>Crisis intervention</td>
<td>141</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Condition (categorised by counsellor/volunteer) (n = 5818)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postnatal depression/anxiety</td>
<td>2096</td>
<td>36.0</td>
</tr>
<tr>
<td>Transition difficulties</td>
<td>941</td>
<td>16.2</td>
</tr>
<tr>
<td>Antenatal depression/anxiety</td>
<td>573</td>
<td>9.9</td>
</tr>
<tr>
<td>Other (e.g. bipolar disorder, psychosis)</td>
<td>227</td>
<td>3.9</td>
</tr>
<tr>
<td>Unknown condition</td>
<td>1981</td>
<td>34.1</td>
</tr>
<tr>
<td><strong>High needs callers (n = 5818)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2314</td>
<td>39.8</td>
</tr>
</tbody>
</table>

*a* Multiple options were possible
Within the sub-categories, the most commonly documented contributing factors to women’s presenting conditions were: ‘expectations of parenthood’ (36%), limited networks (32%) and isolation (29%), sleep deprivation (29%) and previous diagnosed depression (26%).

### PANDA’s ‘interventions’

Table 7 describes PANDA’s suggested strategies, as well as referrals provided to women at the time of their initial call to the Helpline. The most common strategies provided were support (98%), information (82%), self-help suggestions (68%) and lifestyle strategies (53%). Over half of the callers (982/1617, 61%) were also sent an information pack in the mail, containing PANDA fact sheets (based on assessment of each caller’s needs), a fridge magnet and a general PANDA brochure.

The majority of callers received at least one referral (80%), with over half receiving three or more referrals. PANDA maintains a resource and referral information database covering services in Australia, including perinatal mental health support groups and playgroups, doctors, psychiatrists, psychologists, counsellors and support services. These professionals and support services have a specific interest and expertise in working with individuals and families experiencing mental health problems in the perinatal period. The most common referrals were to a counsellor (28%), general practitioner (24%) or a medicine information centre (23%), which provides callers with information regarding the use of medicines in pregnancy and during lactation (Table 7).

### Discussion and conclusions

This study forms part of the first independent evaluation of the PANDA Helpline and is to our knowledge one of the few to...
investigate a community-based perinatal mental health support service internationally. Overall, during the evaluation period, over 5000 women made an initial call to the Helpline. Calls for support from PANDA increased substantially over the data collection period (2010–2013), with the number of women calling the Helpline increasing by a total of 70%.

In the current study, over half of the callers had no prior mental health diagnosis at the time of their initial call to PANDA, and almost one third were documented as having no adequate treatment at the time of their call. In addition to women not seeking professional support for emotional problems (Woolhouse et al. 2009), health professionals may fail to detect perinatal mental illness (Goodman and Tyer-Viola 2010) and/or lack sufficient knowledge of it and treatment options (Dennis and Chung-Lee 2006; Sword et al. 2008).

Factors documented in the PANDA database as contributing to women’s experiences are consistent with other studies. These include isolation and poor social supports (Biaggi et al. 2016; Dennis et al. 2016; O’Hara and McCabe 2013), expectations of parenthood (Eastwood et al. 2012; Henshaw et al. 2014) and mental health history (Biaggi et al. 2016; Patton et al. 2015).

Social circumstances are key risk factors for emotional health and there is a strong association between social health issues and perinatal mental illness (O’Hara and Wisner 2014; Yelland et al. 2010). PANDA plays an important role in adequately addressing caller’s complex circumstances and careful documentation of complexity can enable more targeted approaches to support provision, better community understanding of these issues and of the challenges so many women face in the perinatal period. An important aspect of publication of data such as these is to provide a basis for broader thinking around how to identify women who are high risk of poor mental health, with complex needs, and to develop strategies aimed at preventing women from progressing to a crisis scenario before they are able to access support.

Calls to PANDA were provided with support, information and referral to appropriate services as required. The majority of callers (80%) received at least one referral from PANDA. This suggests that PANDA is playing an important role in educating and facilitating callers’ access to available services and adequate treatment.

Despite the increased demand for support from PANDA, this only represents a small proportion of women in the community who potentially need support. Approximately 2000 new calls were made to PANDA each year, yet over 300,000 women give birth in Australia each year (Australian Institute of Health and Welfare 2017). Given the prevalence of postnatal depression is approximately 17% (Yelland et al. 2010), less than 5% of those affected annually seek help from PANDA. It is important to try and understand why this is the case, given that there are very few support services readily available to women who might be experiencing perinatal mental illness. PANDA is a not-for-profit organisation which necessarily has limited hours of operation and service provision availability. Recently, the Helpline hours increased, and since July 2017 are 9 am to 7.30 pm (personal communication, PANDA Chief Executive Officer, 2017). It may be that this in itself leads to an increase in the number of calls made to PANDA each year.

There are also a number of previously documented factors that affect what support women seek and when, and it is critical that organisations such as PANDA try to address these issues in

| Table 4 Existing diagnosis of mental health issues prior contacting PANDA |
|---------------------------|-----------------|---|
| Existing diagnosis* (n = 2651) | n | % |
| No prior diagnosis | 1559 | 58.8 |
| Had an existing diagnosis | 1092 | 41.2 |
| Postnatal depression | 726 | 66.5% |
| Depression | 158 | 14.5% |
| Antenatal depression | 120 | 11.0% |
| Postnatal anxiety | 117 | 10.7% |
| Antenatal anxiety | 55 | 3.2% |
| Other (e.g. PTSDc, postpartum psychosis, personality disorder) | 126 | 11.5% |

<table>
<thead>
<tr>
<th>Diagnosis made byb (n = 1092)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioner</td>
<td>664</td>
<td>60.8</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>184</td>
<td>16.9</td>
</tr>
<tr>
<td>Self</td>
<td>75</td>
<td>6.9</td>
</tr>
<tr>
<td>Maternal and child health nurse</td>
<td>55</td>
<td>5.0</td>
</tr>
<tr>
<td>Others (e.g. counsellor, family)</td>
<td>72</td>
<td>6.6</td>
</tr>
</tbody>
</table>

* Multiple options were possible
b Only includes those who had a diagnosis
c Post-traumatic stress disorder
order to ensure that those most needing support are targeted. Women often do not seek help for their emotional health problems (Woolhouse et al. 2009), nor may they know where to seek assistance (Buultjens and Liamputtong 2007; Dennis and Chung-Lee 2006), or what support or treatment is available (Dennis and Chung-Lee 2006). Fear of social stigma and being labelled mentally ill are also significant barriers to new mothers experiencing mental illness to seek help (Dennis and Chung-Lee 2006).

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Symptoms recorded for callers</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>% n = 3220</td>
</tr>
<tr>
<td>Emotional symptoms</td>
<td>3116</td>
</tr>
<tr>
<td>Overwhelmed</td>
<td>2091 (67.1)</td>
</tr>
<tr>
<td>Anxious</td>
<td>1936 (62.1)</td>
</tr>
<tr>
<td>Crying</td>
<td>1865 (59.9)</td>
</tr>
<tr>
<td>Depressed</td>
<td>1428 (45.8)</td>
</tr>
<tr>
<td>Feeling guilty</td>
<td>1254 (40.2)</td>
</tr>
<tr>
<td>Unable to cope</td>
<td>994 (31.9)</td>
</tr>
<tr>
<td>Irritable</td>
<td>920 (29.5)</td>
</tr>
<tr>
<td>Flat</td>
<td>838 (26.9)</td>
</tr>
<tr>
<td>Other (e.g. angry, hopeless, lack of interest)</td>
<td>1660 (53.3)</td>
</tr>
<tr>
<td>Physical symptoms</td>
<td>2569</td>
</tr>
<tr>
<td>Poor sleep</td>
<td>1608 (62.6)</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>1353 (52.7)</td>
</tr>
<tr>
<td>Low energy</td>
<td>1314 (51.2)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>1117 (43.5)</td>
</tr>
<tr>
<td>Low appetite</td>
<td>744 (29.0)</td>
</tr>
<tr>
<td>Other (e.g. pain, poor recovery, feeling sick)</td>
<td>828 (32.2)</td>
</tr>
<tr>
<td>Cognitive symptoms</td>
<td>2114</td>
</tr>
<tr>
<td>Negative thinking</td>
<td>1349 (63.8)</td>
</tr>
<tr>
<td>Loss of sense of self</td>
<td>664 (31.4)</td>
</tr>
<tr>
<td>Unclear thinking</td>
<td>540 (25.5)</td>
</tr>
<tr>
<td>Obsessive thinking</td>
<td>520 (24.6)</td>
</tr>
<tr>
<td>Low motivation</td>
<td>417 (19.7)</td>
</tr>
<tr>
<td>Other (e.g. poor concentration, confusion, poor decision)</td>
<td>805 (38.1)</td>
</tr>
<tr>
<td>Social symptoms</td>
<td>1478</td>
</tr>
<tr>
<td>Isolated</td>
<td>1036 (70.1)</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>440 (29.8)</td>
</tr>
<tr>
<td>Difficulty being with family/friends</td>
<td>399 (27.0)</td>
</tr>
<tr>
<td>Other (e.g. fear of being alone, fear of going out)</td>
<td>325 (22.0)</td>
</tr>
<tr>
<td>Relationship symptoms</td>
<td>1105</td>
</tr>
<tr>
<td>Strained relationship</td>
<td>839 (75.9)</td>
</tr>
<tr>
<td>Poor attachment with baby</td>
<td>197 (17.8)</td>
</tr>
<tr>
<td>Other (e.g. breakdown, fear of baby)</td>
<td>220 (19.9)</td>
</tr>
<tr>
<td>Behavioural symptoms</td>
<td>411</td>
</tr>
<tr>
<td>Difficulty managing household/family</td>
<td>181 (44.0)</td>
</tr>
<tr>
<td>Caring for baby/children</td>
<td>138 (38.4)</td>
</tr>
<tr>
<td>Other (e.g. loss of control of behaviour, hypervigilance)</td>
<td>200 (48.7)</td>
</tr>
</tbody>
</table>

**a** Multiple options were possible

**b** In this column, percentages show for sub-variables

**c** Denominator is all women for whom the question was answered

**d** Denominator is the number who responded ‘yes’ to the main category
Some groups of women, e.g. young mothers (Fonseca et al. 2015; Herrick 2002) or immigrant and refugee mothers (Tobin 2015), are less likely to seek help for emotional distress than other mothers. In this study, compared to all Victorian women who gave birth in 2012 and 2013 (CCOPMM 2014), women calling PANDA were more likely to be married or in a

Table 6  Contributing factors to callers’ condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>n (%)</th>
<th>% n = 3027</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health history</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous depression (diagnosed)</td>
<td>1733</td>
<td>57.3</td>
</tr>
<tr>
<td>Previous treatment for mental health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous anxiety (diagnosed)</td>
<td>789</td>
<td>(45.5)</td>
</tr>
<tr>
<td>Family history of mental illness</td>
<td>535</td>
<td>(30.9)</td>
</tr>
<tr>
<td>Previous postnatal depression</td>
<td>429</td>
<td>(24.8)</td>
</tr>
<tr>
<td>Other (e.g. previous depression not treated)</td>
<td>360</td>
<td>(20.8)</td>
</tr>
<tr>
<td>Physical issues</td>
<td>1665</td>
<td>55.0</td>
</tr>
<tr>
<td>Sleep deprivation</td>
<td>862</td>
<td>(51.8)</td>
</tr>
<tr>
<td>Difficult birth</td>
<td>394</td>
<td>(23.7)</td>
</tr>
<tr>
<td>Caesarean section</td>
<td>381</td>
<td>(22.9)</td>
</tr>
<tr>
<td>Difficult pregnancy</td>
<td>315</td>
<td>(18.9)</td>
</tr>
<tr>
<td>Other (e.g. IVF, miscarriage, medical condition)</td>
<td>496</td>
<td>(29.8)</td>
</tr>
<tr>
<td>Emotional issues</td>
<td>1648</td>
<td>54.4</td>
</tr>
<tr>
<td>Expectations of parenthood</td>
<td>1097</td>
<td>(66.6)</td>
</tr>
<tr>
<td>Low self-esteem</td>
<td>904</td>
<td>(54.9)</td>
</tr>
<tr>
<td>Communicating difficulty</td>
<td>585</td>
<td>(35.5)</td>
</tr>
<tr>
<td>Disassociation</td>
<td>35</td>
<td>(2.1)</td>
</tr>
<tr>
<td>Social issues</td>
<td>1512</td>
<td>50.0</td>
</tr>
<tr>
<td>Limited networks</td>
<td>969</td>
<td>(64.1)</td>
</tr>
<tr>
<td>Isolation</td>
<td>886</td>
<td>(58.6)</td>
</tr>
<tr>
<td>Distant extended family</td>
<td>579</td>
<td>(38.3)</td>
</tr>
<tr>
<td>Other (e.g. financial difficulties, domestic violence)</td>
<td>364</td>
<td>(24.1)</td>
</tr>
<tr>
<td>Factors related to baby</td>
<td>1151</td>
<td>38.0</td>
</tr>
<tr>
<td>Baby is wakeful overnight</td>
<td>625</td>
<td>(54.3)</td>
</tr>
<tr>
<td>Unsettled baby</td>
<td>586</td>
<td>(50.9)</td>
</tr>
<tr>
<td>Feeding baby</td>
<td>247</td>
<td>(21.5)</td>
</tr>
<tr>
<td>Baby cries a lot</td>
<td>242</td>
<td>(21.0)</td>
</tr>
<tr>
<td>Baby has been sick</td>
<td>138</td>
<td>(12.0)</td>
</tr>
<tr>
<td>Other (e.g. colic, reflux, premature baby, disability)</td>
<td>272</td>
<td>(23.7)</td>
</tr>
<tr>
<td>Stressful life events</td>
<td>852</td>
<td>28.2</td>
</tr>
<tr>
<td>Moving house</td>
<td>318</td>
<td>(37.3)</td>
</tr>
<tr>
<td>Death in family/death of woman’s mother</td>
<td>179</td>
<td>(21.0)</td>
</tr>
<tr>
<td>Unplanned pregnancy</td>
<td>142</td>
<td>(16.7)</td>
</tr>
<tr>
<td>Missing work</td>
<td>138</td>
<td>(16.2)</td>
</tr>
<tr>
<td>Unwell baby</td>
<td>134</td>
<td>(15.7)</td>
</tr>
<tr>
<td>Other (e.g. partner travelling, illness in family)</td>
<td>190</td>
<td>(22.3)</td>
</tr>
<tr>
<td>Relationship issues</td>
<td>783</td>
<td>25.9</td>
</tr>
<tr>
<td>Unsupportive partner</td>
<td>449</td>
<td>(57.3)</td>
</tr>
<tr>
<td>Unsupportive family/and or in-laws</td>
<td>420</td>
<td>(53.6)</td>
</tr>
<tr>
<td>Partner’s mental illness</td>
<td>86</td>
<td>(11.0)</td>
</tr>
<tr>
<td>Unsupportive friends</td>
<td>44</td>
<td>(5.6)</td>
</tr>
<tr>
<td>Childhood issues</td>
<td>453</td>
<td>15.0</td>
</tr>
<tr>
<td>Family breakdown</td>
<td>284</td>
<td>(62.7)</td>
</tr>
<tr>
<td>Loss of a parent</td>
<td>102</td>
<td>(22.5)</td>
</tr>
<tr>
<td>Childhood physical abuse</td>
<td>89</td>
<td>(19.7)</td>
</tr>
<tr>
<td>Other (e.g. childhood sexual abuse, abuse at school)</td>
<td>98</td>
<td>(21.6)</td>
</tr>
</tbody>
</table>

a Multiple options were possible  
b In this column, percentages show for sub-variables  
c Denominator is all women for whom the question was answered  
d Denominator is the number who responded ‘yes’ to the main category
relationship (94 versus 87%) and less likely to be under 25 years (13 versus 16%). More than half of the callers to PANDA were women from the state of Victoria, with less women calling from other states. This might be explained by the fact that PANDA started as a Victorian-based organisation and therefore had an established presence in Victoria, before becoming a national service in 2010. It is important to increase awareness about the available services for women in the community.

### Strengths and limitations

To our knowledge, this national study is the first of its kind published, contributing a large dataset describing women accessing a large perinatal Helpline service, thus is a rich source of data on Helpline service utilisation and caller characteristics. The study used retrospective routinely collected data which had not been collected for the purpose of this study, and the accuracy of data might have been affected by the interpretation of people entering data (Powell et al. 2003). There may also be some callers who had been entered as an ‘initial’ caller more than once during the study period because they had re-engaged with the service after a significant period of non-contact; however, we believe that this number would be relatively low.

Although most women received referrals from PANDA, information on the outcome of the referrals were missing, e.g. there were no data on whether referrals were timely and whether the woman attended and engaged with services—therefore, this could not be reported here.

Missing data in a number of quantitative data fields is also a limitation of the dataset provided for analysis; more detailed data were recorded in the qualitative data section in many instances, which may explain why the quantitative data fields were not always completed consistently. PANDA was recommended to revise its data collection software and processes to facilitate more reliable and user friendly data entry. Since the time of the evaluation, a new purpose-designed data collection system has been introduced at PANDA, leading to significant improvements in the quality of information being collected. Future studies using qualitative data from the PANDA database will provide more detailed information about caller characteristics and experiences.

### Conclusion

A substantial proportion of women who called PANDA had complex psychosocial issues, and many had received no prior

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**Table 7 PANDA’s interventions**

<table>
<thead>
<tr>
<th>What PANDA provided(^a) (n = 3023)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>2963</td>
<td>98.0</td>
</tr>
<tr>
<td>Information</td>
<td>2472</td>
<td>81.8</td>
</tr>
<tr>
<td>Self-help strategies</td>
<td>2042</td>
<td>67.6</td>
</tr>
<tr>
<td>Lifestyle strategies</td>
<td>1595</td>
<td>52.8</td>
</tr>
<tr>
<td>ASIST(^b) suicide Intervention Model</td>
<td>190</td>
<td>6.3</td>
</tr>
<tr>
<td>High needs interventions</td>
<td>118</td>
<td>3.9</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>45</td>
<td>1.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Referrals made (n = 1655)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1320</td>
<td>79.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of referrals(^a) (n = 1250)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counsellor</td>
<td>349</td>
<td>27.9</td>
</tr>
<tr>
<td>GP</td>
<td>294</td>
<td>23.5</td>
</tr>
<tr>
<td>Monash Medicines Information Centre</td>
<td>288</td>
<td>23.0</td>
</tr>
<tr>
<td>Perinatal depression support group</td>
<td>236</td>
<td>18.9</td>
</tr>
<tr>
<td>Information about Better Access-Medicare funded</td>
<td>141</td>
<td>11.3</td>
</tr>
<tr>
<td>Mental health service</td>
<td>127</td>
<td>10.2</td>
</tr>
<tr>
<td>Perinatal depression playgroup</td>
<td>76</td>
<td>6.1</td>
</tr>
<tr>
<td>Crisis Assessment Team (CAT)</td>
<td>64</td>
<td>5.1</td>
</tr>
<tr>
<td>Mother Baby Unit</td>
<td>53</td>
<td>4.2</td>
</tr>
<tr>
<td>Other (e.g. psychiatrist, emergency department, family violence service)</td>
<td>402</td>
<td>32.2</td>
</tr>
</tbody>
</table>

\(^a\) Multiple options were possible

\(^b\) Applied Suicide Intervention Skills Training

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mental health diagnosis or treatment at the time of their first call. Over the study period, there was a substantial increase in calls to the Helpline.

Effective strategies are needed for early identification and support for women impacted by poor emotional health in the perinatal period. The number of women in this sample noted to have been receiving inadequate care also highlights the need to address barriers to women receiving adequate treatment, including access to high quality, specialist perinatal mental health services.

PANDA plays an important role in providing support, information and referral to a substantial number of women experiencing perinatal mental illness. The evaluation of the PANDA Helpline suggests that PANDA is meeting their aims of addressing the impact of perinatal anxiety and depression through providing information and support to callers (Biggs et al. 2018; Biggs et al. 2015; Shafiei et al. 2014).

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval and consent to participate Ethics approval was obtained from the Faculty of Health Sciences Human Ethics Committee, La Trobe University (reference FHEC 11/32).

For this type of study, formal consent is not required.

References


37 year old woman. Participant in Sub-study three

“I came through the crisis of thinking I couldn't mother my daughter and would have to put her up for adoption. PANDA's advice sent me to appropriate help... now their ongoing assistance makes me feel less ashamed of my problems, so that I am still accessing help as needed. So, I gained the capacity to experience motherhood.”
Chapter Seven
Reasons new and re-engaging callers contact the Helpline

SUB-STUDY TWO


This paper considers the reasons why someone picks up the phone for the first time and asks PANDA for help. Helpline intake forms, completed when a new or re-engaging caller contacts the Helpline, were analysed to better understand help-seeking behaviours and factors which may have contributed to the callers’ emotional distress. Many callers described complex and interrelated psychosocial factors, such as social isolation, or difficult experiences in childhood. Close to a third of callers were identified as ‘at risk’, including a number who were experiencing thoughts of suicide and/or self-harm.

CONTRIBUTION TO PAPER

I declare that I have made a substantial contribution to this paper, including contributing to the overall study design. I undertook data management and analysis, with the support of my supervision team, and drafted the paper. The co-authors all contributed to the overall study design, intellectual input, and editing of the manuscript.

Laura Biggs

I declare that Laura Biggs made a substantial contribution to this paper. She contributed to all aspects and drafted the paper.

Helen McLachlan
ABSTRACT

In Australia, the PANDA - Perinatal Anxiety & Depression Australia National Helpline (the Helpline) offers support to callers impacted by emotional health challenges in the perinatal period. Callers receive counselling from professional staff and peer support from volunteers. An understanding of factors that contribute to callers’ experiences of emotional distress, as well as potential barriers and facilitators to help-seeking, can be used to inform future service design and delivery.

A caller intake form is completed by Helpline staff when an individual contacts the service for the first time, or re-engages after a period of non-contact. We analysed all intake forms of individuals calling about their own (not someone else’s) emotional wellbeing from the middle month of each season in 2014: January, April, July, and October. Content analysis was undertaken, focusing on caller profile, patterns of help-seeking, and reasons for caller engagement.

Of the 365 calls, the majority were from women (n=358, 98%) who were pregnant (n=59, 16%) or had a child 12 months of age or younger (n=241, 75%). Many were seeking support regarding depression (n=186, 51%) or anxiety (n=162, 44%), with a number seeking help for both (n=71, 20%). Callers described complex and interrelating factors that had contributed to their emotional distress, including: stressful life events; difficult pregnancy, birthing and parenting experiences; social isolation; and histories of mental health difficulties.

