

Challenges on the Journey to Parenthood:

What consumers had to say.

To inform the development of a national perinatal emotional health awareness campaign, the Centre of Perinatal Excellence (COPE) undertook research with 1,899 hopeful, expectant and new parents to explore experiences and challenges faced on the journey to parenthood.

This report details key findings and implications to inform the development of a national perinatal mental health awareness campaign.

Executive Summary

The report reveals that hopeful, expectant and new parents face a range of challenges at each stage of their journey to parenthood. These unique challenges ultimately impact upon emotional and mental health.

At each stage, the challenges are largely unexpected. This is leaving consumers feeling unprepared, alone and isolated in their experiences.

The identified challenges ultimately impact on the emotional distress and vulnerability consumers face. This is placing them at greater risk of mental health problems at the time and/or later in their perinatal journey. Mental health distress is exacerbated by lack of awareness, shame and stigma. This is preventing people from talking openly about their experiences, and seeking timely support or treatment.

Consumers' experiences are also compounded by low awareness, knowledge and sensitivities amongst some health professionals - highlighting the need for targeted education in some areas.

The results highlight the need for an awareness campaign that will profile the broad range of issues identified, provide reassurance that consumers are not alone and direction to timely and appropriate support.

Background.

Approach.

Online surveys were developed and disseminated to hopeful, expectant and new parents via social media channels and COPE databases. Individuals and organisations also shared the survey amongst their networks. Surveys were both quantitative and qualitative in nature.

Within the specified time period (May – November 2021) a total of 1,899 respondents took part in the survey, providing high level information. Of these, a sub-sample of 614 respondents provided detailed qualitative insights allowing for exploration of emerging themes.

Sample Description

Almost all of these (97%) were female, the majority being first-time parents (47%) or a parent of more than one child (37%).

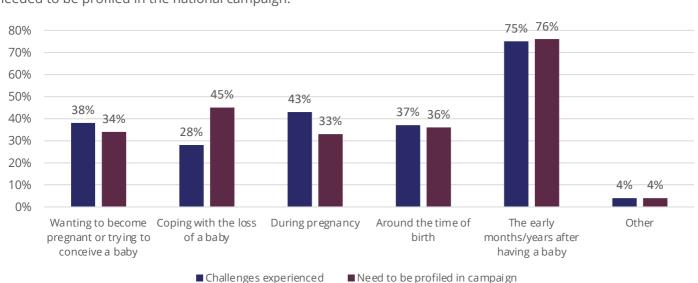
The majority of participants were from Australia (99%), most from the larger populated States of Victoria, (44%) and New South Wales (25%). Representation from the remaining states and territories were in line with population distribution, and across metropolitan (72%), regional (25%) and remote areas (2%).

Reflective of Australia's diverse community, threequarters (76%) of respondents were born in Australia, with almost a quarter of local respondents (24%) born overseas. Less than one per cent identified as Aboriginal or Torres Strait Islander.

Analysis

Open-ended and closed questions pertaining to key challenges faced, were asked with respect to the five key stages: 1) Pre-conception 2) Pregnancy 3) Perinatal Loss 4) Birth and 5) The Postnatal Period. Specific issues within each stage were explored.

Key Findings.



The Perinatal Stages.

Respondents indicated that they experienced personal challenges across each of the identified stages in their journey to parenthood. The experiences aligned closely with perceptions about which stages consumers believed needed to be profiled in the national campaign.

Figure 1: Stages in perinatal journey where experienced emotional or mental health challenges and need for profiling in a national campaign.

Stage 1: Pre-conception.



Over a third (38%) of respondents are experiencing challenges around conception. These particularly relate to infertility, and its consequences. Emotional and mental health impacts of infertility, coping with associated treatments, perinatal loss and coming to terms with not being able to conceive were the key challenges identified at this stage.

The emotional challenges of coping with Infertility and Infertility Treatments

Respondents experienced shock or surprise at being unable to fall pregnant naturally. They described their journey of infertility and its treatments as an 'emotional rollercoaster'. This included:

- Being completely consumed by the desire to conceive.
- Balancing hope and despair with each cycle
- Immense feelings of failure
- Coping with pressure from friends and family to start a family, and in some instances being alienated
- · Living with feelings of jealousy, resentment and grief
- Managing impacts on intimate relationships, friendships, and personal finances
- Grieving and losing hope with each pregnancy loss
- Coming to terms with the painful reality of never being able to have children.

