Miscarriage Support: Where is it needed?

Meredith Temple-Smith

Acknowledgements

Jade Bilardi

STUDENTS

Clare Bellhouse	PhD
Elena Miller	DM
Kirsten Jensen	DM
Lily Claringbold	MPHC
Sophie Russ-Hall	Hons
Vellyna Sumarno	DM

Professor Arri Coomarasamy

Professor of Gynaecology and Obstetrics & Director of Tommy's National Centre for Miscarriage Research, University of Birmingham

Ms Helen Williams

Social Health Researcher, Tommy's National Centre for Miscarriage Research, University of Birmingham

Ms Jane Brewin

CEO, Tommy's Charity, UK

Amanda Bowles

President & Co-founder Bears of Hope Charity

Ms Samantha Payne

Founder & Managing Director, The Pink Elephants Support Network

Dr Jade Bilardi

Sexual & Reproductive Health Researcher, Monash University

Professor Meredith Temple-Smith

Sexual & Reproductive Health Researcher, University of Melbourne

Dr Litza Kiropoulous

Clinical Psychologist, University of Melbourne

Dr Patrick Pang

Health Informatics Researcher, University of Melbourne

Dr Van-Hau Trieu

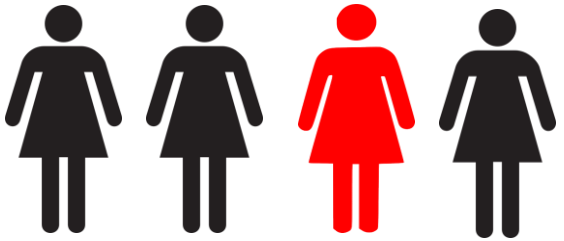
Social Media Researcher, Deakin University

Professor Jayashri Kulkarni

Professor & Director, Monash Alfred Psychiatry research centre (MAPrc)

Miscarriage in Australia

<20 weeks gestation



1 in 4 pregnancies

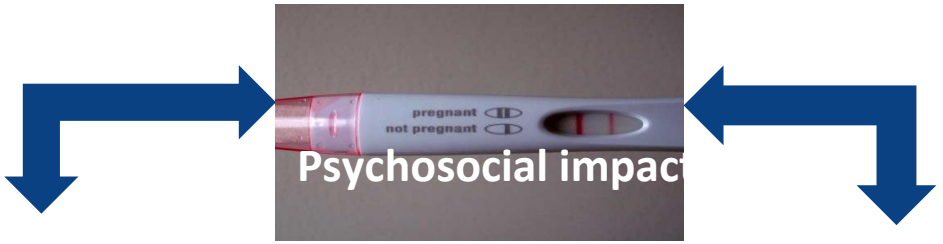
285 miscarriages per day

104,000 couples per year

Psychosocial Impact

High frequency + easily managed physically

= Routine pregnancy complication



What HCPs see

What potential parents see

Psychological Impact

Common emotional responses[1] include:

- *Grief, distress, isolation, anger, self blame, sadness*

Up to 50% women suffer psychological morbidity[2]

- *40%: symptoms of grief, pathological grief can follow*
- *10–50%: some form of major depressive disorder*
- *20–40%: heightened anxiety symptoms*

[1]Frost M, Condon JT: **The psychological sequelae of miscarriage: a critical review of the literature**. *ANZ J of Psychiatry* 1996, 30(1):54-62.