A significant number of parents experience emotional health challenges in the perinatal period, however research indicates many will not receive adequate treatment. Callers’ described complex and interrelating psychosocial factors relating to their distress, highlighting the need for health professionals to undertake thorough psychosocial assessments during the perinatal period to ensure those that would benefit from additional support are identified,
and high quality care provided. Telephone Helplines like PANDAs can assist to overcome barriers to care and provide specialised perinatal mental health support to families.

**What is known about the topic**

- Many parents experience stress, anxiety, or depression in the perinatal period.
- Factors such as social isolation, inadequate support, or mental health history place some individuals at greater chance of mental health difficulties.
- Not all women who experience mental health difficulties will seek help or receive adequate treatment.

**What this paper adds**

- Complex and often interrelated psychosocial factors contributed to callers’ emotional distress.
- A number of callers were in crisis; almost a third of callers were identified as being ‘at risk’ at intake, including a number who were experiencing thoughts of suicide or self-harm.
- Telephone Helplines play an important role in helping to overcome barriers to care, and providing accessible specialised perinatal mental health support.

**INTRODUCTION**

Anxiety and depression are common in the perinatal period (Gavin et al., 2005; O’Hara & Wisner, 2014; O’Hara & Swain, 1996), yet clinical recognition and treatment of perinatal mood disorders remains poor. Up to three quarters of women with anxiety and/or depression are not identified by health care providers (Coates, Schaefer, & Alexander, 2004; Spitzer, Williams, Kroenke, Hornyak, & McMurray, 2000).

A range of psychosocial factors are known to increase a woman’s chance of developing a mood disorder in the perinatal period, including a lack of partner support (Biaggi, Conroy, Pawlby, & Pariante, 2016; Lancaster et al., 2010) or social support (Biaggi et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); a history of abuse or
domestic violence (Biaggi et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008); personal history of mental illness (Biaggi et al., 2016; Dennis, Falah-Hassani, Brown, & Vigod, 2016; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); unintended pregnancy (Biaggi et al., 2016; O’Hara & McCabe, 2013); adverse life events and high perceived stress (Biaggi et al., 2016; Dennis et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O’Hara & McCabe, 2013); past and present pregnancy complications (Biaggi et al., 2016; O’Hara & McCabe, 2013); and low self-esteem (Biaggi et al., 2016; O’Hara & McCabe, 2013).

Not all women with symptoms of perinatal anxiety or depression seek help (Dennis & Chung-Lee, 2006; Gavin, Meltzer-Brody, Glover, & Gaynes, 2015; Woolhouse, Brown, Krastev, Perlen, & Gunn, 2009). In a Victorian prospective cohort study of nulliparous women’s physical and emotional health during pregnancy and postpartum (the Maternal Health Study), only half the women who reported symptoms of anxiety and/or depression had sought help from a health professional (Woolhouse et al., 2009). The study highlighted under-reporting of anxiety symptoms in particular; only 25% of women reporting anxiety symptoms had sought help from a General Practitioner, in contrast to 46% of women reporting symptoms of depression, or 64% of women reporting co-occurring symptoms of anxiety and depression. The most common reasons women did not seek help were a belief that they could deal with their difficulties themselves; being too busy; feeling too embarrassed; or not having anyone with whom they were comfortable to discuss their experiences. Other identified help-seeking barriers include difficulties related to attending appointments, a lack of awareness of postpartum depression, and a perceived lack of time (Dennis & Chung-Lee, 2006).

**Telephone and peer support interventions**

Telephone interventions, including telephone peer support and counselling, have been designed to assist families in the perinatal period with issues such as breastfeeding and emotional health (Lavender, Richens, Milan, Smyth, & Dowswell, 2013). Telephone support
has the potential to overcome some barriers to care including geographical isolation (Lavender et al., 2013; Ugarriza & Schmidt, 2006), fear of stigmatisation, and difficulty accessing transport and attending appointments in person (Dennis & Kingston, 2008; Galinsky, Schopler, & Abell, 1997). Women themselves have also expressed a preference for ‘talking therapies’ over pharmacological treatment (Dennis & Chung-Lee, 2006). Participants in the Maternal Health Study who had sought help for their mental health more commonly reported emotional support as helpful, compared to practical support, medication or counselling (Woolhouse et al., 2009). An earlier Victorian study of women’s experiences of depression following childbirth asked women what advice they would give to others having a similar experience, with the most common suggestion being to find someone to talk to (Small, Brown, Lumley, & Astbury, 1994).

**PANDA - Perinatal Anxiety & Depression Australia National Helpline**

PANDA - Perinatal Anxiety & Depression Australia (formerly PANDA Post and Antenatal Depression Association) was founded in the 1980s in Melbourne, Australia as a peer support organisation offering support to women experiencing postnatal depression. The organisation has evolved since this time, and now provides both counselling from professional staff, and peer support from volunteers who have themselves experienced or supported someone with a perinatal mood disorder. The Helpline has also expanded its reach to include fathers’ mental health, and anxiety. PANDA offers support to callers in multiple ways, with a key component of the support being a National Helpline (the Helpline). The Helpline is free, and available to callers Monday-Friday, 10am-5pm (since the time of data collection service hours have increased to 9am-7.30pm). Each year over 10,000 calls are made to and from the Helpline (Shafiei et al., 2014).
Call process

When an individual phones the Helpline for the first time (or re-engages after a period of non-contact) a member of staff completes a caller intake form. This form includes details such as: the caller’s name and contact details (although a caller may choose to remain anonymous); gender; state of residence; if the caller is pregnant and/or has children; mental health history; if the caller is already linked with mental health services or supports; risk of harm to self or others; and the reason/s for the call. The form includes a combination of checkbox and free text data, and aims to identify callers who may be at high or immediate risk and require crisis assistance; facilitate an understanding of what made the caller pick up the phone and seek assistance; and help to prioritise service delivery. In most instances, the caller will receive a call back from PANDA the same day to allow a full biopsychosocial and risk assessment to be undertaken, however if the caller is identified as being at high or immediate risk of harm to themselves or others, the call is immediately taken by a senior counsellor.

In 2013, an independent evaluation of the Helpline was undertaken by researchers from the Judith Lumley Centre, La Trobe University, Melbourne, Australia. The evaluation included four components: an exploration of the views and experiences of new callers to the helpline (Biggs et al., 2015); a description of the PANDA caller profile, demand and referral pathways; telephone interviews with callers assessed as having moderate-severe needs; and key informant consultations with PANDA staff, volunteers (Biggs et al., 2018), and key stakeholders.

Some of the key findings from the evaluation were: calls to PANDA had increased substantially over time, with a 70% increase between July 2010 and October 2013; and 40% of callers were assessed as ‘high needs’, experiencing significant biopsychosocial symptoms of perinatal depression and/or anxiety, isolation, complex situations or inadequate care and support. Overall, caller satisfaction was very high, with over 98% of callers agreeing that
PANDA staff were encouraging, reassuring and supportive, and that they provided non-judgemental support (Biggs et al., 2015). There was limited information collected during the evaluation that could be used to better understand callers’ help-seeking behaviours, or the barriers and facilitators to help-seeking for perinatal mood disorders. Past research has also highlighted significant knowledge gaps regarding women’s help-seeking behaviour (Dennis & Chung-Lee, 2006; Woolhouse et al., 2009). Given these factors, we aimed to explore and describe the PANDA caller profile, patterns of help-seeking, and reasons for caller engagement. This study is one of the first to use data from a community-based service to better understand help-seeking for emotional distress in the perinatal period.

METHODS
A retrospective, descriptive design was used. Specific study aims were to explore: callers’ descriptions of why they had contacted the Helpline, including what contributing and contextual factors led them to call the Helpline for the first time, or re-engage with the service after a period of non-contact; callers’ mental health presentation, history, and assessed risk at point of first contact with the Helpline; and what callers hoped to gain from their contact with the service. Free text recorded by the intake staff and pre-coded (tick box) data were used to help address the research aims.

Sampling procedures
All PANDA intake forms from the middle month of each season in 2014 were collected and assessed for eligibility (January, April, July and October). These months were selected to take into account possible variation in callers’ mood at different times and seasons of the year. Intake forms recording the details of new or re-engaging callers who had called regarding their own mental health were included. Forms were ineligible for inclusion if they were calls from someone who had contacted the service regarding someone else’s mental health (listed as third-party caller), or from existing callers who were already in contact with the Helpline. In
most cases, it was possible to identify if the intake form was for a new, re-engaging, existing (currently engaged with the service), or third-party caller such as a health professional. In the few instances this could not be ascertained these forms were listed as ‘unknown’.

Data collection

Eligible intake forms were allocated a unique identifier with all personal details removed. Tick-box and free text data from the forms were entered into a Microsoft Access database. Tick-box data included caller presentation (e.g. teary, calm), mental health history, and risk of harm to self and others. The majority of free text data collected at intake was specific to the reason for the call, however there were also comments collected regarding the callers’ existing supports or carers, reported risk, and if any action was taken by the intake worker at the time of the call.

Data analysis

For quantitative data, analysis involved descriptive statistics undertaken using STATA (StataCorp, 2015), with data presented as frequencies and percentages. Free text data were analysed using qualitative content analysis (Altheide, 1987; Krippendorff, 2013; Sandelowski, 2000) by LB and HM. Unlike quantitative content analysis which applies pre-existing codes to the data, qualitative content analysis is a reflexive process that generates codes from the data itself (Sandelowski, 2000). Free text data were coded by hand using In Vivo coding, and a code book developed that included descriptions and examples of each code (Saldaña, 2013). Codes were then organised into categories, based on commonalities in the data (Teddlie & Tashakkori, 2009). Identifiers used for illustrative quotes provided include call type (new or re-engaging/previous caller), and age of youngest child or pregnancy gestation. Unless otherwise specified, quotes are from female callers.
Ethics approval was obtained from the La Trobe University Faculty of Health Sciences Human Ethics Committee, application number FHEC11/32.

RESULTS

Caller characteristics

Of the 590 intake forms completed during the study period, 365 were calls from new and re-engaging callers (Figure 1). Of the 225 forms that were ineligible the majority (n=114) were due to the call being made by a third party.

FIGURE 1: INTAKE FORM ELIGIBILITY ASSESSMENT AND INCLUSION PROCESS

Ninety-eight percent of callers were female (358/364), and almost half (48%; 172/361) resided in the state of Victoria (Table 1). Sixteen percent of callers were themselves pregnant or had a partner who was, with 7% expecting their first child. Of those callers with children, most had one (56%; 197/352) or two (26%; 92/352) children. The age of the youngest child varied: 16% were ≤6 weeks; 15% were 7-12 weeks; and 21% were 4-6 months. Although PANDA is a perinatal service focusing on pregnancy and the first 12 months of a child’s life, 18% (55/318) of callers were either not pregnant or did not have a child less than 12 months
Information regarding country of birth and language were infrequently collected; most intake forms (75%; 274/365) did not document these details (which may indicate that this field was only completed if an interpreter had been needed).

### TABLE 1: CHARACTERISTICS OF CALLERS

<table>
<thead>
<tr>
<th></th>
<th>New caller n=301</th>
<th>Previous caller n=64</th>
<th>Total n=365</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>295 (98.0)</td>
<td>63 (100.0)</td>
<td>358 (98.4)</td>
</tr>
<tr>
<td>Male</td>
<td>6 (2.0)</td>
<td>0 (0.0)</td>
<td>6 (1.6)</td>
</tr>
<tr>
<td><strong>Pregnant (self or partner)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>50 (16.6)</td>
<td>9 (14.1)</td>
<td>59 (16.2)</td>
</tr>
<tr>
<td><strong>Children (including step children)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>29 (9.8)</td>
<td>3 (5.5)</td>
<td>32 (9.1)</td>
</tr>
<tr>
<td>One child</td>
<td>173 (58.2)</td>
<td>24 (43.6)</td>
<td>197 (56.0)</td>
</tr>
<tr>
<td>Two children</td>
<td>72 (24.2)</td>
<td>20 (36.4)</td>
<td>92 (26.1)</td>
</tr>
<tr>
<td>Three children or more</td>
<td>23 (7.7)</td>
<td>8 (14.6)</td>
<td>31 (8.8)</td>
</tr>
<tr>
<td><strong>Age of most recent child</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤6 weeks</td>
<td>48 (18.0)</td>
<td>3 (6.0)</td>
<td>51 (16.0)</td>
</tr>
<tr>
<td>7-12 weeks</td>
<td>39 (14.5)</td>
<td>9 (18.0)</td>
<td>48 (15.1)</td>
</tr>
<tr>
<td>4-6 months</td>
<td>63 (23.5)</td>
<td>5 (10.0)</td>
<td>68 (21.4)</td>
</tr>
<tr>
<td>7-12 months</td>
<td>59 (22.0)</td>
<td>15 (30.0)</td>
<td>74 (23.3)</td>
</tr>
<tr>
<td>&gt;12 months</td>
<td>59 (22.0)</td>
<td>18 (36.0)</td>
<td>77 (21.2)</td>
</tr>
<tr>
<td><strong>State of residence</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>141 (47.0)</td>
<td>31 (50.8)</td>
<td>172 (47.6)</td>
</tr>
<tr>
<td>New South Wales</td>
<td>75 (25.0)</td>
<td>13 (21.3)</td>
<td>88 (24.4)</td>
</tr>
<tr>
<td>Queensland</td>
<td>38 (12.7)</td>
<td>8 (13.1)</td>
<td>46 (12.7)</td>
</tr>
<tr>
<td>South Australia</td>
<td>14 (4.7)</td>
<td>4 (6.6)</td>
<td>18 (5.0)</td>
</tr>
<tr>
<td>Western Australia</td>
<td>22 (7.3)</td>
<td>5 (8.2)</td>
<td>27 (7.5)</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>6 (2.0)</td>
<td>0 (0.0)</td>
<td>6 (1.7)</td>
</tr>
<tr>
<td>Tasmania</td>
<td>3 (1.0)</td>
<td>0 (0.0)</td>
<td>3 (0.8)</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1 (0.3)</td>
<td>0 (0.0)</td>
<td>1 (0.3)</td>
</tr>
</tbody>
</table>

* A Caller’s who had previously contacted the Helpline and were re-engaging with the service after a period of non-contact
* Only those with children

The tick-box section of the intake form allowed for documentation of information regarding the caller’s presentation or perceived emotional state at the time of call. Of those who had information documented regarding their presentation (67%), the most frequent description item selected was calm (52%) or teary (42%) (Table 2).
Of the 301 new callers to the Helpline, data regarding how they had heard about the service were collected for 235 (66%). The largest proportion of new callers heard about the Helpline from internet searches or websites (34%; 79/235), with a further 22% (51/235) referred from a health care provider, such as a General Practitioner, Maternal and Child Health Nurse, or Lactation Consultant.
**Risk assessment and mental health history**

A past history of mental health difficulties was reported by 103 callers (28%) at intake (Table 3). A majority of these callers (86%) identified a specific mood disorder, of which anxiety, depression and postnatal depression were the most common. Others described a less specific past history of difficult or stressful life experiences. Just under half of the 103 callers (43%) reported previously receiving counselling or taking psychotropic medications. It is unknown if callers who disclosed a history of a specific mood disorder had previously received a formal diagnosis.

**TABLE 3: MENTAL HEALTH HISTORY AND RISK ASSESSED AT INTAKE**

<table>
<thead>
<tr>
<th>Mental health history (self-reported)</th>
<th>Total n=365</th>
<th>%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>34</td>
<td>33.0</td>
</tr>
<tr>
<td>Depression</td>
<td>23</td>
<td>22.3</td>
</tr>
<tr>
<td>Postnatal Depression</td>
<td>23</td>
<td>22.3</td>
</tr>
<tr>
<td>Some mental health history, non-specific</td>
<td>21</td>
<td>20.4</td>
</tr>
<tr>
<td>Past history psychotropic medication</td>
<td>14</td>
<td>13.6</td>
</tr>
<tr>
<td>Past history counselling</td>
<td>9</td>
<td>8.7</td>
</tr>
<tr>
<td>Other mental health history (i.e. obsessive compulsive)</td>
<td>9</td>
<td>8.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Identified risk at intake</th>
<th>110</th>
<th>30.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health status</td>
<td>80</td>
<td>72.7</td>
</tr>
<tr>
<td>Suicidal thoughts</td>
<td>45</td>
<td>40.9</td>
</tr>
<tr>
<td>Harm to child</td>
<td>12</td>
<td>10.9</td>
</tr>
<tr>
<td>Self-harm</td>
<td>8</td>
<td>7.3</td>
</tr>
<tr>
<td>Alcohol and/or other drugs</td>
<td>2</td>
<td>1.8</td>
</tr>
<tr>
<td>Family violence</td>
<td>2</td>
<td>1.8</td>
</tr>
</tbody>
</table>

*multiple options could be selected, therefore percentages may add to greater than 100

An assessment of being ‘at risk’ due to mental health status is documented by PANDA staff when a caller is experiencing significant ‘moderate to severe’ symptoms of mental health decline which are impacting on their ability to care for themselves and/or their infant. At intake, 110 callers (30%) were assessed as being impacted by some form of risk (Table 3). Most commonly, callers were assessed as being at risk due to their mental health status (73%), or suicidal ideation (40%).
Reasons for calling the Helpline

One of the main objectives of the intake form is to gain an understanding of why a caller has contacted the Helpline, in order to inform service prioritisation and delivery. This information is collected in two ways; pre-coded tick boxes, with common reasons for calling, and where more than one box could be ticked, and a free text section that allows the intake worker to document the caller’s individual circumstances and story regarding why they contacted the Helpline. Only one caller had no reason at all for their call completed. Overall, 90% of callers had a reason for call documented using the pre-coded section of the form (Table 2). The most common reasons were depression (56%; 186/330), anxiety (49%; 162/330), emotional changes (22%; 72/330), history of mental health difficulties (19%; 61/330), and relationship issues (13%; 44/330). A number of callers (9%) were seeking information regarding the use of psychotropic medications in pregnancy and/or breastfeeding.

There was also documentation in the free text section about the person’s reasons for calling the Helpline in 98% of cases, and four key themes were identified: social factors; reproductive and parenting factors; not feeling ‘right’; and ‘to get help and feel better’ (Figure 2).
FIGURE 2: REASONS NEW AND RE-ENGAGING CALLERS MAKE CONTACT WITH THE PANDA PERINATAL ANXIETY & DEPRESSION HELPLINE

Social factors
Callers’ descriptions of why they had contacted the Helpline demonstrated a range of complex and interrelating social factors. Many were affected by social isolation and limited access to resources and supports:

‘Lonely, sad, isolated - missing friends and family’ (intake form 199, new caller, 8 months pregnant)
‘Has been away from home since [last month], baby born [prematurely]. Feeling down, worried about 4-year-old at home. Lonely, isolated.’ (intake form 739, new caller, 4 week old child)

Changes to relationships with an intimate partner or family member contributed to some callers’ emotional distress:

‘Partner not aware of call, been trying to talk to him. Worried about marriage. Hurts to breathe – stress’ (intake form 514, new caller, 6 month old child)

‘Ex-husband refusing to leave house, not sure how to manage. Feeling powerless’ (intake form 531, previous caller, 2 month old child)

Some callers described difficult situations of intimate partner violence and/or issues regarding alcohol and other drugs:

‘Partner drinking heavily and periodically threatens to hit her - mainly when they argue’ (intake form 120, new caller, 12 month old child)

Callers were also affected by decisions regarding their own or their partner’s employment. Some women with a partner who had recently returned to work (or were about to) following a period of leave described feeling less supported and more anxious:

‘[Husband] back to work this week, upset when on own, transition?? Teary emotional - can’t explain how feeling’ (intake form 209, new caller, 2.5 week old child)

‘[Husband] going back to work has left her feeling unsupported’ (intake form 532, new caller, 7 month old child)

Some women who were themselves returning to work following maternity leave also found this transition back to paid employment difficult:
‘Diagnosed with mild [postnatal depression] early on - no treatment, increased sleep - felt better... Now preparing to return to work - feeling anxious, panic, strong attachment to baby’ (intake form 164, new caller, 4 week old child)

Stressful experiences of grief and loss had also affected some callers’ emotional health:

‘Mother died suddenly when pregnant with first child. Anxiety attacks - describes as daily episodes’ (intake form 513, new caller, 8 month old child)

‘Overwhelmed; baby born [prematurely], [mother in law] died suddenly’ (intake form 775, new caller, 8 week old child)

Reproductive and parenting factors

Factors relating to reproductive decisions, pregnancy and parenting had influenced some callers’ emotional health and reasons for contacting the Helpline. For some, this included decisions about whether to plan another pregnancy, to continue with a current pregnancy, or feelings regarding past reproductive decisions:

‘First pregnancy, planned but now having second thoughts about continuing’ (intake form 511, new caller, 8 weeks pregnant)

“So dumb’ to have another baby’ (intake form 714, new caller, 3 week old child - previous postnatal depression)

Other callers described difficult experiences of complex pregnancy, or negative/traumatic birth experiences:

‘[Diagnosed] self with [postnatal depression]. Wife traumatic birth - thought would lose both’ (intake form 789 – male, new caller, 4 week old child)
‘[Was in the Intensive care unit for] one week - medical appointments - traumatic birth. Separated from baby for days (no holding)... Not happy or excited to be a Mum - not happy about how feeling’ (intake form 1098, new caller, 4.5 month old child)

For some callers their emotional health had been affected by experiences of perinatal loss, including miscarriage, neonatal death, or stillbirth:

‘Caller had baby who died... ’still haunts me every day’” (intake form 793, new caller, 8 month old child)

‘35 weeks pregnant - worried about how feeling... [antenatal depression]... lost two babies last year - very anxious [and] fearful. Worried something may go wrong. Worst felt” (intake form 719, new caller, 35 weeks pregnant)

Difficult parenting experiences were described by some callers, including a sense that their experience had not aligned with their expectations:

‘[Caesarean birth]. Can't do what I think I should be able to do. ’Not what I signed up for’” (intake form 408, new caller, 12 day old child)

Many callers highlighted the challenge of balancing the needs of a young baby with the care of an older child:


‘Tired stressed angry resentful at [children]. Yells/smacks. More forgetful. Wants to be [a] better Mum - has been tired for five years’ (intake form 461, new caller, 3 year old child)
For some callers concerns regarding feeding, sleep and settling the baby were the main factors that motivated them to call the helpline:

‘Crying. Baby doesn't sleep... too much to manage. Managing sleep difficult - past three nights barely any sleep. Could shake her – [but] hasn't. Yelling at baby’ (intake form 721, new caller, 15 week old child)

‘Baby very unsettled, not much sleep... anxious when home alone with baby. Angry and frustrated at not being able to settle baby’ (intake form 524, new caller, 3.5 week old child)

Callers with a baby or older child who was unwell described fear and uncertainty regarding their child’s health, as well as what the future may hold:

‘Baby born at 24 weeks.... In NICU. Struggling to cope and manage fear with current situation and the future. Wants help with this’ (intake form 1020, new caller, 1 month old child)