"The constant grief and anxiety each month it fails; the obsession and consuming toll it takes."

"Feeling isolated, jealous and on hold. Fear of it never happening."

"Relationships with friends suffered as they conceived but we didn't, we were shut out to 'protect' us, but it didn't feel that way."

The impacts upon mental health

The above emotional and mental health challenges had a detrimental impact on emotional and mental health both at the time, and beyond. Grief, anxiety and depression prevailed, even if and when a future pregnancy was achieved.

Mental health impacts were exacerbated by:

- Lack of *awareness and understanding* in the community.
- The *inability of services* to provide empathy or emotional support. People felt they 'were a number' as infertility treatment is so depersonalized. This was more pronounced amongst same-sex couples where there was a lack of understanding and sensitivity.
- Lack of knowledge and understanding by employers and colleagues in the workplace.

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What Helped

Respondents experiencing infertility and its associated impacts shared that support from their partner, family, friends and colleagues was invaluable. Support from professionals (GPs, psychologist/ /counsellors) also made the process easier to understand and cope with.

Hearing stories from others who had also been through infertility, whether it was friends, via social media or in online support groups, helped individuals to feel less alone.

Need for inclusion in the Campaign

With over one-third of respondents indicating that infertility had significant emotional and mental health impacts in the immediate and longer term (even for those who went on to successfully have children), this together with the associated emotional and mental health impacts warrants inclusion in the campaign.

Stage 2: Perinatal Loss.



A high proportion of people (over a third) experienced perinatal loss as a result of miscarriage (63%), stillbirth (11%) terminations (10%) or infant loss (4%). The current lack of understanding and access to support increased emotional vulnerability both around the time of the loss, in subsequent pregnancies and beyond.

Coping with perinatal Loss

Common words used to describe the lived experience of perinatal loss included "shattering", "heartbreaking" and "traumatic".

Miscarriage

Those who experienced miscarriage reported initial shock and devastation, with many noting it was only then that they became aware of just how common miscarriage is. This high incidence, however, leads to experiences being minimized and/or dismissed particularly by health professionals.

With miscarriage often occurring early in a pregnancy, this compounded feelings of being alone, isolated and without access to support as others were unaware of the pregnancy. This silence also contributed to many feeling ashamed.

Understandably, some reported strong feelings of anger or jealousy when others became pregnant. This compounded feelings of isolation, grief and failure.

Not only was emotional and mental health impacted at the time of the loss, but it also carried into subsequent pregnancies, resulting in high anxiety, fear of another loss, distress and often depression. For some repeated miscarriages prevented them from ever wanting to become pregnant again.

"It broke all of us. Mentally and emotionally, we've all been scarred by the loss, and it still affects our day-to-day lives."

Stillbirth

Stillbirth resulted in overwhelming grief which was ongoing regardless of future pregnancies. The emotional and mental health impacts about stillbirth were compounded by an overall lack of understanding of its prevalence, it's impacts, and what to expect both at the individual, family and community level.

"Late term stillbirth, so having publicly announced and purchased many baby items, was a constant reminder of the loss."

Medical Terminations

Those who had a medical termination due to a congenital anomaly (serious health issue with the fetus) experienced strong feelings of guilt, coupled with grief and pregnancy-related fears which carried into the future. This was made more difficult by the lack of information or support available.

"Hearing (others say) 'I would have kept the baby even if it was sick' makes you really upset."

What Helped

Having grief and loss acknowledged is very important for healing and recovery. Deriving support from friends, family and others (including workplaces) helps people to feel less alone and supported. For some, professional support is key to processing their loss.

Need for inclusion in the Campaign

The high prevalence, taboo and stigma associated with perinatal loss, warrants the area being profiled in the national campaign. This is particularly in light of the – mental health impacts experienced in the immediate and longer-term.

Messages also need to be targeted at health professionals, workplaces and the community broadly. Increasing awareness and access to information stands to increase the sensitivity and support able to be offered to those grieving a loss, so that those affected are less likely to feel dismissed, alone and ashamed.

Stage 3: Pregnancy.



Pregnancy was emotionally challenging for over 40% of respondents. Physical and mental health issues make this a highly vulnerable life stage. Being unaware and uninformed about such challenges is leaving consumers feeling alone and without support. "I didn't know [antenatal anxiety and depression] existed so I never mentioned how I felt. I had only ever heard of PND. I felt ashamed to be feeling this way when I was fortunate enough to have conceived easily and naturally."