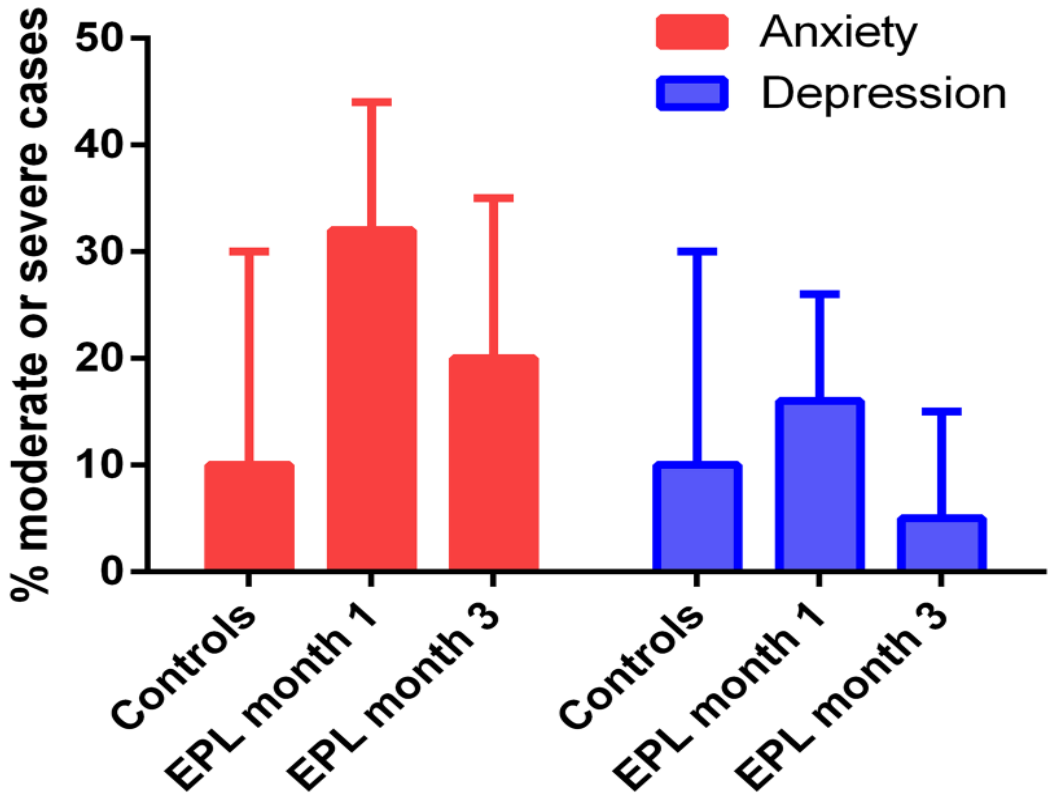
[2]Lok IH, Neugebauer R: **Psychological morbidity following miscarriage**. *Best Practice & Research Clinical O&G* 2007, **21**(2):229-247.

1 month

- 32% anxiety
- 18% depression
- 28% PTSD

3 months

- 20% anxiety
- 5% depression
- **38% PTSD**



[3]Farren J et al. **Post-traumatic stress, anxiety and depression following miscarriage or ectopicpregnancy: a prospective cohort study.** BMJ Open 2016;6.

Similar intensity to other major losses[4]

- Loss of hopes and dreams for the future
- Doubts of ability to have children

Level of psychological distress not associated with:

- gestational age or other obstetric factors[5-8]

[4]Brier N: **Grief following miscarriage: a comprehensive review of the literature**. Journal of Women's Health 2008, 17(3):451

[5]Collins C, Riggs DW, Due C: **The impact of pregnancy loss on women's adult relationships.** Grief Matters: The Aust J of Grief and Bereavement 2014, 17(2):44.

[6]Jackman C, McGee HM, Turner M: **The experience and psychological impact of early miscarriage**. The Irish Journal of Psychology 1991, **12**(2):108-120.

[7]Prettyman R, Cordle C, Cook G: **A three-month follow-up of psychological morbidity after early miscarriage**. British J of Medical Psychology 1993, **66**(4):363-372.

[8]Stratton K, Lloyd L: **Hospital-based interventions at and following miscarriage: Literature to inform a research-practice initiative.** ANZ J of O & G, 2008, 48(1):5-11.