‘Toddler may have neurological disorder - watch and wait (long time)...lots of not knowing. Feeling helpless/tormented’ (intake form 519, new caller, 4 month old child)

Not feeling ‘right’

Analysis of callers’ descriptions of why they had contacted the service highlighted that for many, it was not feeling themselves, or ‘right’ which had been the motivator to call the Helpline. Although each caller presented with their own context and experience, it became apparent during the analysis process that for many callers a complex interplay of relevant reproductive, parenting and social factors had contributed to mental health decline, with some callers identifying that they did not feel themselves:
'Confused about how feeling, ? Baby blues, ? Overwhelmed, no joy, upset, not self'
(intake form 1014, new caller, 3 month old child)

“Thought losing mind’ - not sure if PND, tired, crying all the time - feels sad, can’t think straight, ’doesn’t feel right” (intake form 1103, new caller, 5 month old child)

Callers discussed feeling as though their mental health was in decline, or ‘going downhill’. Some callers highlighted a fear of further mental health decline, and indicated that they wanted to put measures in place to prevent this from occurring:

‘Thought it was baby blues but it never ended. Going downhill. Up and down. At times thinks of suicide when really stressed’ (intake form 207, new caller, 10 month old child)

‘Not coping. Doesn’t know what to do when he cries. Overwhelmed. Escalating - worst day today’ (intake form 1024, new caller, 5 week old child)

‘Melt down this morning - both children crying - felt overwhelmed... doesn’t want to go downhill - two prior episodes of going downhill’ (intake form 456, new caller, 1 month old child)

‘To get help and feel better’

Callers are not asked to define what it is they are hoping to gain from their contact with the Helpline at intake, however some did express specific things they would like to address or help they wanted; this is represented by the theme ‘to get help and feel better’

Some callers were ‘at their wits’ end’ and didn’t know what to do, suggesting a need for practical advice:

‘Breaking point don’t know what to do. Scared. I don’t know how to keep going - don’t know what to do?’ (intake form 464, new caller, 6 week old child)
‘Really anxious [and] nervous - physical symptoms - paranoid about being alone - may not be able to care for baby adequately... Not sure what to do?’ (intake form 1114, new caller, 7 month old child)

For some, gaining an understanding of perinatal emotional health and why they may have been feeling the way they had was of great importance:

‘Getting more emotional [and] teary - feels failing baby. Mood up and down, wants to understand why feeling this way, ‘fragile’ - unsettled feeling’ (intake form 438, previous caller, 6 month old child)

‘Teary, anxious self-esteem - out of character... Wanted baby - why am I feeling this?’ (intake form 1035, new caller, 27 weeks pregnant)

Some were seeking an opportunity to discuss how they were feeling:

‘Caller has had [two] miscarriages, difficulties making decision to have another baby - anxiety on/off. Needing to talk through emotions’ (intake form 102, previous caller, 2 year old child)

‘Struggle dealing with both [children]. Sleeps sometimes. Hopelessness. Just wants someone to listen’ (intake form 1082, new caller, 6 month old child)

Information regarding perinatal emotional health and/or referrals was important to some callers:

‘Anxious and depressed - wants to be prepared before baby comes. Looking for info and referrals to perinatal services’ (intake form 452, new caller, 28 weeks pregnant)

Callers who had been prescribed psychotropic medication frequently expressed concern regarding the possible impact on their baby, either during pregnancy or via breast milk. Some
women who had been prescribed medication had delayed initiating the treatment due to these concerns, and were seeking reassurance and information regarding possible risks:

‘Looking for [mother baby unit] referral details - not sure if needs admission, worried meds will harm baby - refusing [to take]... Extreme anxiety, watching – hyper-vigilant’
(intake form 535, new caller, 4 month old child)

‘Rough few weeks, birth induced... unsettled baby, difficulties feeding, readmission to hospital. 'Devastated'... Has seen GP, has script but not keen to take meds. Feeling this way for weeks’ (intake form 854, previous caller, 8 week old child)

DISCUSSION

This is one of the first studies to use data from a community perinatal mental health service to investigate patterns of help-seeking, risk status, and mental health presentation and history. These data show callers are impacted by complex social, reproductive and parenting factors, with 30% of callers identified as being at substantial risk at intake, highlighting the importance of services like PANDA in helping to meet demand for perinatal mental health care.

Many of the complex social, reproductive and parenting factors described have been previously established as risk factors for poor emotional health in the perinatal period. These include: a past history of mental health difficulties (Biaggi et al., 2016; Dennis et al., 2016; Leigh & Milgrom, 2008; O'Hara & McCabe, 2013; Schmied et al., 2013); limited partner support (Biaggi et al., 2016; Lancaster et al., 2010) or social support (Biaggi et al., 2016; Lancaster et al., 2010; O'Hara & McCabe, 2013); stressful life events (Biaggi et al., 2016; Lancaster et al., 2010; Leigh & Milgrom, 2008; O'Hara & McCabe, 2013); complex pregnancy (Biaggi et al., 2016; O'Hara & McCabe, 2013); and difficult infant temperament (O'Hara & McCabe, 2013). More than a quarter of callers in this study disclosed a history of mental
health difficulties, one of the strongest predictors of perinatal mood disorders (Schmied et al., 2013). The reasons callers contacted the Helpline also reflects the perinatal period as a time of significant transition, demonstrating the impact of unique stressors in the perinatal period, with a number of callers expressing concerns regarding emotional changes, relationships, sleep deprivation, medication safety, feeding, and not having any support.

A significant number of callers may have been in crisis when they contacted PANDA, with almost one third identified as having some level of risk at intake, such as thoughts of self-harm or suicide. While maternal mortality in Australia is decreasing, maternal deaths due to psychosocial causes are rising, with most attributed to suicide, despite the fact that women in the perinatal period are ‘among the most medically supervised members of the population’ (Humphrey, 2016, p. 351). Other identified risk factors included intimate partner violence (IPV), however disclosures were much lower than prevalence estimates, which have indicated up to 20% of women experience violence in pregnancy (Devries et al., 2010; Gazmararian et al., 1996; Walsh, 2008) and are thought to be an underestimate due to under-reporting (Hooker, Samaraweera, Agius, & Taft, 2016). It is likely that some callers would need a longer period of time to feel safe to disclose difficult circumstances such as these to Helpline staff (Feder et al., 2009; Rose et al., 2011). Since the time of the study PANDA has made changes to the call intake process. Calls are now answered by a member of the professional counselling staff (when available), meaning a full biopsychosocial and risk assessment can be undertaken during that first call. The caller may therefore have the opportunity to build a relationship with the counsellor before questions regarding IPV are raised, potentially leading to increased disclosures of early life trauma and IPV (T. Smith, PANDA CEO, personal communication, January 2018).

The central influence of these psychosocial factors for callers to the Helpline demonstrate the important role social and historical factors play in women’s mental health in the perinatal
period. Many of these risk factors can be identified by care providers during pregnancy and the early postpartum period, which would provide the opportunity for extra measures to be put in place to support women’s mental health in pregnancy and the transition to parenthood (Austin, Highet, & Expert Working Group, 2017). A number of callers did report being referred to the Helpline by a health care provider, however the largest proportion of new callers to the service were self-referred, finding details of the Helpline from an internet search or website. This aligns with previous research indicating that although women are likely to be in frequent contact with a range of health care providers in their pregnancy and following birth, many will not be identified by care providers as experiencing emotional distress (Coates et al., 2004; Spitzer et al., 2000). Telephone helplines may help to overcome barriers to help-seeking, including difficulties related to attending scheduled appointments, and the option to remain anonymous may help to overcome feelings of shame or embarrassment.

STRENGTHS AND LIMITATIONS
A potential limitation of this study is the use of data forms which were not originally collected for research purposes, but for service provision; however, the forms provided a unique opportunity to understand callers’ descriptions of their circumstances and reasons for seeking help at the time of their first point of contact with the service. This is a strength of the study, as these may have altered if callers had been contacted subsequently to give their accounts of why they had contacted the Helpline, as memory of this ‘moment of readiness’ to seek help may have changed over time. There has been very little data published about community based perinatal mental health organisations such as PANDA; this study begins to address an important gap in the literature regarding women’s help-seeking behaviour and use of telephone perinatal mental health supports.
CONCLUSION

Anxiety and depression are common in the perinatal period; however, many women will not be identified by care providers, seek help, or receive adequate treatment. Analysis of caller intake forms from the PANDA - Perinatal Anxiety & Depression Australia National Helpline highlighted complex and interrelated psychosocial factors which contribute to emotional distress in the perinatal period. Many callers raised issues relating to social isolation, inadequate support, and difficult pregnancy, birth and parenting experiences. A significant number of callers were identified as having some level of risk at intake, including a number experiencing thoughts of suicide. These findings highlight the importance of health professionals undertaking thorough psychosocial assessments in pregnancy and following birth, so that those in need of additional support are appropriately identified and cared for. Telephone Helplines can play an important role in helping to overcome barriers to care and providing appropriate and accessible specialised perinatal mental health support to families in the perinatal period.
REFERENCES


Part B

The experiences of callers and peer support volunteers
"I was heard. I felt understood. I felt my experience was validated. That I wasn't alone, that my experience wasn't odd or so unique that it couldn't be helped, or that it was all my fault."

35 year old woman. Participant in Sub-study three.
Chapter Eight
A national survey of callers to the Helpline

SUB-STUDY THREE


This paper describes the views and experiences of callers to the Helpline who made their first contact with the service between 1st May and 30th September 2013. Most callers were women, and had contacted the Helpline concerned regarding their own mental health. Although PANDA is not a crisis service, over a third of callers were seeking crisis support and help. Overall callers reported that their contact with the service had been very positive, and they described the Helpline as a safe space to be heard and receive support without judgement.

CONTRIBUTION TO THE PAPER

I declare that I have made substantial contribution to this paper, including the development and piloting of data collection tools, data collection, and analysis. I undertook data management and analysis with the assistance of my supervision team, and drafted the paper. The co-authors all contributed to the overall study design, intellectual input, and editing of the manuscript.

Laura Biggs

I declare that Laura Biggs made a substantial contribution to this paper. She contributed to all aspects and drafted the paper.

Helen McLachlan
Exploring the views and experiences of callers to the PANDA Post and Antenatal Depression Association Australian National Perinatal Depression Helpline: a cross-sectional survey

Laura J. Biggs1*, Touran Shafiei1, Della A. Forster1,2, Rhonda Small1 and Helen L. McLachlan1,3

Abstract

Background: Anxiety and depression are common in the perinatal period. Telephone interventions, including telephone peer support and counselling, have been developed to support those experiencing perinatal mental illness. PANDA Post and Antenatal Depression Association provides support to women and men experiencing perinatal mental illness via the Australian National Perinatal Depression Helpline, encompassing both volunteer peer support and professional counselling. This study aimed to explore the experiences of callers to the Helpline.

Methods: A cross-sectional survey design was used. All new callers from 1st May to 30th September 2013 were invited to participate. The survey, adapted from a previous survey of PANDA callers, included 23 questions using Likert-type scales, demographic and open-ended questions. Thematic network analysis was undertaken for responses to open-ended questions.

Results: 124 responses were received (124/405; 30 % response). The majority of callers had called the Helpline regarding themselves (90 %), with over one third (33 %) of all callers seeking crisis support and help. Ninety-nine per cent of respondents ‘agreed’ or ‘strongly agreed’ that staff and/or volunteers understood their concerns, and 97 % ‘agreed’ or ‘strongly agreed’ that overall PANDA had helped them. Callers described the PANDA service as uniquely tailored to the perinatal period, providing accessible, non-judgemental understanding and support, with a global theme from open-ended comments describing PANDA as ‘a safe space to be heard and receive support without judgement’. Recommendations for service changes included increased hours of availability.

Conclusions: Callers reported positive experiences of accessing support from the PANDA National Perinatal Depression Helpline. The Helpline was described as an accessible and acceptable telephone support for individuals experiencing perinatal mental illness. Recommendations for changes to the service included an increase in hours of operation to enable greater responsiveness at times of need, reduced waiting times, and access to continuity with the same volunteer and/or telephone counsellor. The findings of the study will be useful in informing future service provision, review, and implementation.

Keywords: Perinatal depression, Perinatal anxiety, Perinatal mental illness, Telephone helpline, Volunteer, Peer support, Telephone counselling

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Background
Perinatal mental illness encompasses mental health disorders occurring during pregnancy and the first year after birth, including depression, anxiety disorders and postpartum psychosis [1]. In Australia perinatal mental illness is a leading cause of indirect maternal death [2].

Although the prevalence of perinatal mental illness varies in different studies [1], estimates indicate around 18 % of women will experience depression during their pregnancy [3], and between 13 and 19 % in the first year after birth [3–8]. Approximately 10 % of men may also experience depression during their partner’s pregnancy and/or in the first year after birth [9]. Perinatal anxiety is less commonly researched than depression, but is estimated to affect between 10 to 16 % of women and 4 to 10 % of men in the postpartum period [10].

A wide range of pharmacological, psychosocial, psychological, and complementary and alternative therapies have been used to treat perinatal mental illness [1], including interpersonal psychotherapy, cognitive-behavioural therapy [11], antidepressant medication [12], psychosocial interventions [13], and exercise such as yoga [14]. However, for services supporting those experiencing perinatal mental illness to be accessible and acceptable, understanding is required of both the help-seeking behaviours for, and the facilitators and barriers to, support and treatment. A qualitative systematic review including 40 studies, some of which included women from diverse cultural backgrounds, explored the help-seeking barriers and facilitators for women with postnatal depression. The study identified that many women wanted ‘to be given permission to talk in-depth about their feelings... and have’ recognition that there was a problem and reassurance that other mothers experience similar feelings and that they would get better’ [15] (p.327).

Barriers to women seeking help included inconvenience of attending appointments, insufficient time, and a lack of awareness of postpartum depression [15]. A study exploring help-seeking for anxiety and depression after childbirth conducted in Australia found that women experiencing anxiety were less likely to seek help from a health professional compared to women experiencing depression or both anxiety and depression [16]. Women who did not seek help most commonly cited being able to deal with the problem themselves; being too busy or having not yet ‘got around’ to seeking help; not having anyone they were comfortable to talk to; or feeling embarrassed as reasons they did not access help from a health professional [16] (p.81).

Telephone peer support and counselling
A number of telephone-based interventions have been used in maternity care [17], including volunteer peer support telephone hotlines for breastfeeding and perinatal mental health support [18]. Peer support within the health care context has been defined as ‘the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person’ [19] (p.329).

Telephone-based health support has been identified as private and flexible [20], with the potential to overcome barriers including access to transport, fear of stigmatisation [20, 21], and geographical isolation [17, 22]. Telephone-based health care also appears to be acceptable, with a systematic review of telemedicine compared to face-to-face care finding that telemedicine was well accepted by recipients [23]. Dennis and Kingston however note that telephone support can be impacted by difficulties including language barriers, and that ‘support is less likely when recipients are required to initiate telephone contact compared with provider initiated services’ [20] (p. 301). A 2008 systematic review of telephone support for women during pregnancy and the early postpartum period noted that although the number of telephone interventions in pregnancy and postpartum had increased significantly, there has been limited research evaluating these interventions, and few of the studies conducted included a maternal evaluation of the intervention [20].

A small number of studies have explored the effectiveness of telephone support, including telephone peer support, to prevent or treat maternal postnatal depression and anxiety [24–26]. A multi-site randomised controlled trial (RCT) [24] explored the effect of proactive individualised telephone peer support on the prevention of postnatal depression among women identified as being at high risk of developing postnatal depression. Fourteen percent of women in the intervention group had an Edinburgh Postnatal Depression Score >12 at 12 weeks postpartum, a score indicating probable major depression [27], compared with 25 % of women in the control group. Maternal satisfaction with the intervention was high, with over 80 % of women satisfied with their experience and stating that they would recommend this type of support to a friend [28].

A 2014 qualitative systematic review explored women’s experiences of peer support for perinatal mental illness [29]. Five relevant studies were identified, with peer support received in the form of a peer support group in all studies. The authors identified four themes from the meta-ethnography: isolation: the role of peer support; seeking validation through peer support; the importance of social norms of motherhood, and finding affirmation/ a way forward; and the impact of peer support. Women in the studies identified feeling isolated, with some highlighting that their feelings of isolation were further heightened when other mothers did not share their
experiences of perinatal mental illness. The authors found that women had a need to discuss their thoughts and feelings with someone as a way of reducing their distress. Many women were seeking validation, and the authors note that when women ‘encountered others who validated their feelings and their parenting experiences, life became less difficult’ [29] (p.495).

**PANDA Post and Antenatal Depression Association**

PANDA Post and Antenatal Depression Association began in the 1980s as a peer support organisation in Victoria, Australia [30]. PANDA provides support to the Australian community in multiple ways, including online fact sheets, two websites, and a National Perinatal Depression Helpline, hereafter referred to as the Helpline, which was launched in July 2010. The helpline is available to callers Monday to Friday from 10am to 5pm, with more than ten thousand calls made to and from the Helpline each year. The majority of callers to the Helpline are women [31]. Callers hear of the PANDA Helpline through different pathways, including midwives and other maternity care providers, general practitioners, maternal and child health nurses, the PANDA website, and word of mouth from friends and family.

Volunteers who provide peer support to callers and counsellors who provide professional counselling services staff the Helpline. PANDA recruits and trains volunteer peer support workers for the Helpline and also for home visiting and community education activities. Volunteers are recruited through word of mouth, the PANDA website and online volunteer opportunity websites. Volunteers have experienced, or have supported someone who has experienced perinatal mental illness. Some volunteers join PANDA as they have a professional interest in supporting individuals experiencing perinatal mental illness. Individuals interested in volunteering with PANDA apply and attend an information session to better understand what the role would entail. Prospective volunteers also undergo an individual interview, police and referee checks. Successful telephone support volunteer applicants then undertake a two stage training process; stage one involves 24 h of group education delivered over an eight week period, and stage two includes observing experienced volunteers and/or counsellors on the Helpline until the individual volunteer displays readiness to conduct their first phone call. The education provided to volunteers focuses on perinatal mental health, loss and grief, transition to parenthood, family of origin, attachment theory, the Helpline systems and processes, counselling skills, risk assessment, values and self-care. All volunteers on the Helpline are required to complete a two day Applied Suicide Intervention Skills training (ASIST). A volunteer coordinator is present to support volunteers on the Helpline at all times. Professionally trained counsellors are also employed by the organisation to provide telephone counselling as part of the Helpline services. At the time of the evaluation there were a total of 40 telephone support volunteers and 12 telephone counsellors working on the Helpline.

Incoming calls to the Helpline are answered by the Intake Worker who will record some initial information and conduct an initial risk assessment (Fig. 1). Unless there are immediate concerns regarding the caller’s safety they will receive a phone call back from a PANDA volunteer or telephone counsellor, depending on the caller’s needs, to enable a thorough initial call to be undertaken. This call back is usually undertaken the same day the individual makes contact with the Helpline. It is common at the end of this first call for the PANDA volunteer or counsellor to seek permission for PANDA to initiate follow-up support calls to ensure callers are accessing supports in their local community.

Due to different funding structures callers assessed as ‘moderate to severe’ needs residing outside the state of Victoria are not eligible to receive PANDA initiated follow-up calls once they are considered to be ‘linked’ with a local service provider, such as a GP, however callers can contact the Helpline if they require support.

In 2013 an independent evaluation of the PANDA Helpline was undertaken. The evaluation included four components: a description of the PANDA caller profile, demand and referral pathways; an exploration of the views and experiences of callers to the PANDA Helpline; telephone interviews with callers assessed as moderate-severe needs; and key informant consultations with PANDA staff, volunteers, and key stakeholders. The component of the evaluation that explored the views and experiences of callers to the Helpline is the focus of this paper.

**Methods**

**Aims**

This study used a cross-sectional survey design to explore callers’ views and experiences of their contact with PANDA, including interactions with staff and/or volunteers, their reason(s) for calling the service, overall experiences of care, and their views of how the service was organised.

Specifically, the study aimed to explore:

- callers’ experiences of communication with PANDA, including why they called the Helpline, and what they felt they had gained from their contact with the service;
- how, if at all, the Helpline differed from other support services callers had accessed; and
if there were things that could be improved within the PANDA service.

All new callers to PANDA, from 1st May to 30th September 2013 were invited to participate in the survey four to eight weeks after their initial contact. Callers' contact details, such as an email or postal address, were obtained by PANDA staff and/or volunteers during their first call as part of 'usual care' on the Helpline. Callers were contacted four to eight weeks after the initial contact as it was anticipated that most would no longer be in contact with PANDA and that the timeframe was recent enough for accurate recall. Sample size calculations were not performed as the survey was part of a larger service evaluation and was designed and timed to maximise the number of possible participants while also meeting the time constraints of the overall evaluation.

Survey instrument
The survey was adapted from a previous survey of PANDA callers conducted as part of a Master's study in 2012 [32]. The adapted survey was piloted with experienced maternity clinicians and perinatal researchers who reviewed the survey for content, flow, face and content validity. The survey consisted of 23 questions, and included a range of closed and open-ended questions, as well as a number of statements with Likert-type scale
response options, i.e., ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’ or ‘strongly disagree’. Demographic questions were also included. The questions explored how callers had heard of PANDA, number of contacts, overall experiences with the Helpline, call content, views regarding organisational features, referrals to other support services, and suggestions for changes to the Helpline.

Data collection
Surveys were sent to all new callers within the study period by email if PANDA had email details or by hard copy with a reply paid envelope if only a postal address was available. The surveys were sent by PANDA and received by the research team; therefore, the research team had no knowledge of the caller’s identity, and the PANDA staff had no access to callers’ responses. A detailed letter was sent with the invitation explaining the purpose of the study. The letter explained that all responses would remain anonymous, that they would be sent directly to the research team, and a decision not to participate or any responses provided would not impact on any current or future contact with the Helpline. Callers were sent two reminders using the same method (either email or postal) that they had initially been contacted with, one two weeks after the initial contact and the second two weeks after the first reminder. As all responses were anonymous it was not possible to send reminders to only those who had not completed the survey, and therefore a note was included thanking those who had already responded for their time. Return of the survey was taken as consent to participate.

Analysis
All data were collected and managed within the secure web-based application Research Electronic Data Capture (REDCap) [33], with hard-copy surveys entered directly into the application by one of the research team. Data were entered at the time of the evaluation by a member of the research team, and checked by LB. No errors were identified. Data cleaning included range and logic checks. Data analysis using descriptive statistics was undertaken within STATA 11 [34], and results mostly presented as numbers and per centages. Some survey questions were not asked if a respondent indicated that they had contacted the Helpline for someone other than themselves, such as a partner or family member. As a result some data presented are for respondents who called for themselves only; this is made explicit within tables as ‘called regarding self’ or ‘called regarding partner/other’. Open-ended questions were asked of all survey respondents and analysis has included all responses.