What helped

Key emotional and mental health challenges

Pregnancy is far from the "glowing" experience many parents-to-be expected. A myriad of challenges arose which included:

- Anxiety and depression in pregnancy symptoms were missed as they were considered a 'normal' part of pregnancy. Those with pre-existing conditions were often told to come off medication when the need for treatments increased, resulting in the exacerbation of symptoms and relapse.
- Hyperemesis Gravidarum severe and prolonged nausea and vomiting throughout pregnancy gravely impacted on physical *and* mental health.
- Body image physical changes were confronting, impacting upon self-esteem, confidence in relationships and feelings towards the baby. Those with a history of body image/eating disorders were particularly sensitive and vulnerable.
- Family violence impacts gravely upon physical and emotional safety, highlighting the importance of safe, universal screening.
- The pandemic had a negative impact, resulting in increased anxiety due to the lack of supports and uncertainty related to restrictions, and strong feelings of grief. Loneliness and isolation resulting from lockdowns, compounded mental health impacts.
- Shame and stigma is leaving expectant parents feeling ashamed and unable to speak openly about their experiences. It's also preventing them from seeking help.

When experiencing shock at just how difficult pregnancy was, many find solace connecting with others going through a similar experience. This helps validate their own feelings, normalised some of the challenges not commonly discussed and enabled them to feel less alone. Screening is important to raise awareness and identify those at risk or experiencing symptoms early.

Need for inclusion in the Campaign

With women holding high expectations that their pregnancy would be a positive, 'glowing' experience, the (often unexpected) challenging, unspoken physical and emotional challenges outlined above, left many feeling alone and misunderstood by others. This lead to isolation and mental health impacts in pregnancy – which for those affected were further compounded by the pandemic.

The misattribution of symptoms of anxiety and depression as being a normal part of the pregnancy, reveals the need to raise awareness of these conditions in pregnancy specifically, and highlights the importance of universal screening.

Information about safe and effective treatments of these mental health conditions, including the safety profile of medications, also needs to be directed at health professionals as well as providing information to assure patients.

Stage 4: Birth.



Over a third of people (37%) experienced problems at their birth. Many described that their expectations did not match their experience, culminating in feelings of vulnerability, guilt and failure at the critical entry point to parenthood. This negatively impacted upon emotional and mental health and infant attachment.

Negative birth experiences

High levels of *physical* and *psychological* trauma were described, and seen to impact upon both parents.

This trauma was further compounded by poor delivery of care received from health professionals and the health system at the time of birth. Here powerful language was used to describe experiences of feeling "powerless" "violated" "belittled" "bullied" and "betrayed". This was particularly directed at health professionals who were supposed to care for them.

The impacts of trauma were exacerbated by parents being 'passed around the system' and being 'treated like a number'. When attempting to speak about their struggles, consumers reported their experiences were often minimised by health professionals (and in fewer instances family and friends). The only outcome that seemed to matter was the health of the baby.

"I was told to be grateful that I had a child. As if I wasn't unbelievably grateful that we had survived almost dying. I was told 'at least the baby is OK. As if I didn't matter.'"

The absence of an opportunity to debrief made it more difficult for respondents to process and come to terms with what had happened following a traumatic birth.

Mental health impacts

A traumatic birth experience resulted in emotional and mental health impacts in the immediate and longer term. Anxiety, depression, post-traumatic stress disorder (PTSD), difficulties bonding with the baby and fear of subsequent births resulted for many.

A poor birth experience, also negatively impacted upon breastfeeding, and contributed to sleep -deprivation, exhaustion and difficulties coping with the new baby.

Respondents described being uneducated and unprepared about what to expect in the days and weeks following birth, as antenatal classes focus on the lead-up to, and the actual birth itself, with little focus on the early postnatal period.

Emotional vulnerability in the postnatal period was also made worse by perceived lack of support and receiving conflicting advice. This undermined parents' confidence in their new role, their confidence in professionals and the healthcare system.

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Need for inclusion in the Campaign

Many respondents were clearly unaware and unprepared for the events that unfolded around the time of birth.

Within the context of coping with exhaustion, breastfeeding and adjusting to life with a new infant, respondents described how their trauma was compounded by the lack of acknowledgement, lack of access to debriefing, and lack of empathy and support.

Together, these factors are likely to have all contributed to, and exacerbated respondents' experience of trauma and ongoing mental health vulnerability.