Social & healthcare support matters

- shapes experience & psychological impact

Positive support

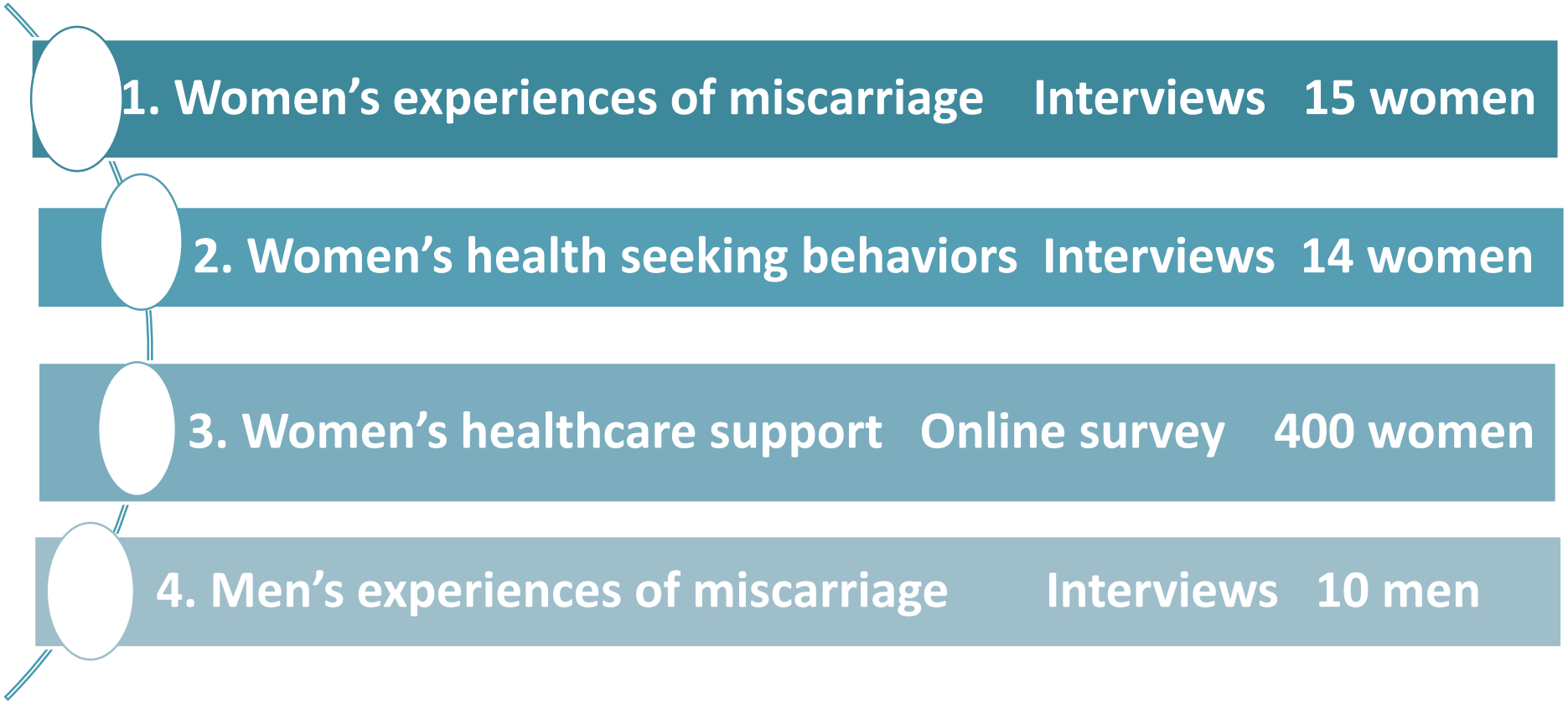
- buffers loss & better psychological outcomes[4,8]

Lack of social support

- major risk factors to psychological morbidity[2,9]

9 Lee C, Slade P: **Miscarriage as a traumatic event: a review of the literature and new implications for intervention**. *J of Psychosomatic Research* 1996, **40**(3):235-244.

Our research so far…



Need for acknowledgement

…I guess you just start planning everything, and you have all these hopes and dreams, but then they were this potential person, and it's like no one else really cares about it. It's not going to make any history, it doesn't have a birth certificate, it's just nothing. But it means so much to you…