Responses to open-ended questions were analysed thematically [35], with both LB and HMcL undertaking qualitative data analysis. The thematic analysis has been presented as a thematic network, a ‘web-like’ illustration which aims to present the key themes within the text and the relationships between them [36] (p.386). The network has three levels of themes: basic themes made up of lowest-order premises; groups of basic themes summaising more abstract principles, known as organising themes; and global themes which encompass the principal metaphors within the text [36].

Some respondents did not answer every question within the survey, and so for some questions the denominator changes. This has been made explicit within tables with each question presented with its own denominator.

Ethics approval was obtained from the La Trobe University Ethics Committee, application number FHEC11/057.

Results
Figure 2 describes the process of distributing the survey to callers and the responses received. A total of 483 new calls were made to the Helpline over the five-month recruitment period, but 59 callers did not provide any contact details. In total 359 emails and 72 postal surveys (n = 431) were sent. Of the original 359 sent by email, 25 of the email addresses were incorrect. Seven of these had postal addresses, so this method was used in these instances. One postal survey was ‘returned to sender’ with an incorrect address. Thus, there was potential for 405 surveys to be completed and of these 124 responses were received, 24 hard copy and 100 via the online survey; a response of 30 %.

Characteristics of respondents
Of the 124 responses received, 112 (90 %) had called PANDA regarding themselves, and six regarding their partner, three for their sister and one for their daughter.

Respondents who called regarding themselves were mostly female (97 %), married (78 %) or living with a partner (17 %), born in Australia (75 %), living in the state of Victoria (50 %), spoke English as a first language (87 %), and had completed a university degree or higher (60 %) (Table 1).

Respondents who called for someone other than themselves were mostly female (77 %), married or living with a partner (100 %), born in Australia (77 %), and spoke English as a first language (100 %).

Contacting PANDA
Table 2 details the reasons respondents had called PANDA; callers were most commonly seeking support (76 %), information about postnatal depression and anxiety (44 %), and reassurance (41 %). Of those who had called PANDA for themselves, 33 % were seeking crisis support. Eighty-six (76 %) callers reported that PANDA suggested they contact other support services, and of
those 74 (88 %) reported that they were able to access these services.

Callers who had accessed PANDA for themselves were asked how they felt before picking up the phone and making their first call. Respondents most commonly reported feeling desperate (64 %), nervous (46 %), unsure of how PANDA could help (45 %), and scared (37 %) (Table 2).

Respondents were asked to estimate how many calls they had made to PANDA, and also how many calls PANDA had made to them (or how many messages PANDA had left) (Table 3). Half of the respondents reported making one call to the Helpline (50 %), and most (89 %) received PANDA initiated follow-up, in the form of phone calls or messages. Of those who did receive calls from PANDA, more than a third (34 %) received five or more phone calls.

**Call content**

Respondents were given a list of topics to respond to regarding what was discussed or provided to them during their call/s with PANDA (Table 4). All callers responded that PANDA staff and/or volunteers had asked them how they were feeling and listened to their story. All except one respondent reported being provided with information they could trust (99 %) and being asked about their relationships (99 %). The majority of callers (97 %) felt that they gained hope and reassurance, and were helped to feel better about being a parent (97 %). Callers also responded that they were supported to help identify what they were doing well and to develop realistic views of what is possible (88 %); to understand the impact of early childhood or young adult life experiences on parenting (65 %); and that they were provided with referrals to other services (83 %). Safety was an important feature of most conversations, with most identifying that they were asked by PANDA staff and/or volunteers if they felt safe (94 %) and if their baby/children were safe (93 %), and most reported that staff and/or volunteers had acted to keep them or their baby/children safe (81 %).

**Views and experiences of callers to PANDA**

Callers were asked a set of questions regarding their views and experiences of their contact with PANDA. Ninety-nine per cent of respondents ‘agreed’ or ‘strongly agreed’ (hereafter referred to as agreed) that PANDA staff and volunteers understood their concerns, and 94 % agreed that they felt emotionally better after speaking with someone from PANDA (Table 5). Over 99 % of respondents agreed that PANDA provided non-judgemental support, and a total of 97 % agreed that overall PANDA had helped them.

Callers were also asked a series of questions regarding what features they considered important for PANDA to offer as an organisation (Table 5). Ninety-six per cent of callers agreed that having access to PANDA during the evening/night and at weekends was important. When asked whether it was important that the person they spoke to at PANDA had personal experience of antenatal and/or postnatal depression or anxiety, this was one of the few areas of mixed response, with 28 % agreeing or strongly agreeing it was important, 38 % disagreeing or strongly disagreeing, and the remaining 32 % neither agreeing nor disagreeing. Responses regarding the option of having someone from PANDA visit them at home as well as receiving telephone support also received mixed response, with 19 % of callers strongly agreeing that they would like this option, 35 % agreeing, 23 % neither agreeing nor disagreeing, and 21 % disagreeing or strongly disagreeing with the statement. Eighteen per cent strongly agreed that it was important to be able to speak to the same person during every call.
Table 1 Characteristics of participants (calling for self or calling for partner)

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<th>Called regarding self</th>
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<td></td>
</tr>
<tr>
<td>Married</td>
<td>78</td>
<td>3</td>
<td>81</td>
</tr>
<tr>
<td>Living with a partner</td>
<td>17</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Have a partner but do not live together</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Single</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>9</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>One child</td>
<td>48</td>
<td>4</td>
<td>52</td>
</tr>
<tr>
<td>Two children</td>
<td>37</td>
<td>1</td>
<td>38</td>
</tr>
<tr>
<td>Three children</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Age of most recent child*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤12 weeks</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>13-26 weeks</td>
<td>29</td>
<td>3</td>
<td>32</td>
</tr>
<tr>
<td>27-51 weeks</td>
<td>33</td>
<td>2</td>
<td>35</td>
</tr>
<tr>
<td>≥52 weeks</td>
<td>21</td>
<td>0</td>
<td>21</td>
</tr>
<tr>
<td>Pregnant at time of survey</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed a degree or higher</td>
<td>60</td>
<td>3</td>
<td>63</td>
</tr>
<tr>
<td>Completed a certificate/diploma/ apprenticeship</td>
<td>31</td>
<td>1</td>
<td>32</td>
</tr>
<tr>
<td>Completed secondary school Year 12</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Have not completed secondary school</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Total before tax household income/week (AUD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $650</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>$650 - $999</td>
<td>13</td>
<td>0</td>
<td>13</td>
</tr>
<tr>
<td>$1000 - $1399</td>
<td>17</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>$1400 - $1999</td>
<td>27</td>
<td>2</td>
<td>29</td>
</tr>
<tr>
<td>&gt; $2000</td>
<td>35</td>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>Pension the main family income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>State of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Victoria</td>
<td>50</td>
<td>4</td>
<td>54</td>
</tr>
<tr>
<td>New South Wales</td>
<td>18</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Queensland</td>
<td>17</td>
<td>0</td>
<td>17</td>
</tr>
</tbody>
</table>
phone call, 35 % agreed, 22 % neither agreed nor disagreed, and 22 % disagreed or strongly disagreed that this was important to them.

Exploring what callers had gained from their contact with PANDA

Thematic analysis [35] was undertaken with responses to two open-ended questions: ’Would you say that the service PANDA provided differed from other services you used, and if so, how?’ (83 responses received) and ‘Please describe in your own words what you think you gained from calling the PANDA Helpline?’ (98 responses received). Analyses have been presented as a thematic network [36] incorporating 11 basic themes, two organising themes and one global theme (Fig. 3).

Thematic network

During early data analysis it became clear that there were commonalities between answers to both questions, which led to the decision to present the analyses as a

Table 1 Characteristics of participants (calling for self or calling for partner) (Continued)

<table>
<thead>
<tr>
<th>Called regarding self</th>
<th>Called regarding partner</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>South Australia</td>
<td>9</td>
<td>9.1</td>
</tr>
<tr>
<td>Western Australia</td>
<td>4</td>
<td>4.0</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Tasmania</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander origin</td>
<td>(n = 98)</td>
<td>(n = 5)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>Torres Strait Islander</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Country of Birth</td>
<td>(n = 98)</td>
<td>(n = 5)</td>
</tr>
<tr>
<td>Australia</td>
<td>74</td>
<td>75.5</td>
</tr>
<tr>
<td>Years since settlement in Australia (non-Australian born)</td>
<td>(n = 23)</td>
<td>(n = 1)</td>
</tr>
<tr>
<td>&lt;5 years</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>First language</td>
<td>(n = 96)</td>
<td>(n = 5)</td>
</tr>
<tr>
<td>English</td>
<td>84</td>
<td>87.5</td>
</tr>
</tbody>
</table>

*Only those who reported having a child *per cent age not supplied due to small numbers

Table 2 Reasons respondents contacted PANDA and feelings before making first call

<table>
<thead>
<tr>
<th>Reasons for contact</th>
<th>Called regarding self</th>
<th>Called regarding other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 112)</td>
<td>%</td>
</tr>
<tr>
<td>Support</td>
<td>86</td>
<td>76.8</td>
</tr>
<tr>
<td>Information about postnatal depression and anxiety</td>
<td>50</td>
<td>44.6</td>
</tr>
<tr>
<td>Reassurance</td>
<td>46</td>
<td>41.1</td>
</tr>
<tr>
<td>Crisis support/help</td>
<td>37</td>
<td>33.0</td>
</tr>
<tr>
<td>Referral to other services</td>
<td>17</td>
<td>15.2</td>
</tr>
<tr>
<td>Information about antenatal depression and anxiety</td>
<td>16</td>
<td>14.3</td>
</tr>
<tr>
<td>Feelings before making first call to PANDA</td>
<td>(n = 112)</td>
<td>%</td>
</tr>
<tr>
<td>Desperate</td>
<td>72</td>
<td>64.3</td>
</tr>
<tr>
<td>Nervous</td>
<td>52</td>
<td>46.4</td>
</tr>
<tr>
<td>Unsure of how PANDA could help</td>
<td>51</td>
<td>45.5</td>
</tr>
<tr>
<td>Scared</td>
<td>42</td>
<td>37.5</td>
</tr>
<tr>
<td>Hopeful</td>
<td>20</td>
<td>17.8</td>
</tr>
<tr>
<td>Optimistic</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>Relieved</td>
<td>3</td>
<td>2.7</td>
</tr>
<tr>
<td>Other (e.g., anxious, worried)</td>
<td>10</td>
<td>8.9</td>
</tr>
</tbody>
</table>

*Respondents could make more than one selection *per cent age not supplied due to small numbers
thematic network; recognising the overall picture the two analyses were able to create whilst keeping the two sides of the network, each originating from responses to different questions separate. The global theme a safe space to be heard and receive support without judgement has been used to describe the thematic network. Callers’ responses describe the PANDA service as unique, accessible and acceptable. Respondents felt that PANDA created a safe space where they could discuss private and complex emotions without fear of judgement. Callers felt that they had been properly heard and understood by the staff and/or volunteers, that their experiences were validated, and that they had received both emotional and practical support to begin to address their individual situation.

Question 1: ‘Would you say that the service PANDA provided differed from other services you used, and if so, how?’

The organising theme ‘accessible and specialised’ was developed from five basic themes incorporating callers’ descriptions of PANDA’s service and how, if at all, it differed from other services they had used: specific/specialised to the perinatal period; volunteers with lived experience; phone service accessible and acceptable; PANDA was different; PANDA initiated follow up.

Callers described PANDA as a service specific/specialised to the perinatal period, with a unique, high level of knowledge regarding both maternal and paternal mental health at this time:

‘The fact that PANDA specialises in post natal/pre natal conditions seems to have made all the difference.’

(Participant 96 - 34 year old woman, called regarding herself)

The benefit of being able to speak to someone who has a lived experience of perinatal mental illness was highlighted, with callers describing this as contributing to them feeling heard and understood:

‘It was fantastic to talk to someone who had been through PND. It makes a difference to know they understand how you are feeling.’ (Participant 52 - 35 year old woman, called regarding herself)

‘Having volunteers that have experience themselves.’ (Participant 34 – 27 year old woman, called regarding herself)

Callers emphasised the increased accessibility and acceptability of the telephone service, describing it as easy, relaxed and not rushed, anonymous, and available
Table 5: Views and experiences of callers to PANDA (all participants)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The PANDA staff/volunteers were relaxed and unhurried on the phone</td>
<td>0.0</td>
<td>0.8</td>
<td>0.0</td>
<td>16.1</td>
<td>83.0</td>
</tr>
<tr>
<td>The PANDA staff/volunteers provided non-judgemental support</td>
<td>0.0</td>
<td>0.0</td>
<td>0.8</td>
<td>21.7</td>
<td>79.5</td>
</tr>
<tr>
<td>Overall, PANDA helped me</td>
<td>0.0</td>
<td>0.9</td>
<td>1.7</td>
<td>19.6</td>
<td>81.0</td>
</tr>
<tr>
<td>I always felt my worries, anxieties or concerns were taken seriously</td>
<td>0.0</td>
<td>0.0</td>
<td>2.1</td>
<td>21.7</td>
<td>79.5</td>
</tr>
<tr>
<td>The PANDA staff/volunteers understood my concerns</td>
<td>0.0</td>
<td>0.0</td>
<td>1.0</td>
<td>24.3</td>
<td>75.7</td>
</tr>
<tr>
<td>I was happy with the emotional support I received from PANDA staff/volunteers</td>
<td>0.0</td>
<td>0.0</td>
<td>4.0</td>
<td>27.3</td>
<td>73.5</td>
</tr>
<tr>
<td>The PANDA staff/volunteers were encouraging and reassuring</td>
<td>0.0</td>
<td>0.0</td>
<td>1.0</td>
<td>30.5</td>
<td>75.5</td>
</tr>
<tr>
<td>Emotionally, I felt much better after speaking with someone from PANDA</td>
<td>0.0</td>
<td>0.0</td>
<td>4.0</td>
<td>36.0</td>
<td>64.4</td>
</tr>
<tr>
<td>The PANDA staff/volunteers helped me to understand antenatal and/or postnatal depression and anxiety</td>
<td>0.0</td>
<td>0.0</td>
<td>4.0</td>
<td>39.0</td>
<td>61.0</td>
</tr>
<tr>
<td>The PANDA staff/volunteers showed that they had asked me any questions</td>
<td>0.0</td>
<td>0.0</td>
<td>1.0</td>
<td>16.5</td>
<td>83.5</td>
</tr>
<tr>
<td>I was NOT happy with the information given to me by the PANDA staff/volunteers</td>
<td>91.0</td>
<td>77.1</td>
<td>20.0</td>
<td>5.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Having access to PANDA during the evening/night and at weekends</td>
<td>0.0</td>
<td>0.0</td>
<td>4.0</td>
<td>34.2</td>
<td>65.8</td>
</tr>
<tr>
<td>It is important to be able to speak to the same person during every phone call with PANDA</td>
<td>3.0</td>
<td>2.5</td>
<td>24.0</td>
<td>20.3</td>
<td>22.9</td>
</tr>
<tr>
<td>I was comfortable leaving my contact details with PANDA so that they could call me back</td>
<td>0.0</td>
<td>0.0</td>
<td>2.0</td>
<td>2.6</td>
<td>38.0</td>
</tr>
<tr>
<td>It is important that the person I talk to at PANDA has personally experienced antenatal and/or postnatal depression or anxiety</td>
<td>9.0</td>
<td>7.6</td>
<td>37.0</td>
<td>31.3</td>
<td>38.2</td>
</tr>
<tr>
<td>It took a long time for a counsellor to return my call</td>
<td>48.0</td>
<td>41.0</td>
<td>45.0</td>
<td>38.5</td>
<td>9.0</td>
</tr>
<tr>
<td>I would have liked the option to have someone from PANDA visit me at home AS WELL AS receiving support by telephone</td>
<td>6.0</td>
<td>5.1</td>
<td>19.0</td>
<td>16.2</td>
<td>27.3</td>
</tr>
</tbody>
</table>

Table 5: Views and experiences of callers to PANDA (all participants)

and responsive at the time of need, as it was not appointment based:

‘PANDA was at the end of the phone line when I needed them - and I could call them crying from the privacy of my home, in my daggy clothes (therefore different to having to make an appointment sometime in the future with a counsellor, or go out in public to see my GP).’ (Participant 54 – 37 year old woman, called regarding self)

‘I felt ashamed so non face to face contact was good for me in the beginning...’ (Participant 11 – 30 year old woman, called regarding self)

Callers made some explicit comments regarding how PANDA was different to other specific services, describing less positive experiences with these services:

‘Other general services I have called have belittled the problems and feelings associated with parenting and made the call as short as possible to get rid of me, telling me to go to my GP.’ (Participant 22 – 37 year old woman, called regarding self)

‘I have been to the doctor, seen a Counsellor [sic], rang [another telephone service] numerous times and it wasn’t until I spoke to PANDA that I felt like I was getting
Callers highlighted how important it was to them that **PANDA initiated follow up calls**, and that the responsibility was not always on them to initiate contact and ask for help and support:

‘Telephone counselling was so useful as I was completely bedridden. I felt so ashamed of being sick/depressed so that they reached out to me with follow up phone calls was helpful’ (woman’s own emphasis - Participant 129 – 34 year old woman, called regarding herself)

‘The offer of regular follow-up is vital as depressed people, myself included, often self-isolate.’ (Participant 88 – 37 year old woman, called regarding self)

‘The offer of regular follow-up is vital as depressed people, myself included, often self-isolate.’ (Participant 88 – 37 year old woman, called regarding self)

**Question 2:** ‘Please describe in your own words what you think you gained from calling the PANDA Helpline?’

Callers’ descriptions of what they had gained from calling the Helpline led to the second organising theme ‘feeling heard and understood,’ which includes five basic themes: a new perspective/reframing; understanding of self and/or perinatal mental illness; practical strategies/support; parenting advice/support; and non-judgemental emotional support.

Respondents discussed the ways that their contact with PANDA had helped them to gain **new perspectives and reframe** their understanding, including helping them to gain a new or more balanced view of their situation. Callers made specific reference to the way PANDA helped them to focus on what they had achieved, rather than focusing on what they felt they had not:

‘…it was so great to hear someone praise me for what I had been able to achieve, rather than (as I had been doing) focusing on what I felt I wasn’t doing well.’ (Participant 16 – 33 year old woman, called regarding herself)

‘Helped me gain perspective on what I was achieving rather than what I was expecting myself to achieve.’ (Participant 50 – 28 year old woman, called regarding herself)

‘…reframed my negative thoughts, gave me hope.’ (Participant 73 – 32 year old woman, called regarding herself)

Callers also described the way PANDA helped them gain a **better understanding of self and/or perinatal mental illness**, be it their own experiences and situation or that of a partner/family member:

‘Understanding of post natal depression and how to support my wife’ (Participant 104 – 30 year old man, called regarding his wife)

‘Help with understanding my feelings & emotions. Understanding!’ (Participant 118 – 35 year old woman, called regarding herself)

Respondents described varied ways that PANDA provided **practical support and guidance** to assist callers on a day-to-day basis, including advice regarding how to manage situations of increased anxiety by using tools such as mindfulness techniques. PANDA also helped callers access local perinatal mental health resources and...
gave assistance regarding ongoing care planning and support, either for themselves or for the partner/family member they were calling regarding:

‘Objective viewpoint, validation and practical advice on how to proceed with supporting my partner/encouraging him to seek help.’ (Participant 91 – 33 year old woman, called regarding her partner)

‘Practical assistance in accessing an enhanced maternal and child health nurse who put in to place access to a mother baby unit which helped in my recovery.’ (Participant 87 – 32 year old woman, called regarding herself)

‘Helped me with strategies to consider during moments of anxiety.’ (Participant 50 – 28 year old woman, called regarding herself)

Respondents describe PANDA as providing important parenting advice and support, with a unique understanding of the experience of becoming a parent and the ways this may impact emotional wellbeing. Callers felt reassured that they were a good parent, gained confidence in their ability to parent well, and accessed practical, day to day parenting advice and support:

‘Helped me maintain parenting confidence and [recognise] my strengths and that I am doing a great job despite other [people's] judgements’ (Participant 75 – 26 year old woman, called regarding herself)

‘Reassurance that I was on the right track, ideas about how to tackle parenting problems’ (Participant 38 – 39 year old woman, called regarding herself)

Callers described the positive impact of the non-judgemental emotional support they received from PANDA, including feeling calmed, supported, validated, understood and not judged. They were able to feel that they were not beyond help, that their issues were genuine and that other women had experienced the same thing:

‘I was heard. I felt understood. I felt my experience was validated. That I wasn’t alone that my experience wasn’t odd or so unique that it couldn’t be helped or that it was all my fault.’ (Participant 15 – 35 year old woman, called regarding herself)

‘Understanding, and a freedom to talk about feelings that are very personal without any judgement.’ (Participant 22 – 37 year old woman, called regarding herself)

**Suggestions for service change**

Callers were asked in open-ended questions to outline any suggestions for improvements which could be made to the PANDA service (41 responses received), as well as whether there was anything they had hoped to gain from their contact with the service which they did not receive (20 responses received). Similarly to the closed-ended questions regarding what service features callers considered important, responses included increased hours of availability, access to a known volunteer and/or counsellor, reduced waiting times, possible access to face to face services and increased availability of PANDA initiated follow up.

Callers suggested increased hours of availability to include evening, overnight and weekend times, emphasising the barriers to accessing the service during operating times:

‘More funding so you could provide 24/7 help to women and families dealing with this illness.’ (Participant 27 – 31 year old woman, called regarding herself)

‘I couldn't even call after hours when the kids are in bed as the service is not running. I did not want to call when I was at work. I need to be 'together' and functioning at work ... so I don't have a meltdown in my professional environment... There were only two little windows available and it would have been much better to have been able to speak to someone when I was available to ring.’ (Participant 15 – 35 year old woman, called regarding herself)

Respondents suggested greater availability of PANDA staff in order to reduce waiting times:

‘More staff, shorter waiting times...’ (Participant 25 – 33 year old woman, called regarding herself)

‘They also need more people available to take calls when u (sic) need them, not when they are available to call you back, when the crisis has passed.’ (Participant 43 – 37 year old woman, called regarding herself)

Some callers would have liked to access continuity with the same volunteer and/or counsellor:

‘The thought that the first counsellor you speak to is the same person who calls back/is always there is nice (but prob not possible!) only because that person earns your trust - you have to go through it all again with someone else.’ (Participant 107 – 38 year old woman, called regarding herself)

Callers suggested PANDA could develop face-to-face drop in spaces or home visiting services:

‘It would be great to have a drop in centre for face to face counselling or the option of home visits.’ (Participant 35 – 32 year old woman, called regarding herself)

Some callers who were not eligible for PANDA initiated follow up calls highlighted increased availability of proactive follow up calls as important:

‘I would have enjoyed having staff follow up with me, but I understood that that service was no longer being offered.’ (Participant 16 – 33 year old woman, called regarding herself)

**Discussion**

Overall, callers reported very positive experiences of their contact with the PANDA National Perinatal Depression Helpline. The majority of callers reported feeling better emotionally after speaking with someone from
PANDA. Respondents had initiated contact with PANDA for support, information, and reassurance, with over one third of callers seeking crisis help and support. The reasons callers had initiated contact with the Helpline align well with the focus of the organisation as a telephone Helpline offering information, support and referral services. The large difference between the number of respondents seeking information for postnatal depression and anxiety (44 %) compared to antenatal depression and anxiety (14 %) might in part be explained by the greater clinical and research focus on perinatal mental illness in the postpartum period compared with pregnancy [37], or PANDA’s origins as an organisation focusing on supporting women experiencing postnatal depression.