Given the extent breadth and depth of responses relating to negative birth experiences and associated trauma, this needs to be profiled in the campaign. A particular focus on education for expectant and new parents as well as training and support for health professionals and maternity care providers is needed.

Stage 5: The Postnatal Period.



Reflective of the three in four respondents identifying challenges in the postnatal period, multiple themes emerged. Some related to adjusting and looking after a new baby, others pertained to mental health issues and distress. These challenges were often not anticipated, leaving new parents unaware, uninformed, unprepared and more vulnerable in early parenthood.

Factors contributing to poor mental health

Several factors were perceived to have contributed significantly to distress in early parenthood.

- Pressure and struggles to successfully breastfeed resulted in immense feelings of guilt, failure and often compromised feelings towards their baby.
- Coping with an unsettled baby was among the most stressful aspects of having a newborn. This undermined people's *confidence* in their new role as a parent.
- Sleep deprivation affected parents' ability to function and had detrimental impacts upon mental health, and feelings towards the infant.
- Being bombarded and overwhelmed with advice, (often conflicting) even amongst health professionals further eroded confidence and selfesteem in their new role.
- Managing relationship adjustments came as a surprise to many, who were unprepared for these challenges.
- Concerns around post-baby body image were commonly reported, with many struggling to adjust to their new shape.
- Unmet expectations (often formed via social media) added to the stress of adjusting at this time.

"I feel resentment towards my baby, feel rejected. Question myself and lose confidence in my ability to be a Mum."

Mental health impacts

Anxiety and depression were experienced by many as were unexpected feelings of anger and rage. Too often these conditions were not identified as symptoms, but rather were misattributed as being 'a normal part of early parenthood'. They were also often dismissed by health professionals. This highlights the importance of education and universal screening. People also described feeling guilty and ashamed as their experiences did not align with their personal or societal expectations of early parenthood. This further delayed help-seeking.

Loss of identity, loneliness and a longing for their old life featured, as did themes around the challenges managing the transition back to work. This was often hindered by inadequate parental leave policies and support from workplaces.

Fathers and partners specifically described challenges in not being included in the provision of maternity and postnatal care. Many felt unsupported in a system around their partner's mental health. Same sex survey respondents shared the challenges of navigating a heteronormative public health system, making it difficult to seek support and feel included.

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Need for inclusion in the Campaign

As new parents were unaware and uninformed about the realities of early parenthood, this highlights the need to profile and remind parents that these struggles are common and reassure them that information and support is available.

Such experiences are likely to negatively impact and contribute to the development of mental health conditions. This reinforces the need for education of parents and health professionals alike, whilst simultaneously demonstrating the importance of mental health screening and referral pathways.

Longer-term struggles were likely to be further hindered by the absence of community networks of support, the pandemic and in some instances, difficulties when transitioning back to work.

Campaign Recommendations.

The qualitative results reveal insights into the broad range and types of challenges that are commonly faced on the journey to parenthood, and the impact they potentially have on emotional and mental health at this vulnerable life stage.

Further, the lack of awareness about these challenges is compounding the potential impacts as people feel alone in their experience and unaware of where to go for help and support.

It is recommended that the campaign has the following objectives:

- 1. Raise awareness of the *unique* and *broad range* of emotional and mental health challenges that many parents experienced *at* each stage of the journey to parenthood.
- 2. Profile common challenges likely to be contributing to mental health distress. This preventative approach stands to reassure parents they are not alone and direct them to specialist services to alleviate distress *early* and protect their mental health.
- 3. Profile mental health conditions to raise awareness of symptoms and reduce the likelihood of these being misattributed as being a 'normal' part of pregnancy, birth or early parenthood.
- 4. Ensure access to timely referral pathways (includes treatment and community support services).
- 5. Education of health professionals in targeted areas namely:
 - i. Consideration of mental health when providing infertility treatments.
 - ii. Empathy and support around miscarriage.
 - iii. Education around the high prevalence of mental health conditions and family violence in pregnancy and the importance of safe screening.
 - iv. Education about safe and effective medications that can be used in pregnancy and when breast-feeding.
 - v. Awareness surrounding hyperemesis gravidarum and its management.
 - vi. Management following a traumatic birth including debriefing.
 - vii. Knowledge and promotion of resources and referral pathways for hopeful, expectant and new parents.

We gratefully acknowledge the contribution of all respondents. COPE is committed to drawing on these valuable insights to raise the profile of these issues and ensure people are more aware and feel more supported through the development of this campaign.

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