Angelina

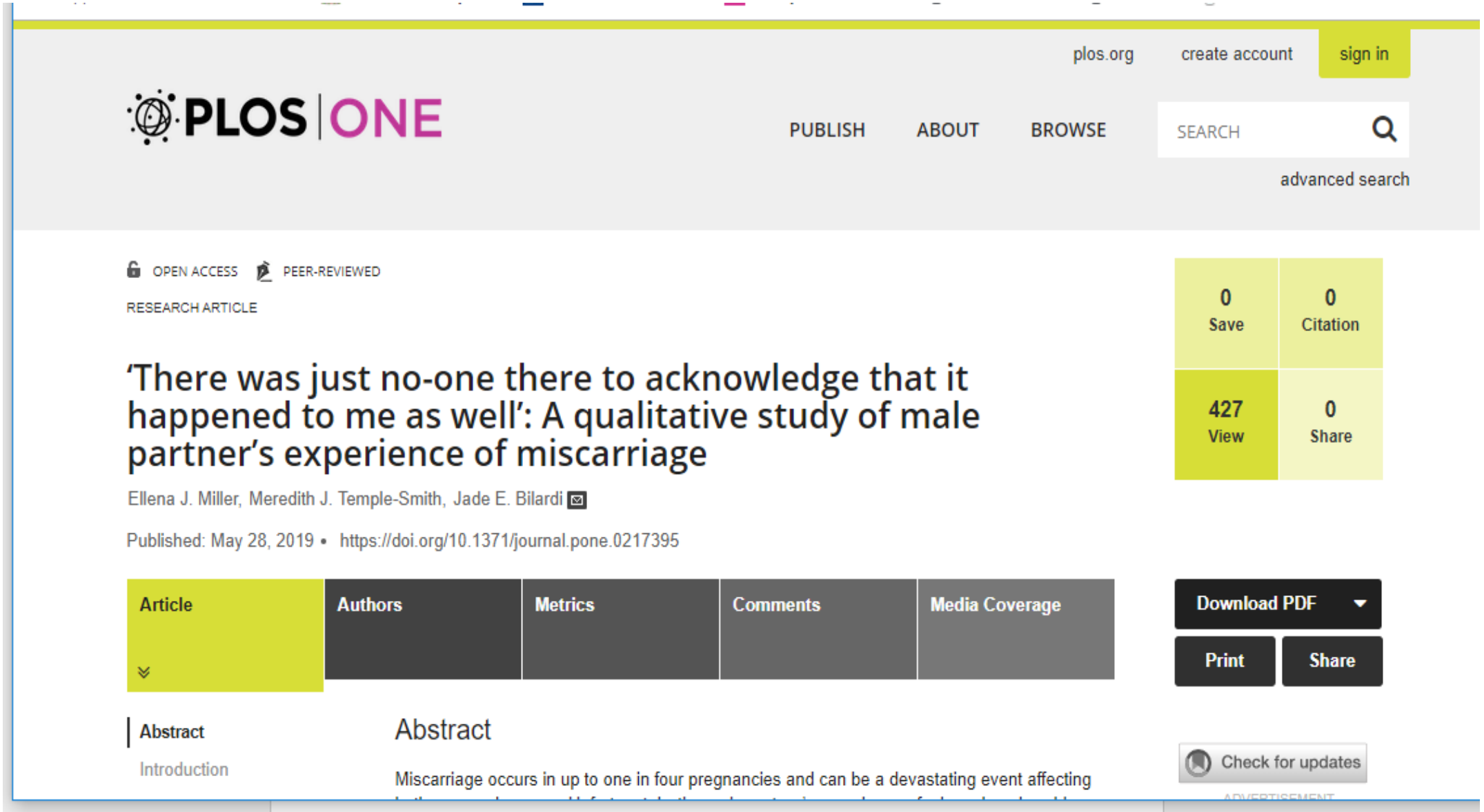
Need for acknowledgement

…even though they were still in the womb and it wasn't very long, but the acknowledgement that they were alive and that they mattered was extremely important to me…

Male participant 10, 29 years, 1 miscarriage

Dave

Need for acknowledgement



plos.org create account sign in

PLOS ONE

PUBLISH ABOUT BROWSE SEARCH

advanced search

OPEN ACCESS PEER-REVIEWED

RESEARCH ARTICLE

'There was just no-one there to acknowledge that it happened to me as well': A qualitative study of male partner's experience of miscarriage

Ellena J. Miller, Meredith J. Temple-Smith, Jade E. Bilardi

Published: May 28, 2019 • https://doi.org/10.1371/journal.pone.0217395

0 Save | 0 Citation | 427 View | 0 Share

Article | Authors | Metrics | Comments | Media Coverage

Download PDF | Print | Share

Abstract

Introduction

Abstract

Miscarriage occurs in up to one in four pregnancies and can be a devastating event affecting

Check for updates

Silence around miscarriage

Bellhouse et al. BMC Women's Health (2018) 18:176
https://doi.org/10.1186/s12905-018-0672-3

BMC Women's Health

RESEARCH ARTICLE Open Access

"It's just one of those things people don't seem to talk about..." women's experiences of social support following miscarriage: a qualitative study

Clare Bellhouse[1,2*], Meredith J. Temple-Smith[2] and Jade E. Bilardi[2,3,4]

Abstract

Background: Miscarriage is a common event which is estimated to occur in approximately one in four confirmed pregnancies (Collins et al, Grief Matters Aust J Grief Bereave_ 17:44, 2014, St John et al, Aust J Adv Nurs_ 23:8, 2006). Social networks play an important role in supporting women following this event and positive support experiences can play a role in buffering women's experiences of grief, loss and psychological distress following miscarriage (Rowlands et al, J Reprod Infant Psychol_ 28:274–86, 2010, Stratton et al, Aust New Zeal J Obstet Gynaecol_ 48:5–11).

Methods: Women were recruited through existing networks known to the researcher, miscarriage support organisations and snowball sampling methods. Fifteen women living in Australia completed semi-structured interviews either in person or by telephone regarding their experiences of social support following miscarriage, and their recommendations for how this could be improved.