The majority of callers to the Helpline agreed that PANDA was able to provide them with non-judgemental support, information they could trust, and that overall their contact with the service helped them. This was also reflected strongly in the thematic network, with callers describing in depth the different ways PANDA was able to provide them with emotional, practical and parenting support that was accessible and acceptable, as well as what they perceived made the service unique to others they had accessed. The majority of callers reported being helped by PANDA to feel better about being a parent, as well as gaining reassurance and hope.

The high levels of satisfaction expressed by respondents has similarities with previous studies exploring women’s experiences of perinatal mental illness, including the emphasis women place on the importance of having others to discuss experiences with [29, 38], the importance of social connection [39], women’s preferences for ‘talking therapies’ [15], and women’s satisfaction with a telephone peer support intervention [28].

Although less than one third of callers considered it important that the person they talked to at PANDA had personally experienced antenatal and/or postnatal depression or anxiety, analysis of the open-ended responses suggested that for some callers speaking with someone with a lived experience of perinatal mental illness was something that made PANDA’s service different to other services callers had accessed, and something that respondents saw as facilitating them feeling understood and supported. The concept of peer support focuses on the peer having lived experience similar to those whom they are supporting [19], and this has been a central feature of peer support interventions to date [18, 24], however this was not seen as essential by all respondents in this study.

Callers’ recommendations for possible changes to how the PANDA service is organised emphasised the importance of PANDA being more available at times of need, including afternoon/evening and weekend availability. The majority of respondents agreed that they would have liked the option of having someone from PANDA visit them at home as well as receiving telephone support, and that it was important to them to be able to speak with the same staff member/volunteer on each phone call they made to the service.

Strengths and limitations

Very few studies have explored the experiences of those accessing telephone supports for perinatal mental health support. The findings of this study expand our knowledge of this, and could be used to help design and review telephone support services.

The representativeness of the survey sample was assessed by comparing routinely collected demographic data on all new callers over the previous ten-month period (January-October 2013). Survey respondents were generally representative of all new callers to the Helpline January - October 2013; mostly female (91 %), married (78 %), between the ages of 30-40 (70 %), and from the state of Victoria (53 %) [31]. Due to the way perinatal statistics are reported in Australia, the only demographic characteristic that could be used to compare our sample directly with the whole population of birthing women in Australia is mean age with callers to PANDA older than the overall population (mean age 32.4 versus 30.1) [40]. Marital status data were only available for the state of Victoria. Women in our sample more likely to be married (78.1 % versus 69.1 %) than the overall childbearing population in Victoria in 2011 [41].

The callers who access the PANDA Helpline are mostly female, older, and generally have a high level of education and income. While this is not representative of the general birthing population within Australia, or of those who experience perinatal mental illness, it was the aim of this study to explore the experiences of those accessing the Helpline and our sample reflected these characteristics.

While there is a need for more research about men’s mental health in the perinatal period [42], this study could not contribute to what is known about fathers’ experiences of help-seeking for perinatal mental illness as so few men contacted PANDA in 2013, and only three responded to the survey. This might in part be explained by men being less likely to seek help for mental illness than women [43].

The response to the survey was similar to the survey of callers to the PANDA Helpline in 2012, which was 32 % [32]. However, this is somewhat lower than earlier surveys of new mothers in Victoria [44] and is reflective of a widespread reduction in responses in population-based studies noted in the literature [45]. The response from this population might be expected to be lower than in other studies considering those contacting PANDA are likely to be experiencing distress.
Conclusion

Overall, respondents reported very positive experiences of accessing support from PANDA Post and Antenatal Depression Association National Perinatal Depression Helpline. Callers describe the PANDA service as unique, specifically tailored to provide support and care to individuals experiencing perinatal mental illness and their partners, friends and family. Respondents emphasised the accessibility, acceptability and value of the telephone service, and made recommendations for changes to the service including an increase in hours of operation to enable greater responsiveness at times of need, reduced waiting times, and access to continuity with the same volunteer and/or telephone counsellor.

The Helpline is an accessible and acceptable telephone support for individuals experiencing perinatal mental illness. The findings of the study will be useful in informing future service provision, review, and implementation.

Endnotes

1 Callers may have previously contacted PANDA but be considered ‘new’ if they are not currently being counselled or followed up by PANDA staff and/or volunteers at the time of their call. As a result some callers classified as ‘new’ may have previously accessed support through the Helpline but are now re-engaging with the service after a period of non-contact (i.e., having sought support in pregnancy and then re-engage with service after birth).

Abbreviations

PANDA: PANDA Post and Antenatal Depression Association; RCT: Randomised controlled trial.

Competing interests

The authors declare that they have no competing interests.

Authors’ contributions

HMCL, DF, RS and TS contributed to the design of the service evaluation, including survey design and piloting, and data collection processes. LB was involved in piloting the survey. LB, TS, HMCL and DF undertook quantitative analysis and LB and HMCL undertook qualitative analysis. LB drafted the manuscript and all authors participated in revising it and approved the final version.

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Acknowledgements

Thank you to the callers who took the time to complete the survey. Thank you to the PANDA staff and volunteers who facilitated the distribution of online and hard copy invitations to all new callers within the study period.

Funding for the evaluation was provided as part of the Federal Government funding of the National Perinatal Depression Helpline.

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Received: 17 March 2015 Accepted: 15 July 2015

Published online: 07 September 2015

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34. Stata statistical software: Release 11 [http://www.stata.com/]


“It’s not about having to solve the problems of the world, it’s just an opportunity [for callers to] share their story that day and how they’re feeling, and our main role is to listen.”

PANDA volunteer. Participant in Sub-study four
This study describes the experiences of volunteers providing peer support on the Helpline. An online survey and two focus groups were used to explore volunteers’ motivations for becoming a peer support volunteer, if the role has any impact on their own emotional wellbeing, what they see as the positive and negative aspects of the role, and experiences of training and supervision. Volunteers described a strong desire to help parents experiencing emotional distress, and they felt that the Helpline played a really important, positive role supporting the community.

CONTRIBUTION TO PAPER

I declare that I have made a substantial contribution to this paper, including contributing to the overall study design. I undertook data management and analysis, with the support of my supervision team, and drafted the paper. The co-authors all contributed to the overall study design, intellectual input, and editing of the manuscript.

Laura Biggs

I declare that Laura Biggs made a substantial contribution to this paper. She contributed to all aspects and drafted the paper.

Helen McLachlan
Peer supporters’ experiences on an Australian perinatal mental health helpline

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Summary

Perinatal mental health is an important public health issue, and peer support is a potentially important strategy for emotional well-being in the perinatal period. PANDA Perinatal Anxiety & Depression Australia provides support to individuals impacted by perinatal mental health issues via the National Perinatal Anxiety & Depression Helpline. Callers receive peer support from volunteers and counseling from paid professional staff. The views and experiences of PANDA peer support volunteers have not previously been studied. We conducted two focus groups and an online survey to explore the experiences of women providing volunteer peer support on the Helpline. Data collection took place in October and November 2013. Two social theories were used in framing and addressing the study aims and in interpreting our findings: the Empathy–Altruism Hypothesis, and the Helper Therapy Principle. All PANDA volunteers were invited to participate (n = 40). Eight volunteers attended a focus group, and 11 survey responses were received. Descriptive statistics were used to analyse quantitative data. All survey respondents ‘strongly agreed’ that they felt positive about being part of PANDA. Thematic analysis of data from focus groups and open-ended survey responses identified the following themes: motivated to help others, supported to support callers, helping to make a difference and emotional impacts for volunteers. Respondents described a strong desire to support others experiencing emotional distress as a motivator to volunteer. Although perinatal peer support services are designed to benefit those who receive support, this study suggests volunteers may also experience personal benefits from the role.

Key words: volunteers, perinatal, depression, mental health, peers, anxiety

INTRODUCTION

Perinatal mental health problems are a major public health issue. Despite many strategies and interventions, there has been little shift in population prevalence over time (Astbury et al., 1994; O’Hara and Swain, 1996; Brown and Lumley, 1998; Brown et al., 2004; Gavin et al., 2005; Woolhouse et al., 2014). Peer support is an area that has the potential to address some of the key issues associated with poor perinatal mental health, such as poor social...
supports (O’Hara and McCabe, 2013), poor emotional support, and social isolation (Eastwood et al., 2012). Additionally, women experiencing emotional distress in the perinatal period have themselves expressed a preference for ‘talking therapies’, with the opportunity to discuss their feelings in depth and receive reassurance that other women experience similar challenges and that things will improve (Dennis and Chung-Lee, 2006). One type of peer support that has increasingly been implemented and evaluated in the perinatal period is telephone peer support (Lavender et al., 2013). Telephone health support has a number of advantages; it can be private and flexible (Dennis and Kingston, 2008), and can help to overcome barriers to care and support, such as fear of stigmatization (Galinsky et al., 1997; Dennis and Kingston, 2008) and geographical isolation (Ugariza and Schmidt, 2006; Lavender et al., 2013).

Peer support in the mental health field developed within the consumer and mental health recovery movement (Pound et al., 2011) which sought ‘social justice through understanding of mental illness in terms of human rights, the social suppression of difference and treating differences through psychiatric diagnosis’ [(Mead et al., 2001, p. 134]. There are different models and definitions of peer support, however, broadly it is considered that people who have had similar experiences to those they are supporting can relate better, and offer more authentic empathy and validation (Mead and MacNeil, 2006). The recovery model promotes peer support as a way to begin to address the social determinants of an individual’s health and empower them to become active participants within their own care (Pound et al., 2011).

It has, however, been noted that peer support is a complex concept, with large differences and inconsistencies in its application in practice (Dennis, 2003; McLeish and Redshaw, 2015). Although a variety of social or peer support interventions have been designed and implemented in the perinatal period, evaluations have varied in quality and demonstrated mixed findings (Small et al., 2011; Lavender et al., 2013). Two randomized controlled trials of telephone peer support in the postnatal period have demonstrated positive outcomes though, with high levels of acceptability for those receiving and providing peer support (Dennis, 2002, 2010), improved breastfeeding duration (Dennis et al., 2002) and reduced rates of postpartum depression amongst at risk women (Dennis et al., 2009).

It has been argued that when evaluations of peer support programs for mental health are undertaken, an evaluation of the peer providers should also be included (Salzer and Shear, 2002; Dennis, 2013), particularly as there is not the same clear distinction between provider and service recipient as there is with more traditional mental health care (e.g. psychotherapy) (Salzer and Shear, 2002). Further, the need to understand the views and experiences of peer supporters is important as the success of peer support interventions relies upon dedicated and competent volunteers (Dennis, 2013). Despite this, very few studies have explored the views and experiences of volunteers providing peer support in the perinatal period.

This study
PANDA Perinatal Anxiety & Depression Australia (formerly PANDA Post and Antenatal Depression Association) was founded in the 1980s in Melbourne, Australia as a peer support organization supporting women experiencing antenatal and postnatal depression. Since that time, the organization has grown considerably and offers support to people impacted by perinatal mental health issues in multiple ways, including the National Perinatal Anxiety & Depression Helpline (the Helpline). The Helpline is free and available to callers Monday–Friday, 10 a.m.–5 p.m. and is staffed by peer support volunteers, also known as support workers and paid professional counsellors. Individuals are able to contact the Helpline at times they need support, and when consent has been provided, PANDA staff and volunteers also make proactive follow-up calls. Due to the nature of the Helpline, continuity with the same volunteer and/or counsellor is not always possible, thus a caller may have contact with various members of the PANDA team over time. Callers can hear about the Helpline in different ways, including word of mouth; via maternity care providers, general practitioners and child health workers; and the internet. Each year over 10,000 calls are made to and from the Helpline (Shafiei et al., 2014).

In 2013, an independent evaluation of the Helpline was undertaken at the Judith Lumley Centre for mother, infant and family health research, La Trobe University. The evaluation included four components: an exploration of the views and experiences of new callers to the Helpline (Biggs et al., 2015); a description of the PANDA caller profile, demand and referral pathways; telephone interviews with callers assessed as having moderate-severe needs; and key informant consultations with PANDA staff, volunteers and key stakeholders (Shafiei et al., 2014). The views and experiences of PANDA volunteers are the focus of this paper.

Two social theories have been helpful in framing and addressing the study aims and in interpreting our findings; the Empathy–Altruism Hypothesis, and the Helper Therapy Principle.
Why do we help others? The Empathy–Altruism Hypothesis

The Empathy–Altruism Hypothesis attempts to answer the question of why we help others (Batson, 1991). The majority view in Western philosophy and psychology, known as universal egoism, is that everything we do, even if it benefits others, is done with the ultimate goal of benefiting ourselves (Batson, 1991). In contrast to this, the Empathy–Altruism Hypothesis proposes that some people, at least at times and under certain circumstances, are capable of a form of motivation with the ultimate goal of benefitting someone else (Batson et al., 2002). The hypothesis acknowledges that a person may benefit from helping another, however, the motivation for this helping would still be considered altruistic if these self-benefits are an unintended consequence rather than the ultimate goal (Batson and Shaw, 1991). Participant descriptions of why they volunteer with PANDA will be examined in light of this hypothesis.

Why can helping others benefit individuals?
The Helper Therapy Principle

Salzer identifies five theories underpinning the benefits of peer support: social comparison theory, social learning theory, social support theories, experiential knowledge and the Helper Therapy Principle (Salzer, 2002). Of these theories, the Helper Therapy Principle was the best fit to help explain our study findings. The Helper Therapy Principle was developed to begin to understand the benefits noted for individuals helping others (Riessman, 1965). Helping can be very beneficial, especially for individuals with similar problems to those they are helping (Salzer and Shear, 2002). These benefits have been described as: an increased feeling of interpersonal competence due to impacting another’s life, developing a sense of equality in giving and taking between self and others, developing new personally relevant knowledge while helping others, and receiving social approval from the people they help (Skovholt, 1974). This principle will be used to inform understanding of the benefits of helping described by PANDA volunteers.

METHODS

This study utilized a mixed-methods design, incorporating two focus groups and an online survey, to explore the views and experiences of volunteers providing peer support on the PANDA National Perinatal Anxiety & Depression Helpline. We included the online survey as an additional component (incorporated at the study commencement) to address the possibility that some individuals might not feel comfortable expressing their views in a focus group with peers.

Specifically, the study aimed to explore: why participants decided to volunteer with PANDA; volunteers’ descriptions of positive and challenging aspects of their role; the impact of their role, if any, for those volunteers with personal experience of perinatal depression and/or anxiety; volunteers’ experiences of training, support and supervision; and volunteers’ experiences of the PANDA culture and work environment.

Study location—PANDA

Although the PANDA Helpline is a national service, all staff and volunteers are physically located in Melbourne, a city with a population of more than four million people in the south eastern state of Victoria. The Helpline staff and volunteers sit in an open plan space, with offices for senior and administrative staff joining this main communal area.

PANDA volunteers are recruited through word of mouth, the PANDA website and/or online volunteer opportunity websites. All volunteers have personally experienced, or have supported someone who has experienced perinatal mental illness. Some volunteers join PANDA as they also have a professional interest in supporting individuals experiencing perinatal mental illness. Individuals interested in volunteering with PANDA apply and attend an information session to better understand what the role entails. They also participate in an individual interview and undergo police and referee checks.

Successful volunteer applicants undertake a two-stage training process focusing on perinatal mental health, loss and grief, transition to parenthood, family of origin, attachment theory, the Helpline systems and processes, counselling skills, risk assessment, values and self-care and a 2-day Applied Suicide Intervention Skills Training (ASSIST) session. The first stage of this training is held over 10 days and is focused on theoretical knowledge and Helpline systems and processes. The second stage of training involves volunteers sitting in the Helpline observing more experienced PANDA staff and volunteers. This stage of training does not have a set timeline; volunteers will elect when they feel confident enough to take their first phone call. A volunteer coordinator is present to support volunteers on the Helpline at all times.

Data collection

At the time of the evaluation there were a total of 40 telephone support volunteers and 12 telephone counsellors working on the Helpline. All PANDA Helpline volunteers...
were invited to participate in this aspect of the overall study (counsellors participated as a separate group).

All PANDA volunteers were sent an email from the Helpline Manager with a participant information statement inviting them to participate in a focus group and to complete a short online survey in October 2013, as part of the independent evaluation of the Helpline. Volunteers were informed that they were under no obligation to participate, that their survey responses would be anonymous and be returned directly to the independent research team. Volunteers could choose to complete the online survey, attend a focus group or do both. Volunteers who attended a focus group completed a consent form, and return of the online survey was considered as consent.

Times were selected on different days for the two focus groups to allow volunteers to attend the time that was most convenient for them. Two email reminders to complete the online survey were sent fortnightly from the initial email invitation. As the responses received were anonymous it was not possible to send reminders only to those who had not completed the survey, therefore, a note was included with reminders thanking those who had already responded for their time.

The survey was designed specifically for the purpose of the evaluation and was piloted with experienced researchers to assess survey content and flow, as well as face and content validity. The survey consisted of 16 questions, and included a range of demographic, closed and open-ended questions and a number of statements with Likert-type scale response options, i.e. ‘strongly agree’, ‘agree’, ‘neither’, ‘disagree’ or ‘strongly disagree’.

Focus groups were held at PANDA by two members of the research team (LB and TS) and no member of the PANDA management group attended. A semi-structured focus group schedule was developed specifically for the study, which explored volunteers’ experiences overall, as well as positive and negative aspects of their role. Focus groups were audio recorded with participants’ consent, and one of the researchers present took field notes, including details such as participant interactions, and both noted initial analytical impressions immediately following completion of the focus group.

Data analysis
Survey data were collected and managed within the web-based application Research Electronic Data Capture (REDCap) (Harris et al., 2009). Data cleaning included range and logic checks. Descriptive statistics were used to analyse quantitative data, and results presented as frequencies and percentages. STATA 13 (StataCorp, 2013) was used for this analysis.

Focus group recordings were transcribed verbatim by LB using Audacity 2.1.0 (Audacity Team, 2015). Focus group transcripts and responses to open-ended survey questions were analysed thematically by LB and HM (Liamputtong and Serry, 2010). In Vivo coding (also known as literal or verbatim coding) was used to code transcripts and survey responses, prioritizing the language and voices of participants (Saldaña, 2013). This coding was initially undertaken by hand, and then organized into a ‘coding book’ using a word processing program. LB then used a paper-based system to undertake code mapping, organizing groups of codes together to identify meaning and begin to organize codes into categories and themes.

The approach used in the qualitative components of this study are similar to what has been described as fundamental qualitative description by Sandelowski (2000); the focus of the research is to describe and does not demand the use of ‘a conceptual, philosophical, or other highly abstract framework or system[s]’ (2000, p. 336). She notes that this is one of the most commonly adopted methodologic approaches in the practice disciplines, aiming to present accurate accounts of events and the meanings participants attribute to them.

Reflexivity
LB is a midwife and has been a peer support volunteer with a community mental health organization since 2008. The possibility of the author’s own personal volunteer experiences influencing data analysis was acknowledged before analysis commenced and a number of reflexive measures were, therefore, adopted: HM contributed to the coding/category development process, and LB utilized analytic/reflective memos during the analysis process.

Ethics approval was obtained from the La Trobe University Ethics Committee, application number FHEC11/057.

RESULTS
Online survey
Eleven of the 40 volunteers (28%) participated in the online survey. The survey was ‘open’ and available for completion throughout October and November 2013.

Table 1 describes the characteristics of the volunteers who responded to the online survey. At the time of the study all volunteers at PANDA were female. Six of the
11 respondents were ≥40 years old, and all had completed some form of post-secondary education. Most had been volunteering at PANDA between 1 month and 3 years, and the majority spent less than 4 h per week volunteering at PANDA.

All respondents ‘strongly agreed’ that they felt positive about being part of PANDA (Table 2), and all ‘agreed’ or ‘strongly agreed’ (hereafter referred to as agreed) that they were able to provide individualized support to callers and that their work at PANDA makes a positive contribution to others.

Two respondents agreed with the statement that they often feel frustrated in their role as a support worker, and one agreed that volunteering as a PANDA support worker was stressful. No volunteers reported that volunteering at PANDA impacted negatively on their well-being, and two volunteers reported that their work at PANDA had helped them work through their own personal problems.

Respondents reported very positive experiences of support and supervision for them in their role, with all agreeing they received adequate support from their supervisor and colleagues, that their supervisor was approachable, and that they received enough debriefing and support (Table 3). All except one agreed that their supervisor appreciated their work and effort, and all reported feeling valued by both their supervisor and other PANDA staff and volunteers.

**Focus groups and open-ended survey questions**

Of the 40 volunteers who were invited to participate in a focus group, eight volunteers attended one of the two focus groups (five at one, three at the other—20% participation). The focus groups were held in October 2013 and November 2013, and ran for 45 and 22 min.

Table 1 describes the characteristics of focus group participants. Participants in the larger focus group had generally been at PANDA for a longer period of time than

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**Table 1: Characteristics of participants**

<table>
<thead>
<tr>
<th></th>
<th>Online survey</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 11)</td>
<td>(n = 8)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–39 years</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>≥40</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed degree or higher</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Completed a certificate, diploma or apprenticeship</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Length of time volunteering at PANDA</td>
<td>(n = 11)</td>
<td>(n = 8)</td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>1–3 years</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>&gt;3 years</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Average hours volunteering per week at PANDA</td>
<td>(n = 11)</td>
<td>(n = 8)</td>
</tr>
<tr>
<td>&lt;4</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>≥4</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

---

**Table 2: Views and experiences of PANDA peer support volunteers**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel positive about being part of PANDA (n = 11)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>I am clear about my role and responsibilities as a PANDA support worker (n = 10)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am confident in my role as a PANDA support worker (n = 11)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>I often feel frustrated in my role as a PANDA support worker (n = 11)</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>As a PANDA support worker, I am able to provide individualized support to callers (n = 11)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Working as a PANDA support worker is stressful (n = 11)</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>I am satisfied with my role as a PANDA support worker (n = 10)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall, working as a PANDA support worker is a positive experience (n = 10)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>I feel valued in my role as a PANDA volunteer (n = 10)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Working as a volunteer contributes to my own emotional well-being (n = 11)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>My work as a PANDA volunteer sometimes impacts negatively on my well-being (n = 11)</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My work as a PANDA volunteer helps me work through my own personal problems (n = 11)</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>I feel that my work at PANDA makes a positive contribution to others (n = 11)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>8</td>
</tr>
</tbody>
</table>
those attending the smaller focus group, possibly contributing to its longer running time and some of the differences in experience discussed by the two groups. On the basis of participant characteristics, such as age and length of time volunteering at PANDA, the research team was able to identify that only one volunteer who completed the online survey also took part in a focus group (overall study participation, therefore, 18 individuals/40; 45%).

The focus groups were held on two different days to attempt to allow more volunteers to attend. However, volunteers have a regular time and day each week that they attend PANDA, meaning that unless these focus groups were held at their usual attendance time they would have needed to make a special trip into the centre to participate, which for some volunteers would have been difficult with other employment and childcare commitments. We do not have data regarding

### Table 3: Volunteer experiences of support and supervision

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, I receive adequate support from my PANDA supervisor ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall, I receive adequate support from my colleagues at PANDA ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My concerns are taken seriously by my PANDA supervisor ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel valued by other PANDA staff and volunteers ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel valued by my PANDA supervisor ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think my work and effort is appreciated by my PANDA supervisor ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I receive enough debriefing/support when I need it ((n = 11))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>I feel comfortable to discuss issues that impact on my work with my supervisor ((n = 11))</td>
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<td>My direct supervisor is approachable ((n = 11))</td>
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**Fig. 1:** The views and experiences of volunteer telephone support workers on the PANDA Perinatal Anxiety & Depression Australia National Helpline.
non-responders, so we cannot comment on the characteristics of non-responding volunteers compared to responding volunteers.

Figure 1 presents combined thematic analysis from the focus groups and the open-ended survey question responses. Themes identified were: motivated to help others, supported to support callers, helping to make a difference and emotional impacts for volunteers.

**Motivated to help others**

When discussing their decision to volunteer with PANDA, participants described themselves as motivated to help others. There was a drive to support people experiencing emotional distress and to give back to their community:

- Having had some experience in difficult early parenting, I feel I am in a position to empathise and give back. (survey, participant 11)
- To support people with [postnatal depression]. Parents are special and need support. (survey, participant 2)

Some were motivated to volunteer on the Helpline as a way of accessing further professional development and growth. Some participants worked in caring professions and talked about strengthening their confidence and skills caring for individuals experiencing emotional distress in the perinatal period.

- I just felt that it would be beneficial for me to have a deeper understanding of how to support [women with perinatal depression and/or anxiety] through that. (focus group 2, participant 2)
- To gain counselling experience and give back. (survey, participant 10)

Participants with lived experience of mental illness identified this as motivating their decision to volunteer with PANDA, describing these personal experiences as relevant and useful:

- Because I had experienced [postnatal depression] twice I felt I could offer some depth of understanding to others in similar positions. (survey, participant 6)
- Being able to share with someone on the phone that they’re normal, this is a normal experience. (focus group 1, participant 1)

**Supported to support callers**

The theme ‘supported to support callers’ incorporates volunteers’ descriptions of their experiences volunteering at PANDA. Participants described their early experiences at PANDA as a process of growing confidence: in their ability to support callers; their knowledge of the different systems and processes at PANDA; and what community supports are available to help support callers. They felt comfortable with this process knowing they could progress through the later parts of training at their own pace, with the individual volunteer making the final decision regarding when they were ready to take their first call:

- I’ve been able to work at my own pace to gain my confidence. (focus group 2, participant 3)
- We get to choose what we feel comfortable with. (focus group 1, participant 1)

Some experienced moments of fear or doubt in their ability to support callers:

- Initially making those calls you go through this: arrive [at PANDA], think it’s really nice, then think ‘oh god, gotta do a call’, then you go through that whole process and make [the call], then [after], [you think] ‘that was great’! (focus group 2, participant 3)

They also emphasized the positive impact the supportive and inclusive PANDA culture has on their experiences. This support included formal training and debriefing processes, as well as more informal and spontaneous support from other volunteers and staff:

- There’s lots of support, lots of debriefing, lots of training, [a] very very special culture, [I] feel very well supported. (focus group 1, participant 2)
- Everyone is so grateful that you are giving your time and then I’m so grateful for the support. (focus group 2, participant 2)
- The culture at PANDA is the most nurturing and supporting positive environment I have EVER worked in. (survey, participant 2)

A less experienced volunteer who was still undertaking the second stage of her training described themselves as lacking confidence at times:

- I struggle with confidence... so knowing that everyone can hear me... [is] a little bit intimidating as well. (focus group 2, participant 1)

In direct response to the above statement a more experienced participant provided some reassurance:

- I’ve definitely felt that apprehension as well but when you’re on a call all of that disappears. (focus group 2, participant 3)
Participants described how accessible and safe the support and training is at PANDA:

[The training] was really good preparation.
(focus group 2, participant 3)
You felt like you were really well equipped, quite knowledgeable at the end of it.
(focus group 2, participant 1)
We’re very much supported into this role and independence at all times.
(focus group 1, participant 2)

Helping to make a difference
Participants explained that their role made them feel that they were helping to make a difference to the lives of callers. Volunteers described how this positive impact for callers made them feel:

I go away feeling that I’ve made a difference to someone.
(focus group 1, participant 1)
Feeling as though you can and have made a difference.
(survey, participant 3)

They also described their understanding of the value of volunteers and the Helpline itself in helping to have this positive impact for callers:

It’s not about having to solve the problems of the world, it’s just an opportunity to share their story that day of how they’re feeling, and our main role is to listen.
(focus group 2, participant 3)
I think also the different calls, it’s not the same [volunteer or counsellor] who speaks to the person on the phone… each time it’s a different experience and a different perspective, from each of the volunteers or the telephone counsellors… so it almost feels like, you know, because there are so many people supporting this person they could kind of help them a lot more.
(focus group 1, participant 3)
I speak for everyone in that we are so passionate about getting this message out and helping women.
(focus group 1, participant 1)

Some volunteers also felt that helping callers added meaning to their own lived experiences, and in turn this further assisted them to help support callers:

I feel like it’s giving purpose to what I went through and using it to help someone.
(focus group 1, participant 4)
All experiences are very different but there are common threads and this can assist in engaging and connecting with callers and it is personally satisfying knowing that my personal experiences have positively contributed to a caller’s recovery in some small way. Some good has come of my experience and I derive a sense of satisfaction from this knowledge.
(survey, participant 9)

Emotional impacts for volunteers
Varying emotional impacts for volunteers were discussed, including experiences of personal growth and healing:

I’m having to face some of my own demons here… as much as people come here with a good heart to look after others, you know the Buddha says what you give out you get back three times, and I really get a sense of that here.
(focus group 1, participant 2)
My role at PANDA does not impact negatively with regards to my own personal experience with PND. If anything it has been positive as it has allowed me to intellectually understand why I [fell] prey to this mental health issue.
(survey, participant 1)

Participants also discussed times when they had felt emotionally triggered or distressed by a caller’s story. Although volunteers described these experiences as difficult, they also emphasized how well supported they felt during these times:

I was really triggered a couple of weeks ago and had to leave. That’s the hardest thing is when you’re speaking to someone who is voicing things that you’ve experienced or there is something there that they’re saying that you think… it’s like, it brings it back sometimes… for your own experiences, whatever is happening in your world at the time, sometimes the calls can bring up stuff for us as well, so that’s challenging I think, but I think it’s managed well here, as you said we’re really well looked after, but it is a hard thing to come back and go back on another call and think ‘okay, here we go again’.
(focus group 1, participant 1)

…I’ve always felt very supported when I’ve had difficulties with a particular caller or I’ve read a file and I think ‘I don’t know if I can handle this, I think this might be a bit beyond me’ and I’ve always felt that I’ve been able to talk to one of the volunteer coordinators and say ‘I just don’t think I’ve got it today, for this’…
(focus group 1, participant 4)

A need to manage boundaries and their expectations of themselves was also often discussed. These descriptions included feeling as though they wanted to do more for callers:

We want to give more, so that’s a challenge for all of us.
(focus group 1, participant 1)
It’s all the pressure you put on yourself, isn’t it?
(focus group 1, participant 1)
Participants mentioned needing to remind themselves that ‘just’ peer support is enough, and that at times they unreasonably compared themselves to the professional counsellors who work on the Helpline:

It’s just peer support, and that’s massive, and that’s okay.
(focus group 1, participant 3)

As volunteers, let’s remind ourselves of that. Just do your best.
(focus group 1, participant 4)

We all sit in that space and these [counsellors] are awesome, and we are providing peer support.
(focus group 1, participant 2)

**DISCUSSION**

Volunteers felt that they were able to make a significant, helpful contribution to callers’ lives, and some volunteers with lived experience of perinatal mental illness gained a sense of satisfaction knowing that their experiences were useful and supportive for callers. Safe and accessible support, supervision and training had a significant impact on volunteers’ experiences, assisting them to grow confidence in their abilities and contributing to an ongoing feeling of being supported and valued within the organization. The correct amount of training for peer support volunteers is still unknown (Dennis, 2003), with warnings that over training may lead peer supporters to become ‘paraprofessionals’, losing their ‘peerness’ and, therefore, a vital component of their role (Dennis, 2003; Fisher et al., 2014). Volunteers in this study seemed to value the degree of training they received, feeling this was an important process which allowed them to develop important knowledge necessary to feel confident on the Helpline.

In both the focus group and survey, volunteers described a strong drive to support and assist others experiencing emotional distress, emphasizing this as a significant motivator behind their decision to volunteer at PANDA. Batson’s Empathy–Altruism Hypothesis proposes that empathy can act as an altruistic motivator, and that the greater the feelings of empathy the greater the altruistic motivation (Batson, 1991; Batson and Shaw, 1991; Batson et al., 2002). As volunteers either have lived experience of or have supported someone with perinatal mental illness, volunteers are likely to experience significant empathy for Helpline callers, facilitating ongoing altruistic motivation to volunteer with PANDA. Volunteers described a desire to reassure callers that their feelings were normal, and that their own personal experiences facilitated a greater depth of empathy and understanding of callers’ experiences and needs.

The Empathy–Altruism Hypothesis acknowledges that while a person’s motivations may be altruistic in nature, they may still experience self-benefits as a result of their actions; the Helper Therapy Principle helps to explain this. Some volunteers described volunteering as an opportunity to develop professionally relevant experience for a different role they held within a ‘caring profession’. Volunteers also described gaining a better understanding of their personal experiences, or having to ‘face some of their own demons’. These descriptions of personal growth and healing are linked with Skovholt’s concepts of increasing interpersonal competence and social approval (1974). Volunteers’ descriptions of the great sense of satisfaction they experience as a result of feeling that they had been able to have a positive impact on another person’s life clearly exemplify the concepts described in the theory.

It has been previously highlighted that the support and ongoing supervision of peer supporters may be as important as their initial training, and could help them to cope with some of the challenges of their roles, including coping with emotional distress (Fisher et al., 2014). This was reflected in our findings, with respondents’ positive experiences of debriefing, support and the PANDA workplace culture and environment contributing to their overall positive experiences of volunteering on the Helpline. They emphasized that these organizational features gave them confidence in their role and helped to reduce any negative emotional impacts of volunteering. This supportive environment was observed by LB and TS during the focus groups, and is evidenced by the reassurance provided to a less experienced volunteer regarding feeling uncomfortable that other members of the team could hear her Helpline conversations (p. 7). The physical organization of PANDA as a large communal space may assist volunteers to feel supported and connected with others, as volunteers are working in close proximity with other paid staff and volunteers who can respond promptly to a need for support or debriefing which would not be the case if they were working in isolation. Supporting positive volunteer experiences is particularly important in organizations like PANDA given the emotional content of the role and volunteers’ personal experiences of perinatal mental illness. Ensuring close physical proximity to support and supervision may be an important factor to consider when designing peer support programs to help safeguard the emotional well-being of volunteers. Further, volunteers working in the same physical space as their supervisors may serve to improve the quality of the support provided to callers.

Our findings have similarities with previous studies exploring the experiences of volunteers providing peer support.
support in the perinatal period. Volunteers in previous studies have also reported that their own lived experiences had motivated their decision to volunteer (McLeish and Redshaw, 2015), including an Australian study of volunteers providing telephone peer support with Australian Stillbirth and Newborn Death Support (SANDs) (Boyle et al., 2015). Previous studies have reported high levels of volunteer satisfaction (Dennis, 2013; Boyle et al., 2015; McLeish and Redshaw, 2015), with some volunteers stating that their role had helped to give further meaning to their own experiences (Boyle et al., 2015) and helped them grow as individuals (Dennis, 2013).

**STRENGTHS AND LIMITATIONS**

Data from focus groups and an online survey have been used to explore the experiences of volunteers on the PANDA Helpline. The use of two data sources strengthens our findings, overcoming some of the potential limitations of conducting focus groups with peers where participants may feel that they cannot share certain views or ideas and difficulty some volunteers may have had in attending one of the two scheduled focus group times. One focus group was longer than the other, however, as previously highlighted this might be in part attributed to the fact that volunteers in the longer focus group had been at PANDA for a greater period of time. The same schedule was followed in both focus groups, with participants having the same opportunities to discuss topics.

Overall 18 volunteers took part in this study (18/40, 45%). It is acknowledged that non-participants may have had different experiences of volunteering at PANDA than those who participated. Data regarding the number of volunteers who had not completed training, and overall volunteer retention were not collected as part of the evaluation, so it is not possible to comment on any potential impact of these factors. This is a small study of volunteers in a very specific service, however, the views and experiences of the respondents presented in this paper add to the limited literature on this topic. Understanding the views and experiences of peer volunteers providing perinatal mental health support is critical to the ongoing establishment and sustainability of programs such as PANDA.

**CONCLUSIONS**

Participants chose to volunteer on the PANDA Helpline as they were motivated to support parents experiencing emotional distress. Volunteers described feeling very well supported in their role, and experienced a sense of satisfaction and meaning in being able to help others. Calls could sometimes be triggering for volunteers with lived experience of perinatal mental illness, but this did not cause these volunteers to describe their experience overall as negative or traumatic, with some describing the role as facilitating personal growth and healing. Our findings highlight that volunteers feeling supported and having accessible debriefing can assist in reducing the potentially difficult emotional impacts of volunteering, an important consideration in the design of peer support services. Physical proximity to supervision and debriefing may play an important role in volunteers feeling safe and supported. Perinatal peer support services are designed to benefit those receiving the support, however, this study suggests that volunteers may also experience significant benefits from their role.

**REFERENCES**


…trying to give them a place where they feel safe to share, that’s so positive... I go away feeling that I’ve made a difference to someone, and particularly wish that I had that in my experience... I wish it was available for every mother.
Chapter Ten
Discussion and conclusion

INTRODUCTION

This is the first time that an evaluation of the PANDA Perinatal Anxiety & Depression Helpline has been undertaken, and one of the first studies exploring a community-based perinatal mental health service. This thesis has demonstrated the role a specialist consumer organisation like PANDA can play in supporting families affected by mental health issues in the perinatal period. In this chapter, the key thesis findings will be discussed, as well as the implications for future research, and Helpline service provision.

KEY STUDY FINDINGS – PART A: CHARACTERISTICS OF HELPLINE CALLERS AND REASONS FOR SEEKING HELP

Demand for Helpline services increased substantially over time; in just over three years of operation there was a 70% increase in initial calls alone. The majority of callers to the Helpline were women concerned about their own mental health, however the service also received calls from partners, friends, and families, and health care professionals. Callers to the Helpline were generally more highly educated, older, and more likely to be married than the general Australian birthing population. This could be explained by the known barriers to seeking help for mental health challenges, such as a lack of awareness of where to access help (Dennis & Chung-Lee, 2006), poverty, and discrimination (O’Mahony & Donnelly, 2013). Although telephone services may help to overcome some of these barriers, many women still will not seek help. This study is not able to contribute to knowledge regarding those who do not seek help, however the most vulnerable women in the community will likely experience multiple barriers to help-seeking and adequate treatment for perinatal mental illness.
Of the women who were already receiving some care when they first called the service, it was not uncommon for this care to be assessed as inadequate by PANDA counselling staff; a demonstration of what is known from the literature regarding the significant number of women who don’t receive adequate treatment and support (Coates et al., 2004; Spitzer et al., 2000), even once they are identified as having poor mental health (Gavin et al., 2015). This finding was also reflected in the survey of recent callers to the Helpline (Sub-study three); some respondents detailed multiple help-seeking attempts, including attending face-to-face services and accessing other helplines, before they felt they were able to access the advice and care they needed.

It has been hypothesised that traditional approaches to treating mental health issues in the perinatal period may be ineffective if the woman’s social health issues are not also addressed (Yelland et al., 2010). PANDA is experienced in providing support to callers affected by multiple complex psychosocial factors, including issues relating to family violence, alcohol and other drug use, and social isolation. This experience, along with the range of interventions and flexible support offered by the Helpline is a key strength of the service; PANDA’s skills and knowledge extend beyond what is traditionally considered mental health care, meaning they are well equipped to respond to callers’ holistically, rather than focusing on someone’s mental health presentation alone. This is particularly important given what is known about the relationship between social adversity and perinatal mental health: women experiencing psychosocial adversity are more likely to experience perinatal mental health issues (Yelland et al., 2010); the relationship between social complexity and risk of harm, highlighted by research indicating that women who experience IPV are more likely to have thoughts of suicide than women who are not (Gavin et al., 2011); and the number of maternal deaths relating to psychosocial causes, mostly attributed to suicide, increasing in Australia (Humphrey, 2016).
KEY STUDY FINDINGS – PART B: THE EXPERIENCES OF CALLERS AND PEER SUPPORT VOLUNTEERS

Callers reported positive experiences of accessing support from the Helpline, with most feeling better emotionally after speaking with the service. A third of callers identified that one of the reasons they had contacted PANDA was for crisis help and support, providing insight into the frequency that PANDA is managing callers in crisis. Most callers reported that they received non-judgemental support and information they could trust from Helpline staff and volunteers. Callers valued having access to a service that understood the specific challenges facing families in the perinatal period, expertise that non-specialised mental health services are less likely to have. These findings support previous research reporting a high level of satisfaction with perinatal peer support interventions (Dennis, 2010), and that women value the opportunity to have someone to speak to about how they are feeling (Jones, Jomeen, & Hayter, 2014; Small et al., 1994), and that many prefer forms of ‘talking therapy’ compared to pharmacological treatments (Dennis & Chung-Lee, 2006).

A number of the descriptions of support provided by the Helpline align with the concept of Source of Strength (SOS) support, described by Feeney and Collins in their Thriving Through Relationships model (Feeney & Collins, 2015b, 2015a). Using the concept of ‘thriving’, the model seeks to explain how relationships can help or hinder someone’s wellbeing in stressful and non-stressful times. Respondents described PANDA’s service as a safe space to be heard and receive support without judgement, which demonstrates that PANDA’s staff and volunteers are able to provide the first stage of SOS support; to provide a safe haven. Providing a safe haven means creating an environment where individuals experiencing adversity feel free to express difficult or negative emotions, and responding appropriately to these disclosures with reassurance, understanding, and instrumental aid. Callers described a process of fortification, which allowed them to identify their strengths and feel more able to respond to the challenges and adversity they were experiencing. The final two components of
SOS support were also apparent in caller’s descriptions of the service; reconstruction, focused on motivating the caller to use their strengths to act and respond positively to begin a process of rebuilding, which requires reframing or redefining, allowing the caller to see the adversity or challenge as able to be overcome, and developing the possibility of the caller thriving through the experience, not simply surviving it.

Feeney and Collins argue that it is possible for someone to thrive through experiences of adversity, meaning the experience is one of personal growth and development, leading to increased knowledge and strength (Feeney & Collins, 2015a). Volunteers providing peer support on the Helpline are an example of thriving through adversity. Volunteers are motivated to join PANDA by a strong desire to help other parents experiencing emotional distress, demonstrating that they have developed something useful and constructive from their own experiences of perinatal mental illness. This is supported by Batson’s Empathy-Altruism Hypothesis (Batson, 1991; Batson et al., 2002; Batson & Shaw, 1991), which explains empathy originating from lived experience as a strong altruistic motivator. Volunteers also described feeling as though providing peer support facilitated experiences of personal growth and development. This suggests that volunteering may contribute to thriving in the absence of adversity, which Feeney and Collins argue is achieved through meaningful and fulfilling participation in one’s community (Feeney & Collins, 2015a), which is supported by the Helper-Therapy Principle (Riessman, 1965; Salzer & Shear, 2002).

Volunteers reported feeling valued and supported at PANDA, which appeared to be protective against some of the potential challenges to their own mental health inherent in providing this kind of support. Although a small number of volunteers did experience stress at times on the Helpline, none felt that the role had a negative impact on their mental health, with many describing positive experiences of growth and healing. It has been argued that ongoing supervision and support may be just as important as initial training in helping
volunteers to cope with challenges (Fisher et al., 2014). Supervision and support was described as accessible and safe, and volunteers valued being in the same physical space as their supervisors, which made it very easy to access support during or after a challenging phone call. This is in contrast to other peer support services, where volunteers answer support calls in their own homes (Boyle et al., 2015), which may present a potential barrier to receiving support and supervision. Although concerns have been raised that if volunteers receive too much training they may lose their ‘peerness’ and become para-professionals (Dennis, 2003; Fisher et al., 2014), PANDA volunteers reported that their training and the accessibility of support and debriefing helped them to feel safe and well prepared to work on the Helpline.

STUDY IMPACT - CHANGES TO SERVICE Provision

The findings of this thesis have been used to inform ongoing Helpline service design and provision. The study findings have strengthened the evidence base regarding the Helpline’s services, and have been used to advocate for additional funding to facilitate increased hours of operation, which began on July 1st, 2017. An increase to Helpline hours of operation was one of the key recommendations for change made by respondents in Sub-study three. Another recommendation for change to the service related to the initial call process; respondents reported that waiting for a call back to conduct an initial call could be disconcerting when they had just worked up the courage to finally pick up the phone and seek help. Service changes mean that a member of staff now conducts a complete initial call at the first point of contact, removing this time of waiting. In instances where a member of staff is not free to answer the phone at the time someone calls, they are asked to leave a voice message for staff to return their call, which is usually completed the same day (T.Smith, PANDA CEO, personal communication, 2018).
STRENGTHS AND LIMITATIONS

This is the first time the National Perinatal Anxiety & Depression Helpline has been evaluated, providing the first in-depth understanding of caller characteristics and reasons for seeking help, changes to service demand over time, and the experiences of callers and peer support volunteers.