Results: Women reported both positive and negative social support experiences following miscarriage. Women's partners

Interaction with health care practitioners

Contents lists available at ScienceDirect

Women and Birth

journal homepage: www.elsevier.com/locate/wombi

"The loss was traumatic . . . some healthcare providers added to that": Women's experiences of miscarriage

Clare Bellhouse[a], Meredith Temple-Smith[b], Shaun Watson[a], Jade Bilardi[b,c,d,*]

[a] School of Health Sciences, Federation University, Victoria, Australia
[b] Department of General Practice, University of Melbourne, Victoria, Australia
[c] Melbourne Sexual Health Centre, Alfred Health, Victoria, Australia
[d] Central Clinical School, Monash University, Victoria, Australia

ARTICLE INFO

Article history:
Received 15 August 2017
Received in revised form 25 May 2018
Accepted 5 June 2018
Available online xxx

Keywords:
Miscarriage
distress
healthcare

ABSTRACT

Background: Miscarriage is a common event in Australia and is estimated to occur in up to one in four confirmed pregnancies. Prior research has demonstrated that miscarriage is associated with significant distress, grief and loss, and in some cases clinically significant levels of depression, anxiety, and Post Traumatic Stress Disorder. Despite these consequences for women's emotional and mental health, studies have commonly found that women feel that healthcare providers often lack empathy, support, and acknowledgement of their loss.

Aim: The aim of this study is to explore the psychological distress experienced by women as a result of miscarriage, as well as the perceived support provided by healthcare professionals.

Methods: Fifteen women were recruited in Australia and participated in semi-structured interviews

Interaction with health care practitioners

(Afterwards) I called my private obstetrician…and she said, 'Why didn't you call me?!' and I said, 'Because it happened at Easter, you're on holidays!' and she said, 'You call me anytime'. And she was so firm about it. She said, '…My phone number should be on your speed dial, you call me if you have a question, or if anything happens', and she was so responsive, and yeah…she was totally on my team.
Miranda

Interaction with health care practitioners

…it was absolutely appalling, like absolutely appalling. To the extent where I've actually wondered if there's anything I can do, like there's a huge lack of services…people need help while they're going through this… I found the doctors, to be honest, to be patronizing and condescending… I felt like through that whole thing I had no one in my corner.

Erica

Interaction with health care practitioners

She [healthcare professional] was like, 'Oh good, go off and try again'. And there was absolutely no sympathy whatsoever.

Oh fuck, and during the consultation, one of her staff knocked on the door and brought in her dry cleaning.

Amanda

Interaction with health care practitioners

The whole process was really clinical …there wasn't much support in terms of understanding, trying to explain what the issues were….it was just 'yep there's no heartbeat; off you go to the next room'

Male participant 3, aged 41, 3 miscarriages

George

Interaction with health care practitioners

There was no direction for me to go into, there was no "oh maybe you should try this, maybe you should try that" there was nothing like that. It was all directed at her.

Participant 7, 32 years, 1 miscarriage

Ray

Online survey with Pink Elephants

Online Survey: 400 women responded

236 (59%) not offered any information about

- Miscarriage
- Support services
- Referral for emotional support

Of these 88% would have liked information or leaflets about pregnancy loss support organisations.

Care wanted

- Acknowledgment

- Emotional care
- Follow up
- Lack of information


5. Hospital based health professionals' views
Interviews 12 HPs
6. Support in Early Pregnancy Assessment Services
Interviews 31 Staff
7. General practitioners' practices around miscarriage
Interviews 8 GPs

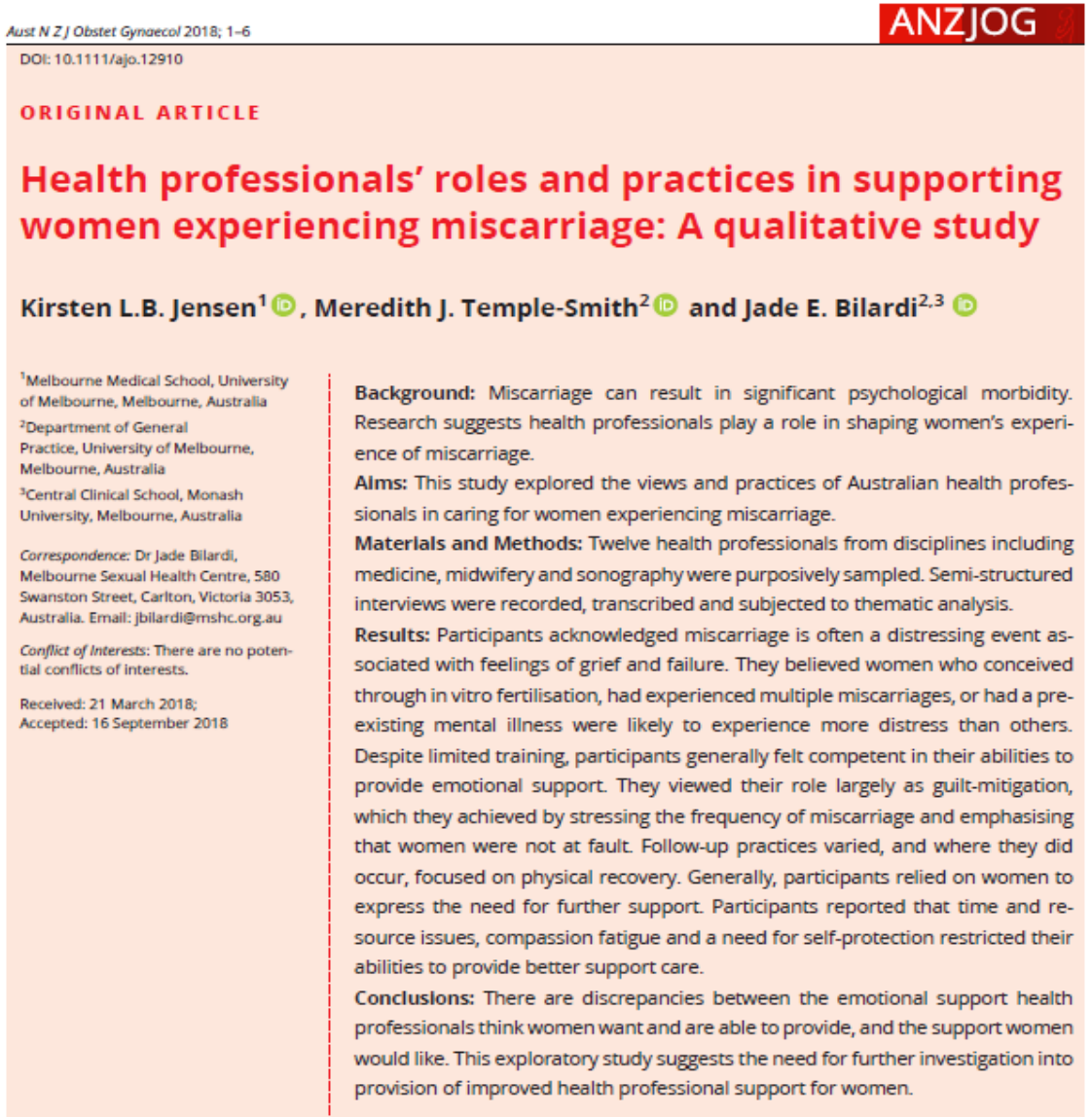
Perception of women's emotions

I'd say if they've had children before they're far less distressed. So if it's their first pregnancy, or if they've had multiple miscarriages in a row they're far more likely to be distressed.

O&G 4

Focus on the physical

- Physical not emotional
  - Top priority
  - Time/patient load
  - Discontinuity of care
  - Compassion fatigue



Aust N Z J Obstet Gynaecol 2018; 1–6
ANZJOG
DOI: 10.1111/ajo.12910

ORIGINAL ARTICLE

Health professionals' roles and practices in supporting women experiencing miscarriage: A qualitative study

Kirsten L.B. Jensen[1], Meredith J. Temple-Smith[2] and Jade E. Bilardi[2,3]

[1]Melbourne Medical School, University of Melbourne, Melbourne, Australia
[2]Department of General Practice, University of Melbourne, Melbourne, Australia
[3]Central Clinical School, Monash University, Melbourne, Australia

Correspondence: Dr Jade Bilardi, Melbourne Sexual Health Centre, 580 Swanston Street, Carlton, Victoria 3053, Australia. Email: jbilardi@mshc.org.au

Conflict of Interests: There are no potential conflicts of interests.

Received: 21 March 2018;
Accepted: 16 September 2018

Background: Miscarriage can result in significant psychological morbidity. Research suggests health professionals play a role in shaping women's experience of miscarriage.
Aims: This study explored the views and practices of Australian health professionals in caring for women experiencing miscarriage.
Materials and Methods: Twelve health professionals from disciplines including medicine, midwifery and sonography were purposively sampled. Semi-structured interviews were recorded, transcribed and subjected to thematic analysis.
Results: Participants acknowledged miscarriage is often a distressing event associated with feelings of grief and failure. They believed women who conceived through in vitro fertilisation, had experienced multiple miscarriages, or had a pre-existing mental illness were likely to experience more distress than others. Despite limited training, participants generally felt competent in their abilities to provide emotional support. They viewed their role largely as guilt-mitigation, which they achieved by stressing the frequency of miscarriage and emphasising that women were not at fault. Follow-up practices varied, and where they did occur, focused on physical recovery. Generally, participants relied on women to express the need for further support. Participants reported that time and resource issues, compassion fatigue and a need for self-protection restricted their abilities to provide better support care.
Conclusions: There are discrepancies between the emotional support health professionals think women want and are able to provide, and the support women would like. This exploratory study suggests the need for further investigation into provision of improved health professional support for women.