This study has a number of strengths and limitations. The use of data routinely collected for service provision is both a strength and limitation of Sub-studies one and two. A strength is the use of a large population based dataset of all callers to the Helpline, which would not have been possible if routinely collected service data had not been used. Use of secondary data in Sub-study two is also a strength, as the intake forms detail callers’ descriptions of why they contacted the Helpline at that point of first contact, meaning that the data are not influenced by issues of recall or callers’ evolving understanding of their situations over time. In this regard, the intake forms are able to capture callers at their ‘moment of readiness’ to seek help. A limitation to the use of routinely collected data is that the accuracy of data can be affected by the interpretation of those collecting it. Another limitation is that the research team are not able to be involved in data collection processes, meaning that some data that are relevant to the research question may not be collected, and validation processes are not able to be employed.

Sub-study three and four add to the limited literature exploring the views and experiences of individuals accessing telephone support for mental health in the perinatal period, and volunteers providing peer support. A strength of Sub-study four is its use of two data sources, potentially overcoming some of the limitations of conducting focus groups with peers where participants may feel that they are unable to share certain views. Both Sub-studies in Part B received reasonable response fractions given the study populations, however these studies were not able to expand on the views, experiences, or characteristics of non-responders, and
it is acknowledged that these individuals may have had different experiences of Helpline support (Sub-study three), and providing peer support (Sub-study four).

FUTURE RESEARCH DIRECTIONS

This study provides valuable insights into who calls the National Perinatal Anxiety & Depression Helpline concerned regarding their mental health, and patterns in service demand over time. The thesis cannot however provide insights into who isn’t seeking help, or patterns relating to unsuccessful help-seeking attempts. With more than 300,000 women giving birth in Australia each year (Australian Institute of Health and Welfare, 2017), and an estimated 66,000 of these experiencing postnatal depression and/or anxiety (based on an approximate prevalence of 22% (Yelland et al., 2010)), a relatively small proportion of affected women are contacting PANDA for help. Future research to better understand barriers and facilitators to help-seeking, and circumstances relating to both successful and unsuccessful attempts to access support may help to reduce the number of women who do not receive adequate treatment for perinatal mental illness, and the significant and long term affects this can have on the entire family unit.

As this was the first time the Helpline has been studied, an exploratory descriptive design was used to explore patterns in Helpline service demand, user profile, and the experiences of callers and peer support volunteers. Future longitudinal research would be needed to draw any conclusions relating to caller outcomes, such as the number of successful referrals, and improvements in caller mental health over time, as well as patterns in volunteer participation.

A defining feature of peer support is lived experience; those providing support have experienced something similar to the person receiving support, and may therefore be able to offer more authentic support and validation (Dennis, 2003). Less than one third of the callers who responded to the survey agreed that it was important for the person they speak with to have lived experience, perhaps indicating that for many, lived experience was not necessary.
in order for them to feel heard and understood. Some respondents did however stress how important speaking to someone who had lived experience was for them; they described this as something that made PANDA’s service unique, and helped them feel that the person they were speaking with really understood them and what they were experiencing. It would be beneficial to better understand how critical lived experience is to the peer support provider-recipient relationship, given less than a third of survey respondents indicated that this was important to them. The success and sustainability of peer support programs is dependent on the availability of dedicated volunteers, therefore understanding the role of lived experience in the provision of peer support may assist the implementation, evaluation and design of peer support services.

Since the time of data collection, PANDA has introduced a new, purpose-built database, which is reported to have greatly improved the consistency, breadth, and quality of Helpline service data collected. Future research using these data will be able to provide further insights into caller characteristics, service demand, and the care provided to Helpline callers over time. It is recommended that PANDA continues to engage in regular service evaluation activities, especially given the expanded evaluation and research possibilities this new database provides, including in-depth analysis of individual caller case studies.

CONCLUSION
This study is one of the first to explore a community based perinatal mental health service, and begins to address an important gap in the literature regarding the role of the service, women’s experiences of accessing support from the Helpline, and volunteers’ experiences providing peer support.

PANDA provides a specialist, holistic perinatal mental health telephone support service that is responsive to women’s needs, including complex social issues. The service is well utilised, and provides care that is well aligned with women’s preferences for ‘talking therapies’. Flexible
services like PANDA may help to overcome barriers to care such as stigma, geographical isolation, poverty, and transportation issues, and provides a powerful opportunity for individuals with lived experience to support others through perinatal mental illness.
Epi logue

There is a clear need to identify interventions that can help to prevent and treat mental health issues in the perinatal period, which are questions best answered by adequately powered randomised studies. However, there is also a need to study what already exists, especially if what exists appears to be working. PANDA provides important and much needed support to people in the community affected by perinatal mental illness, and has managed to do so for longer than I have existed. Perhaps better understanding sustainable organisations like PANDA can help to inform the translation of public health interventions into everyday practice, one of the greatest problems facing the evidence-based healthcare movement.

My PhD thesis was not my first contact with PANDA – I had been referring families to their services for years as a midwife. Like most practitioners, I was making these referrals with relatively limited knowledge of what would happen when the woman picked up the phone and asked for help. As part of my thesis, I have had the opportunity to observe and understand organisational and Helpline practices far beyond what is demonstrated in this thesis, and I am so thankful to have had the opportunity to work so closely with the dedicated and compassionate team of staff and volunteers at PANDA.

I started this PhD with aspirations that can only be described as idealistic. I was convinced that undertaking a PhD was something you did when you wanted to help change people’s lives, or even the world. I am not sure that my PhD has changed anyone’s life, however I think that it has been able to demonstrate that the Helpline can and does change the lives of some of its callers, and I am proud to have played a part in documenting that.
Appendices

I. Conference posters
- Perinatal Society of Australia and New Zealand (PSANZ) Annual Conference, 17 April 2015, Melbourne
- International Confederation of Midwives Triennial Congress, 18-22 June 2017, Toronto

II. Ethics approvals
- FHEC11_057
- FHEC11_032

III. Recruitment information and consent
- Caller survey invitation to participate (online)
- Caller survey invitation to participate (hard copy)
- Caller survey reminder (online)
- Caller survey reminder (hard copy)
- Volunteer invitation to participate focus group
- Volunteer invitation to participate online survey
- Caller survey
- Volunteer focus group schedule
- Volunteer survey

IV. Data collection tools
- Caller survey
- Volunteer focus group schedule
- Volunteer survey
APPENDIX I

Exploring the views and experiences of callers to the PANDA Post and Antenatal Depression Association National Perinatal Depression Helpline
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1Judge Lumley Centre, La Trobe University 2The Royal Women’s Hospital 3School of Nursing & Midwifery, La Trobe University

PANDA Post and Antenatal Depression Association supports those impacted by perinatal mental illness via the National Perinatal Depression Helpline. Peer support is provided on the helpline by volunteers, many of whom have lived experience of perinatal mental illness. Counselling is also available, provided by professional counselors. Each year more than ten thousand calls are made to and from the Helpline.1

Background
Women experiencing perinatal mental illness have expressed a preference for ‘talking therapies’,2 emphasising the importance of having someone to discuss their feelings and experiences with.3 Telephone interventions, including telephone peer support and counseling, have been developed to support those experiencing perinatal mental illness. Telephone services may help to overcome barriers to care including lack of time, difficulty attending appointments,4 fear of stigmatisation,5 and geographical isolation.6

Although there has been an increase in the number of telephone interventions designed to support women in the perinatal period, there has been limited research evaluating these interventions, and of those studies conducted few have included maternal perceptions of support.7 This study was undertaken as part of an independent evaluation of the PANDA National Perinatal Depression Helpline.

Methods
A cross-sectional survey design was used. All new callers to PANDA from 1st May to 30th September 2013 were invited to participate.

The study aimed to explore:
• Callers’ experiences of communication with PANDA, including whether they called the Helpline and what they felt they gained from their contact with the service;
• How, if at all, the Helpline differed from other support services callers had accessed.

Open and closed-ended questions were used, along with a series of questions using Likert-type scales. Descriptive statistics have been utilised, and responses to open-ended questions analysed thematically.1

Results
124 responses were received (124/406, 30% response fraction).

Table 1: Participant characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>99 (95)</td>
</tr>
<tr>
<td>Female</td>
<td>95 (95)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>87 (77)</td>
</tr>
<tr>
<td>Single</td>
<td>17 (16)</td>
</tr>
<tr>
<td>One child (n=103)</td>
<td>52 (50)</td>
</tr>
<tr>
<td>None</td>
<td>8 (8)</td>
</tr>
<tr>
<td>Most recent child 13-51 weeks old (n=86)</td>
<td>57 (68)</td>
</tr>
<tr>
<td>Age of residence (n=154)</td>
<td></td>
</tr>
<tr>
<td>Under 25</td>
<td>54 (52)</td>
</tr>
<tr>
<td>25-34</td>
<td>42 (40)</td>
</tr>
<tr>
<td>35-44</td>
<td>42 (40)</td>
</tr>
<tr>
<td>45-54</td>
<td>36 (35)</td>
</tr>
<tr>
<td>Over 55</td>
<td>10 (10)</td>
</tr>
<tr>
<td>English as first language (n=101)</td>
<td>99 (98)</td>
</tr>
</tbody>
</table>

Residents most commonly contacted PANDA seeking support (77%), information regarding perinatal anxiety and/or depression (45%), reassurance (41%), and crisis help and support (33%). The majority of callers felt they had gained hope and reassurance (87%) and were helped to feel better about being a parent (87%).

Conclusions
Overall, callers reported very positive experiences of accessing support from the PANDA Post and Antenatal Depression Association National Perinatal Depression Helpline.

Callers felt better emotionally after speaking to someone from PANDA, describing the service as unique, accessible and non-judgemental.

Few studies have explored the experiences of those accessing telephone support for perinatal mental illness. This study adds to our existing knowledge, and could be used to inform future service/ research design, review, and implementation.

Acknowledgements
Thank you to all the callers who took the time to complete the survey.
Thank you to the PANDA staff and volunteers who facilitated the distribution of online and hard copy invitations to all new callers within the study period.
APPENDIX II

Volunteers’ experiences of providing peer support by telephone to callers to the PANDA Perinatal Anxiety and Depression Australia Helpline

Laura J Biggs1, Helen L McLachlan1-3, Touran Shafiei4, Rhonda Small1, and Della A Forster1,3
1Judith Lumley Centre, La Trobe University, 2School of Nursing & Midwifery, La Trobe University, 3The Royal Women’s Hospital

Background
Peer support is a potentially important strategy for perinatal mental health, as it can help to address some key issues associated with poor perinatal mental health, such as poor social support1, and social isolation2. When delivered by telephone, it can help to overcome barriers to care such as geographical isolation3 and fear of stigmatisation4.

PANDA Perinatal Anxiety and Depression Australia provides support to individuals via the free National Perinatal Anxiety and Depression Helpline. Callers receive peer support from volunteers and counselling from paid professional staff. Each year more than 12,000 calls are made to and from the Helpline.

Volunteers have lived experience of a perinatal mood disorder, or have supported someone who has. The views and experiences of PANDA volunteers have not previously been studied.

Methods
We conducted two focus groups and an online survey to explore the experiences of women providing peer support on the Helpline. Data were collected in October and November 2013.

Descriptive statistics were used to analyse quantitative data. Focus group recordings were transcribed verbatim and analysed thematically.

Results
All volunteers were invited to participate (n=40). Eight attended a focus group, and 11 survey responses were received, with an overall response fraction of 45%.

Volunteers who responded were mostly aged 40 years or older (58%), had been at PANDA between one and three years (47%), and spent on average less than four hours volunteering per week (74%).

Figure 1: Views and experiences of volunteer telephone support workers

Participants chose to volunteer at PANDA as they were motivated to support parents experiencing emotional distress.

Volunteers felt that they were able to make a significant, helpful contribution to callers’ lives. Some volunteers with lived experience of perinatal mental illness gained a sense of satisfaction knowing that their experiences were useful and supportive for callers.

Safe and accessible support, supervision and training had a significant impact on volunteers’ experiences. Volunteers felt these positive organisational features gave them confidence and helped to reduce negative emotional impacts of their role.

Calls could sometimes be triggering for volunteers with lived experience, but this did not cause them to describe their experience overall as negative.

Our findings have similarities with previous studies exploring the experiences of peer volunteers in the perinatal period; reporting high levels of satisfaction1-7 and personal growth8.

Conclusion
Although perinatal peer support services are designed to benefit those who receive support, this study suggests volunteers may also experience personal benefits from the role.

References

@ LauraBiggs
Laura.Biggs@latrobe.edu.au

153
Thank you for submitting your modification request for ethics approval to the College Human Ethics Sub-Committee (HESC) for the project referred to above. The HESC has reviewed and approved the following modification/s which may commence now:

**Extension of time to 31 December, 2016.**

**Additional investigator - Laura Biggs**

Please note that your request has been reviewed by a sub-committee of the UHEC to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. However, you may commence prior to ratification and you will be notified if the approval status of your project changes.

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the HESC.

- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the HESC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: Ethics - Application for Modification to Project which is available on the Research Services website at http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics. If the HESC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.

- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the hesc.she@latrobe.edu.au. Any complaints about the project received by the researchers must also be referred immediately to the HESC Secretary.

- **Withdrawal of Project.** If you decide to discontinue your research before its planned completion, you
must advise the HESC and clarify the circumstances.

- **Monitoring.** All projects are subject to monitoring at any time by the HESC.

- **Annual Progress Reports.** If your project continues for more than 12 months, you are required to submit an *Ethics - Progress/Final Report Form* annually, on or just prior to **12 February**. The form is available on the Research Services website (see above address). Failure to submit a Progress Report will mean approval for this project will lapse.

- **Auditing.** An audit of the project may be conducted by members of the HESC.

- **Final Report.** A Final Report (see above address) is required within six months of the completion of the project.

If you have any queries on the information above or require further clarification please contact me at [hesc.she@latrobe.edu.au](mailto:hesc.she@latrobe.edu.au).

Ms Kate Ferris  
Human Ethics Officer  
Secretariat – SHE College Human Ethics Sub-Committee  
Ethics and Integrity / Research Office  
La Trobe University Bundoora, Victoria  3086  
E: [hesc.she@latrobe.edu.au](mailto:hesc.she@latrobe.edu.au)  
P: (03) 9479 – 3370  
To: Helen McLachlan – Department of Nursing & Midwifery
Student: Laura Biggs
From: Secretariat, SHE College Human Ethics Sub-Committee (SHE CHESC)
Reference: FEHC11/032 - Ethics application for modification to project - Approved
Title: A retrospective analysis of routinely collected data of the Post and Antenatal Depression Association's (PANDA) telephone helpline
Date: 28 March, 2017

Thank you for submitting your modification request for ethics approval to the SHE College Human Ethics Sub-Committee (SHE CHESC) for the project referred to above. The CHESC has reviewed and approved the following modification/s which may commence now:

Extension of time to 31 December, 2017.

Please note that your request has been reviewed by a sub-committee of the UHEC to facilitate a decision before the next Committee meeting. This decision will require ratification by the UHEC and it reserves the right to alter conditions of approval or withdraw approval at that time. However, you may commence prior to ratification and you will be notified if the approval status of your project changes.

The following standard conditions apply to your project:

- **Limit of Approval.** Approval is limited strictly to the research proposal as submitted in your application while taking into account any additional conditions advised by the SHE CHESC.

- **Variation to Project.** Any subsequent variations or modifications you wish to make to your project must be formally notified to the SHE CHESC for approval in advance of these modifications being introduced into the project. This can be done using the appropriate form: *Ethics - Application for Modification to Project* which is available on the Research Services website at [http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics](http://www.latrobe.edu.au/researchers/starting-your-research/human-ethics). If the SHE CHESC considers that the proposed changes are significant, you may be required to submit a new application form for approval of the revised project.

- **Adverse Events.** If any unforeseen or adverse events occur, including adverse effects on participants, during the course of the project which may affect the ethical acceptability of the project, the Chief Investigator must immediately notify the chesc.she@latrobe.edu.au. Any complaints about the project received by the researchers must also be referred immediately to the SHE CHESC Secretary.

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Ms Kate Ferris  
Human Ethics Officer  
Secretariat – SHE College Human Ethics Sub-Committee  
Ethics and Integrity / Research Office  
La Trobe University Bundoora, Victoria 3086  
E: cCHESC.she@latrobe.edu.au  
P: (03) 9479 – 3370  
Dear PANDA caller,

Mother and Child Health Research at La Trobe University is conducting an independent evaluation of PANDA. As a recent caller to PANDA, I am writing to invite you to complete a brief survey about how you found the service you received. All recent callers to PANDA are being invited to participate in the evaluation.

PANDA has asked Mother and Child Health Research (MCHR) to conduct this evaluation. MCHR will not know who the survey goes to (i.e. does not have access to your personal details), and PANDA will not know who completes the survey (i.e. information will not go to PANDA) – ensuring your responses are treated confidentially.

The survey will ask your views on how PANDA assisted you, factors (if any) you found helpful and what (if anything) could be improved with the PANDA service. We expect that the survey will take no more than 10-15 minutes to complete.

Your participation is voluntary and your decision to take part in this project or not will not affect any services that you receive from PANDA. All answers will come directly to Mother and Child Health Research, La Trobe University. We will then provide feedback to PANDA, who have asked us to undertake this evaluation of their service. Only non-identifying information from the survey will be used in any publications or conference presentations arising from the evaluation.

If you would like further information, do not hesitate to call Touran Shafiei on (03) 9479 8798.

The ethical aspects of this research project have been approved by the Faculty Human Research Ethics Committee, Faculty of Health Sciences of La Trobe University.

If you have any complaints or concerns about your participation in the study that the researchers have not been able to answer to your satisfaction, you may contact the Secretary, Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University, Victoria, 3086, (P: 03 9479 3583, E: fhechealth@latrobe.edu.au). Please quote FHEC application reference number 11/57.

If you are willing to participate, please complete the survey online through the link below.

https://redcap.latrobe.edu.au/redcap/surveys/?s=tlL8syvmbq
Thank you for considering participating in this evaluation of PANDA.

Yours sincerely,

Associate Professor Helen McLachlan  
* h.mclachlan@latrobe.edu.au

Professor Rhonda Small  
* r.small@latrobe.edu.au

Professor Della Forster  
* d.forster@latrobe.edu.au

Dr Touran Shafiei  
* t.shafiei@latrobe.edu.au
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If you are willing to participate, please complete the attached questionnaire and return it to us using the reply-paid envelope enclosed. If you would prefer to complete the survey online, please go to: https://redcap.latrobe.edu.au/redcap/surveys/?s=tiL8syvmbq
Thank you for considering participating in this evaluation of PANDA.

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*d.forster@latrobe.edu.au*

Professor Rhonda Small  
*r.small@latrobe.edu.au*

Dr Touran Shafiei  
*t.shafiei@latrobe.edu.au*
Dear PANDA caller,

You may recall receiving an email a couple of weeks ago inviting you to participate in the evaluation of PANDA which asked about how you found the service you received. If you have already completed the survey, we would like to say thank you for the time and trouble you have taken.

As all survey responses are anonymous, we cannot know who has already completed the survey, so everyone will receive two reminders. Please ignore these if you have completed the survey.

If you haven’t completed the survey, we would be grateful if you would consider participating in this evaluation and complete the survey online through the link below:

https://redcap.latrobe.edu.au/redcap/surveys/?s=tiL8syvmbg

If you would like further information, do not hesitate to call Touran Shafiei on (03) 9479 8798.

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Dr Touran Shafiei  
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Dear PANDA caller,

You may recall receiving a questionnaire in the mail a couple of weeks ago inviting you to participate in the evaluation of PANDA which asked about how you found the service you received. If you have already returned the questionnaire, we would like to say thank you for the time and trouble you have taken.

As all survey responses are anonymous, we cannot know who has already completed the survey, so everyone will receive two reminders. Please ignore these if you have completed the survey.

If you haven’t returned the questionnaire, we would be grateful if you would consider participating in this evaluation, and complete and return it to us using the reply-paid envelope enclosed. If you would prefer to complete the survey online, please go to:

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r.small@latrobe.edu.au

Dr Touran Shafiei  
t.shafiei@latrobe.edu.au
PARTICIPANT INFORMATION STATEMENT-FOCUS GROUP

AN EXPLORATION OF THE VIEWS AND EXPERIENCES OF PANDA STAFF AND VOLUNTEERS

Mother and Child Health Research (MCHR) at La Trobe University is conducting an independent evaluation of PANDA. As a counsellor you play a key role in the PANDA perinatal helpline, and exploring your views and experiences is an important aspect of this evaluation. All PANDA staff and volunteers are being invited to participate in a focus group. The focus group will explore your roles and responsibilities, support and supervision, training and documentation processes.

Your participation will involve attendance at a one off focus group discussion with other PANDA staff and volunteers. There will be two focus groups held at different days for your convenience. We anticipate the focus group will take no longer than one hour. It will be conducted by two research team members from MCHR. Neither the helpline manager nor the CEO will be present. Focus groups will be audio recorded with your permission to ensure the accuracy of notes.

Your participation will contribute to the overall evaluation of PANDA currently being conducted by MCHR. It will also assist PANDA in terms of what aspects of the service are going well and what areas may need improvement.

We believe there are no foreseeable risks, side effects or discomforts associated with participation in this project. You may refuse to answer any question during group discussion and you may withdraw from the project at any time during the focus group although it is not possible to withdraw your contribution to the focus group discussion.

Your participation is voluntary and your decision to take part in the focus group or not will not affect in any way your relationship with PANDA.

Any information obtained for the purpose of this project that can identify you will be treated as confidential and securely stored. Surveys will be anonymous. Data from hard copies will be entered onto a computer database and password protected. Only members of the research team will have access to the information.
Data will be stored in locked filing cabinets in a locked room at MCHR, La Trobe University, Level 3 / 215 Franklin Street, Melbourne 3000, and accessed only by the research team.

As per La Trobe University Policy, all data will be retained for five years after publication. Data including informed consent forms and notes will be shredded following this time. Electronic data will be aggregated with no means of identifying individuals.

The information you provide may be used for academic publications, reports to PANDA and presented at conferences, but no individuals will be identified.

The ethical aspects of this research project have been approved by the Faculty Human Research Ethics Committee, Faculty of Health Sciences of La Trobe University.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

If you want any further information concerning this project, you can contact Dr Touran Shafiei on 03 9479 8798, Email: t.shafiei@latrobe.edu.au.

If you have any complaints or concerns about your participation in the study that the researchers have not been able to answer to your satisfaction, you may contact the Secretary, Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University, Victoria, 3086, (P: 03 9479 3583, E: fhechealth@latrobe.edu.au). Please quote FHEC application reference number 11/057.

Thank you for considering participating in this evaluation of PANDA.

Yours sincerely

Associate Professor Helen McLachlan  
h.mclachlan@latrobe.edu.au  
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Professor Della Forster  
d.forster@latrobe.edu.au  
9479 8783

Professor Rhonda Small  
r.small@latrobe.edu.au  
9479 8799

Dr Touran Shafiei  
t.shafiei@latrobe.edu.au  
9479 8798
CONSENT FORM

AN EXPLORATION OF THE VIEWS AND EXPERIENCES OF PANDA STAFF AND VOLUNTEERS

I have read and understood the Participant Information Statement and Consent Form, and any questions I have asked have been answered to my satisfaction.