Training and guidelines

It was certainly absolutely and completely no training in the emotional side…GP2

I think I probably have learned a bit by trial and error. I don't feel like I've had formal training. O&G 3

It's quite distressing for these patients and having done the clinic on my own a couple of times, it's really hard for junior registrars to run it, or even be there for these patients. P4

Follow up

- Follow up – focus on physical recovery
- Women to instigate need for support
- Some assess mental state by ‘How are you feeling?’
- Small number asked specific screening questions:
  - How has your mood been?
  - Have you been crying much?
- None used psychological screening

Care wanted

- Acknowledgment
- Emotional care
- Follow up
- Lack of information

Care often received

- Lack of acknowledgment - ‘it’s common’
- Focus on physical care
- Lack of follow up
- Little information

WHAT IS NEEDED

Despite limitations to the data

Discrepancy between the care wanted by women and men and what HCPs are able to provide.

Resource restrictions

- Inadequate emotional support education & training
- Well-intentioned but non-evidence based assumptions

Could this be overcome?

- Changes to training and guidelines
- Increased referral to miscarriage support services may augment care

Psychosocial supports

sands
miscarriage, stillbirth & newborn death support

THE Pink elephants SUPPORT NETWORK

red nose grief and loss

COPE
Centre of Perinatal Excellence

PANDA
Perinatal Anxiety & Depression Australia

pregnancybirth&baby

www.bearsofhope.org.au

Home | Contact Us | Help Make A Difference | Events | Sign our Guestbook | Latest News

bears of hope®

Pregnancy & Infant Loss Support

- PARENT INFORMATION
- FOR FAMILY & FRIENDS
- MEMORY CREATING IDEAS
- BEARS OF HOPE RESOURCES
- ABOUT US
- FOR ALLIED HEALTH STAFF
- BEYOND THE BEAR SUPPORT
- MISCARRIAGE INFORMATION
- BEARS OF HOPE COLLECTION
- PURCHASE OR DONATE A BEAR
- RESEARCH & STATISTICS
- JEWELLERY COLLECTION
- LIVE AMONG ANGELS SONG
- STILLBIRTH INFORMATION
- BEARS OF HOPE PACKAGES
- BEARS OF HOPE STORE

"A life so brief, a child so small, you had the power to touch us all"

Bears Of Hope Pregnancy & Infant Loss Support provides leading support and exceptional care for families who experience the loss of their baby.

We seek to provide crucial information and embrace families during their difficult time of loss, and beyond. There are two key elements to our program that guide families through their choices when saying Hello and Goodbye to their much loved baby.

Families receive a Bear Of Hope donated by another bereaved family. This allows the donating family to give their childs brief life a purpose and lasting legacy, whilst filling the empty arms of another family as they walk out of the hospital without their baby. It reinforces the understanding that they are not alone, and that there is an existing community of support. Families also receive extensive information, either in printed or online format, to help them make decisions and memories in hospital, during the memorial and beyond.

Our Beyond the Bear support is unequalled by any other organisation. We provide exclusive and invaluable support packages that include; a credible foundation of parent led and psychologist facilitated support groups, private online groups, phone and email counselling and annual community events that remember individual baby's and recognize their parents love. Additionally we have a *Hope and Healing Resource Library*.

Bears Of Hope comfort, acknowledge, inform, empower, and guide families during their time of loss. As a registered non-profit organisation we are dedicated to the

CONTACT

Enquiries: 1300 11 BEAR
Email: contact@bearsofhope.org.au

Grief Support: 1300 11 HOPE
Email: support@bearsofhope.org.au

VISION

Providing leading support and exceptional care for families who experience the loss of their baby.

DONATE TODAY

- Make a Donation
- Fundraise for Bears Of Hope
- Donate a Bear of Hope
- Donate a Baby Keepsake Book

NEWSLETTER SUBSCRIPTION

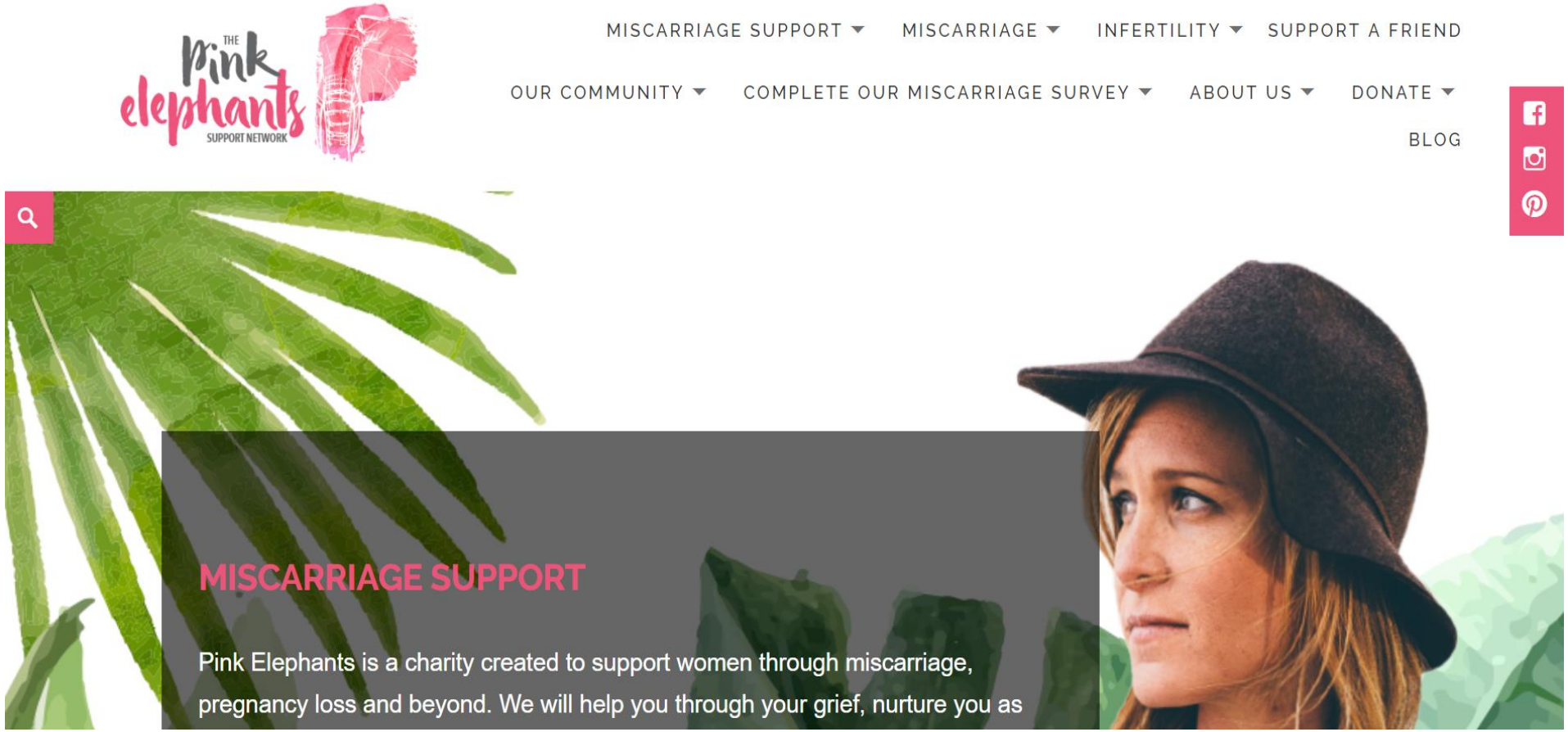
Receive our newsletter and information on Bears Of Hope events Complete this form.

Name:

Email:

Subscribe

The Pink Elephants



CARE WANTED BY WOMEN & MEN	CAN HOSPITAL STAFF PROVIDE?	CAN GPs PROVIDE?	CAN PARENT GROUPS PROVIDE?
Acknowledgement of loss	Misperception about patient's emotional needs; Patients don't ask	Can provide, but timing often wrong	Can provide
Emotional care	Lack of time – too stretched providing physical care	Physical care takes priority, could provide emotional care but timing wrong	Can provide some support
Follow up, especially of emotional well-being	Impossible due to volume of work	Can provide if patient initiates	Support can be offered, to those who request it
More information	Lack written resources	Lack written resources	Can provide written resources, but currently lacking specifically for men

WHERE TO FROM HERE?

Community consultations

12-18 months

metro, regional and rural, and marginalised groups

Where should miscarriage support be offered?

Who should provide this?

THE UNIVERSITY OF
MELBOURNE