I agree to participate in the project, realising that I may withdraw at any time during the focus group. I agree that research data provided by me or with my permission during the project may be presented at conferences and published in journals on the condition that neither my name nor any other identifying information is used.

I give my permission for an audio recording to be taken of me during the focus group session. (Please tick the appropriate box below).

☐ YES  ☐ No

Name of Participant (block letters):
Signature:  Date

Name of Researcher (block letters):
Signature:  Date
Mother and Child Health Research (MCHR) at La Trobe University is conducting an independent evaluation of PANDA. As a counsellor you play a key role in the PANDA perinatal helpline, and exploring your views and experiences is an important aspect of this evaluation.

All PANDA staff and volunteers are being invited to complete a short online survey exploring their views and experiences of working with PANDA. We expect that the survey will take no longer than ten minutes to complete.

Your participation will contribute to the overall evaluation of PANDA currently being conducted by MCHR. It will also assist PANDA in terms of what aspects of the service are going well and what areas may need improvement.

We believe there are no foreseeable risks, side effects or discomforts associated with participation in this project. Your participation is voluntary and your decision to complete the survey or not will not affect in any way your relationship with PANDA. Submitting the survey will imply consent to participate. All responses to the survey are anonymous and we will not know who completes the survey; for this reason data cannot be withdrawn after submission. All answers will come directly to MCHR, La Trobe University. We will then provide feedback to PANDA, who have asked us to undertake this evaluation of their service.

The information you provide may be used for academic publications, reports to PANDA and presented at conferences, but no individuals will be identified.

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If you are willing to participate, please complete the survey online through the link below.

<link provided to participants>

Thank you for considering participating in this evaluation of PANDA.

Yours sincerely

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9479 8783

Professor Rhonda Small
r.small@latrobe.edu.au
9479 8799

Dr Touran Shafiei
t.shafiei@latrobe.edu.au
9479 8798
APPENDIX XI

Views and experiences of callers to the PANDA National Perinatal Depression Helpline

1. What is today’s date?
   DD   MM   YYYY
   /   /

2. PANDA receives calls from mothers, fathers, grandparents, and other relatives/friends of people experiencing antenatal or postnatal depression and anxiety.
   Was your contact with PANDA about:
   [ ] Yourself
   [ ] Partner
   [ ] Daughter
   [ ] Son
   [ ] Sister
   [ ] Brother
   [ ] Friend
   [ ] Other (please specify)

3. We are interested to know why you made your first call to PANDA. Were you seeking: (please tick all that apply)
   [ ] Support
   [ ] Reassurance
   [ ] Information about antenatal depression and anxiety
   [ ] Information about postnatal depression and anxiety
   [ ] Referral to other services
   [ ] Crisis support/help
   [ ] Other (please add details)

4. Can you tell us how you HEARD about PANDA? (please tick all that apply)
   [ ] PANDA website
   [ ] Maternity hospital
   [ ] Other websites
   [ ] Midwife
5. **Can you tell us who ENCOURAGED (or what PROMPTED) you to call PANDA?**
(please tick all that apply)

- [ ] No one, I just decided myself
- [ ] PANDA website
- [ ] Maternity hospital
- [ ] Other websites
- [ ] Midwife
- [ ] Family/friends
- [ ] Maternal and Child Health Nurse/Child Health Nurse
- [ ] Beyondblue
- [ ] Obstetrician
- [ ] Pregnancy Baby Birth Helpline
- [ ] Psychologist/Counsellor
- [ ] Previous contact with PANDA
- [ ] Social worker
- [ ] From the Heart WA
- [ ] Media (e.g. TV, newspaper, magazine)
- [ ] PANDSI ACT
- [ ] Mother and Baby Unit
- [ ] Parenting booklets
- [ ] Early Parenting Centre
- [ ] GP
- [ ] PEHP
- [ ] Psychiatrist
- [ ] Other (please specify)
6. Approximately when did you first call PANDA?

- ☐ May 2013
- ☐ June 2013
- ☐ July 2013
- ☐ August 2013
- ☐ September 2013
- ☐ Other (please specify)

7. Can you estimate the total number of calls you have made to PANDA? (do not include calls PANDA made to you)

8. Has PANDA made any calls to you (or left messages)?

- ☐ Yes
- ☐ No (go to Q10)

9. If YES, can you estimate how many?

- ☐ Calls to me
- ☐ Messages left for me
10. **We are interested in your overall experiences of your calls to and from PANDA.**
*For the following series of statements please mark the box that best describes your view*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The PANDA staff/volunteers were relaxed and unhurried on the phone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. The PANDA staff/volunteers understood my concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. It took too long for a counsellor to return my call</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>d. Having access to PANDA during the evening/night and at weekends is</td>
<td></td>
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<tr>
<td>important</td>
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<tr>
<td>e. I was comfortable leaving my contact details with PANDA so that they</td>
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</tr>
<tr>
<td>could call me back</td>
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</tr>
<tr>
<td>f. I would have liked the option to have someone from PANDA visit me at</td>
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<tr>
<td>home AS WELL AS receiving support by telephone</td>
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<tr>
<td>g. Emotionally, I felt much better after speaking with someone from PANDA</td>
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<tr>
<td>h. I was NOT satisfied with the advice provided by PANDA staff/volunteers</td>
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<tr>
<td>i. During the phone conversations with PANDA, I was always asked whether</td>
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<tr>
<td>I had any questions</td>
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<td>j. I always felt my worries, anxieties or concerns were taken seriously by</td>
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<tr>
<td>the PANDA staff/volunteers</td>
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<tr>
<td>k. The PANDA staff/volunteers helped me to understand antenatal and/or</td>
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<tr>
<td>postnatal depression and anxiety</td>
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<tr>
<td>l. I was NOT happy with the information given to me by the PANDA staff/</td>
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<tr>
<td>volunteers</td>
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<td>m. It is important to be able to speak to the same person during every</td>
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<tr>
<td>phone call with PANDA</td>
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<tr>
<td>n. It is important that the person I talk to at PANDA has personally</td>
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<tr>
<td>experienced antenatal and/or postnatal depression or anxiety</td>
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<tr>
<td>o. The PANDA staff/volunteers were encouraging and reassuring</td>
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<td>p. I was happy with the emotional support I received from PANDA staff/</td>
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<td>volunteers</td>
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<tr>
<td>q. The PANDA staff/volunteers provided non-judgemental support</td>
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<tr>
<td>r. Overall, PANDA helped me</td>
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</tbody>
</table>
11. We are interested in what the PANDA staff/volunteers talked with you about during your phone call/s. Please say if any of the following occurred during your phone call/s.

☐ Not applicable - I was calling about someone else (e.g. friend, daughter) (go to Q13)

<table>
<thead>
<tr>
<th>The PANDA staff/volunteers:</th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Asked me how I was feeling</td>
<td></td>
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<tr>
<td>b. Encouraged me to get an accurate diagnosis</td>
<td></td>
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<tr>
<td>c. Made sure I was seeing my health care providers</td>
<td></td>
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<tr>
<td>d. Followed up on things from previous calls</td>
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<tr>
<td>e. Asked me if I was feeling safe</td>
<td></td>
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<tr>
<td>f. Asked me if my baby/children were safe</td>
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<tr>
<td>g. Acted to keep me or my baby/children safe</td>
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<tr>
<td>h. Sent me an information pack</td>
<td></td>
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<tr>
<td>i. Listened to my story</td>
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<tr>
<td>j. Provided me with referrals to other services</td>
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<tr>
<td>k. Discussed strategies to manage my distress</td>
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<tr>
<td>l. Reassured me and gave me hope</td>
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<tr>
<td>m. Offered to talk to my health care providers</td>
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<tr>
<td>n. Asked me about my relationships</td>
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<tr>
<td>o. Supported people who were helping me</td>
<td></td>
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<tr>
<td>p. Provided me with information I could trust</td>
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<tr>
<td>q. Helped me to feel better about being a parent</td>
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<tr>
<td>r. Asked me about my experience of the birth</td>
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<tr>
<td>s. Encouraged me to spend time connecting with my baby</td>
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<tr>
<td>t. Encouraged me to talk with my partner or family about my experiences</td>
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<tr>
<td>u. Other (please specify)</td>
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</tbody>
</table>
12. Did PANDA staff/volunteers talk with you about the following aspects of emotional health and well-being?

☐ Not applicable - I was calling about someone else (e.g. friend, daughter) (go to Q13)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Sharing my experience of the birth</td>
<td></td>
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<tr>
<td>b. Talking with my partner about my experiences</td>
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<tr>
<td>c. Spending time connecting with my/our baby, gazing and touching</td>
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<tr>
<td>d. Developing parenting strategies that work for me/us</td>
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<tr>
<td>e. Identifying what I am doing well and developing a realistic view of what is possible</td>
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<tr>
<td>f. Understanding the impact of my life as a child and young adult on my experience of becoming a parent</td>
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</table>

13. How would you rate the importance of the following regarding PANDA staff/volunteers?

For this series of statements please mark the box that best describes your view

<table>
<thead>
<tr>
<th></th>
<th>Not important</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Staff/volunteers who are understanding</td>
<td></td>
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<td></td>
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<tr>
<td>b. Staff/volunteers who are non-judgemental</td>
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<tr>
<td>c. Follow-up phone calls arranged by the staff/volunteers</td>
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<tr>
<td>d. To receive information on antenatal and/or postnatal depression and anxiety</td>
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<tr>
<td>e. To receive information and practical guidance for recovery</td>
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<tr>
<td>f. Staff/volunteers to speak with services on my behalf</td>
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<tr>
<td>g. To receive information on available resources</td>
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</table>

14. Did PANDA suggest that you contact any support services other than PANDA?

☐ Yes
☐ No (go to Q16)

If YES, what were these services?
15. Were you able to access the services suggested by PANDA?

☐ Yes (go to Q16)
☐ No

If NO, please explain

16. Did PANDA assist/arrange contact with any services (e.g. hospital, acute mental health team, GP) for you?

☐ Yes
☐ No (go to Q17)

If YES, what services?

17. If you have not been in contact with PANDA recently, can you tell us why?

For this series of statements please mark the box that best describes your view

☐ I am still in regular contact with PANDA (go to Q18)
☐ Not applicable - I was calling about someone else (e.g. friend, daughter) (go to Q18)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I felt I could manage things myself</td>
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<tr>
<td>b. My depression and/or anxiety settled</td>
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<tr>
<td>c. I was able to rely more on others (e.g. partner, family and friends) for help and support</td>
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<tr>
<td>d. I was seeing my family doctor and no longer needed PANDA</td>
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<tr>
<td>e. I was seeing a counsellor and no longer needed PANDA</td>
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<tr>
<td>f. I joined a support group/playgroup and no longer needed PANDA</td>
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<td>g. I didn't find the calls from PANDA helpful</td>
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<td>h. The PANDA worker told me they didn't need to call me anymore</td>
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<tr>
<td>i. I felt able to manage on my own using the strategies developed with a PANDA counsellor</td>
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</tbody>
</table>
18. Would you say that the service PANDA provided differed from other services you used, and if so, how? (please describe)

19. Please describe in your own words what you think you gained from calling the PANDA Helpline?

20. Was there anything you had hoped to gain from your contact with the PANDA Helpline that you didn’t receive?

21. Do you have any suggestions about how PANDA could improve their service?

To finish, a few questions about you

(Please remember back to when you first made contact with PANDA)

If you were calling about someone else (e.g. partner, friend, daughter), please go to Q8 (you do not need to answer Q1 to Q7)

1. Can you remember how you felt before picking up the phone to make your first call to PANDA? (please tick all that apply)
   - Nervous
   - Scared
   - Desperate
   - Relieved
   - Hopeful
   - Optimistic
   - Unsure of how PANDA could help
   - Other (please specify)
2. How would you rate your emotional health and well-being at the time you first made contact with the PANDA Helpline? Please mark the box that best describes your view

(1= Not well at all, 5=Extremely well)

1 2 3 4 5

3. Did you already have a diagnosis prior to your first contact with PANDA?

☐ Yes
☐ No (go to Q6)

4. If YES, what was this diagnosis? (please tick all that apply)

☐ Don’t know/not sure ☐ Adjustment disorder
☐ Antenatal depression ☐ Postnatal psychosis
☐ Antenatal anxiety ☐ Post-traumatic stress disorder
☐ Postnatal depression ☐ Bipolar disorder
☐ Postnatal anxiety ☐ Personality disorder
☐ Transition difficulties ☐ Obsessive compulsive disorder
☐ Eating disorder ☐ Other (please specify)

5. Who gave you this diagnosis?

☐ Family doctor
☐ Psychiatrist
☐ Maternal and child health nurse
☐ Psychologist
☐ Other (please specify)

6. If you did NOT have a diagnosis at the time of your first call to the PANDA Helpline, what did you think was happening to you?

I thought....
7. If you were given a diagnosis later what was this diagnosis? (please tick all that apply)
   - Don’t know/not sure
   - Not applicable, previously had a diagnosis
   - Not applicable, was not given a diagnosis
   - Adjustment disorder
   - Transition difficulties
   - Postnatal psychosis
   - Antenatal depression
   - Antenatal anxiety
   - Postnatal depression
   - Postnatal anxiety
   - Eating disorder
   - Post-traumatic stress disorder
   - Bipolar disorder
   - Personality disorder
   - Obsessive compulsive disorder
   - Other (please specify)

   We need this information only to describe the group of people who responded.

8. Which state do you currently live in?
   - VIC
   - NSW
   - QLD
   - SA
   - WA
   - TAS
   - ACT
   - NT

9. Are you....?
   - Male
   - Female

10. Are you....?
    - Married
    - Living with a partner
    - Have a partner but do not live together
    - Separated or divorced
    - Widowed
    - Single
    - Other (please specify)
11. How many children do you have altogether?
   ____ (number)

   □ Not applicable – I was calling about someone else (e.g. friend, grandchild) (go to Q14)

12. When was your most recent child born?
    □ Weeks ago  OR  □ Months ago

13. Are you or your partner currently pregnant?
    □ Yes  □ No

14. What is the highest level of education you have completed?
    □ Completed a degree or higher
    □ Completed a certificate/diploma/apprenticeship
    □ Completed secondary school to Year 12 (or equivalent)
    □ Did not/have not completed secondary school

15. What is the total BEFORE tax income your household (all family members living at home) usually receives?
    □ Less than $650 per week (less than $33,800 per year)
    □ $650 - $999 per week ($33,800 - $51,999 per year)
    □ $1000 - $1399 per week ($52,000 - $72,799 per year)
    □ $1400 - $1999 per week ($72,800 - $103,999 per year)
    □ More than $2000 per week ($104,000 or more per year)

16. Is a pension or benefit the main income for your family?
    □ Yes  □ No

17. Do you hold a Health Care Card?
    □ Yes  □ No

18. Are you of Aboriginal or Torres Strait Islander origin? (For persons of both Aboriginal and Torres Strait Islander origin, mark both ‘Yes’ boxes)
    □ No  □ Yes, Aboriginal  □ Yes, Torres Strait Islander
19. In which country were you born?

20. If you were not born in Australia, in which year did you first settle in Australia?

21. Is English your first language?
   - Yes (go to Q21)
   - No

   If NO, what is your first language?

22. How old are you? (years)

23. Is there anything else you would like to tell us?

   Thank you very much for taking the time to answer these questions

   Your feedback is very important to us and will assist PANDA to improve its support to women, men and their families who are concerned about or affected by perinatal depression and anxiety.
Introduction and welcome

The purpose of the discussion today is to explore your views and experiences of working with PANDA. We have been asked to conduct this evaluation by PANDA in order to identify what aspects of the service are going well and what areas may need improvement.

Thank you for letting us audio-tape the discussion. As detailed in the participant information statement, everything that is said in this group will be confidential. No individual will be identified in any reports, papers or presentations on the findings from this study.

Focus group theme list

Roles and responsibilities
- Just to get started, can you please (to help us understand) describe your role as a PANDA volunteer?

- Can you tell us about any positive aspects of your role as volunteer with PANDA?

- Can you tell us about any negative aspects of your role?

- Why did you decide to take on this role?

Support, supervision and debriefing processes
- Can you tell us about the support and supervision that is provided to you in your role and whether you think the support and supervision is adequate?

- Can you tell us about the debriefing processes in PANDA? (Prompt: what is the procedure? Is it adequate?)

Training
- Can you tell us about training and preparation you received for this role? (Was it adequate?)

Documentation requirements (e.g. call review forms)
- Can you tell us about the documentation requirements in PANDA? (Prompt: are they clear? Is there anything that should be changed?)

Do you have any further comments or anything else you would like to comment on?
APPENDIX XIII

ONLINE SURVEY-PANDA COUNSELLORS/SUPPORT WORKERS

Exploring the views & experiences of PANDA staff and volunteers

1. We would like to know what you think about your role as a PANDA counsellor/support worker.
For this series of statements please mark the box that best describes your view.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel positive about being part of PANDA</td>
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<tr>
<td>I am clear about my role and responsibilities as a PANDA counsellor/support worker</td>
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<td>In my role, I am often too busy to do my job properly</td>
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<tr>
<td>As a PANDA counsellor/support worker, I am able to provide individualised support to callers</td>
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<tr>
<td>I am confident in my role as a PANDA counsellor/support worker</td>
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<td>I often feel frustrated in my role as a PANDA counsellor/support worker</td>
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<td>Working as a PANDA counsellor/support worker is stressful</td>
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<tr>
<td>I am satisfied with my role as a PANDA counsellor/support worker</td>
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<tr>
<td>Overall, working as a PANDA counsellor/support worker is a positive experience</td>
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2. Please describe what, if any, are the most positive aspects of your role as a PANDA counsellor/support worker?
3. Please describe what, if any, are the most challenging aspects of your role as a PANDA counsellor/support worker?

4. What is your work status with PANDA?
   - [ ] Employed (skip to Q7)
   - [ ] Volunteer

5. We are interested in your views and experiences of being a PANDA volunteer. Please mark the box that best describes your view.
   - [ ] Not applicable – I am employed at PANDA (skip to Q7)

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel valued in my role as a PANDA volunteer</td>
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<tr>
<td>Working as a volunteer contributes to my own emotional well-being</td>
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<tr>
<td>My work as a PANDA volunteer sometimes impacts negatively on my well-being</td>
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<tr>
<td>My work as a PANDA volunteer helps me work through my own personal problems</td>
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<tr>
<td>I feel that my work at PANDA makes a positive contribution to others</td>
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6. Please add any comments about your experiences as a volunteer with PANDA.

7. If you have personal experience of perinatal depression or anxiety, please describe how your role impacts on your own emotional well-being.
   - [ ] Not applicable – I do not have personal experience of perinatal depression or anxiety

8. We are interested in your overall experiences of working with PANDA and any support and supervision you receive. For this series of statements please mark the box that best describes your view.
Please note: the use of the term supervisor refers to your direct supervisor or coordinator.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, I receive adequate support from my PANDA supervisor</td>
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<tr>
<td>Overall, I receive adequate support from my colleagues at PANDA</td>
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<td>My concerns are taken seriously by my PANDA supervisor</td>
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<tr>
<td>I feel valued by other PANDA staff and volunteers</td>
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</tr>
<tr>
<td>I feel valued by my PANDA supervisor</td>
<td></td>
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<tr>
<td>I think my work and effort is appreciated by my PANDA supervisor</td>
<td></td>
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<tr>
<td>I receive enough debriefing/support when I need it</td>
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<tr>
<td>I feel comfortable to discuss issues that impact on my work with my supervisor</td>
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<tr>
<td>My direct supervisor is approachable</td>
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</tbody>
</table>

9. Please add any comments about the support you receive from your supervisor in relation to your role, debriefing processes and supervision.
10. Please complete the following series of statements. *Mark the box that best describes your view.*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>When commencing this role I received adequate education/training</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I have limited opportunities for skill development</td>
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<td></td>
</tr>
<tr>
<td>All PANDA counsellors/support workers should have ongoing training</td>
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<tr>
<td>There are resources available if I need to update my knowledge and skills</td>
<td></td>
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<tr>
<td>I feel I have appropriate skills for this role</td>
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<tr>
<td>I think I need more training</td>
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<tr>
<td>I believe I have enough knowledge to work as a PANDA counsellor/support worker</td>
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</tr>
</tbody>
</table>

11. Please add any comments you would like to make about training and ongoing professional development.
12. We are interested in the documentation requirements of PANDA and any procedures for managing calls. For this series of statements please mark the box that best describes your view.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I often feel unsure about how to document calls</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I don’t have time to document calls properly</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I think documentation of calls is very important</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>The documentation procedures need to be changed</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Documenting calls is easy</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There are clear documentation procedures for callers who present with risk</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>I mostly rely on my own judgment when making management decisions about callers presenting at risk</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There are clear guidelines for dealing with callers who present at risk</td>
<td>□</td>
<td>□</td>
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<td>□</td>
</tr>
<tr>
<td>There are enough senior staff for me to consult regarding the management of callers</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There is adequate time for me to consult with senior staff regarding management of callers</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

13. Please add any comments you would like about documentation processes and procedures for PANDA calls.

14. Please describe any changes you have seen at PANDA since commencing your role and your thoughts about their impact on you.

15. Please describe why you chose PANDA as a place of work as a counsellor/support worker?
16. We are interested in your views of the PANDA culture/work environment. Please comment.

SOME INFORMATION ABOUT YOU

1. Which of the following best describes your age?

☐ 20 – 29 yrs
☐ 30 – 39 yrs
☐ 40 – 49 yrs
☐ ≥ 50 years

2. Are you....?

☐ Married
☐ Living with a partner
☐ Have a partner but do not live together
☐ Separated or divorced
☐ Widowed
☐ Single
☐ Other (please specify)

3. What is the highest level of education you have completed?

☐ Completed a degree or higher
☐ Completed a certificate/diploma/apprenticeship
☐ Completed secondary school to Year 12 (or equivalent)
☐ Did not/have not completed secondary school

4. How long have you been working with PANDA?

---------- months OR
---------- years

5. On average, can you estimate how many hours per week you spend working with PANDA?

---------- Hours/week

6. How long are you planning to work with PANDA?

---------- months OR
---------- years
☐ Not sure
☐ Other (please specify)
7. Do you have anything else you would like to comment on?

Thank you very much for taking the time to answer these questions.

Your feedback is very important to us and will assist PANDA to improve its support to women, men and their families who are concerned about or affected by perinatal depression and anxiety.


Cohen, L. S., Althshuler, L. L., Harlow, B. L., Nonacs, R., Newport, D. J., Viguera, A. C., ... Stowe,


Pliszka, M. (2012). Exploring the views and experiences of callers to the PANDA (post and antenatal depression association) National Helpline. La Trobe University.


StataCorp. (2009). Stata statistical software: Release 11. College Station, TX: StataCorp LP.


