Research Article

Women's Experiences of Preeclampsia: Australian Action on Preeclampsia Survey of Women and Their Confidants

C. East,¹ K. Conway,² W. Pollock,³ N. Frawley,⁴ and S. Brennecke¹

¹ Department of Obstetrics & Gynaecology, The University of Melbourne and Department of Perinatal Medicine,

Royal Women's Hospital, 20 Flemington Road, Parkville, VIC 3052, Australia

² Australian Action on Pre-Eclampsia, P.O. Box 29, Carlton South, VIC 3053, Australia

³ Division of Nursing & Midwifery, La Trobe University/Mercy Hospital for Women, 163 Studley Road, Heidelberg, VIC 3084, Australia

⁴ Department of Perinatal Medicine, Royal Women's Hospital, 20 Flemington Road, Parkville, VIC 3052, Australia

Correspondence should be addressed to C. East, eastc@unimelb.edu.au

Received 19 October 2010; Accepted 18 January 2011

Academic Editor: Keith A. Eddleman

Copyright © 2011 C. East et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Introduction. The experience of normal pregnancy is often disrupted for women with preeclampsia (PE). Materials and Methods. Postal survey of the 112 members of the consumer group, Australian Action on Pre-Eclampsia (AAPEC). Results. Surveys were returned by 68 women (61% response rate) and from 64 (57%) partners, close relatives or friends. Respondents reported experiencing pre-eclampsia (n = 53), eclampsia (n = 5), and/or Hemolysis, Elevated Liver enzymes, and Low Platelets (HELLP syndrome) (n = 26). Many women had no knowledge of PE prior to diagnosis (77%) and, once diagnosed, did not appreciate how serious or life threatening it was (50%). Women wanted access to information about PE. Their experience contributed substantial anxiety towards future pregnancies. Partners/friends/relatives expressed fear for the woman and/or her baby and had no prior understanding of PE. Conclusions. The PE experience had a substantial effect on women, their confidants, and their babies and affected their approach to future pregnancies. Access to information about PE was viewed as very important.

1. Introduction

Preeclampsia (PE) is a pregnancy specific, heterogeneous, multisystem disorder, which has the classic clinical features of pregnancy-induced hypertension and proteinuria and may lead to eclampsia (E) [1-3]. The presence of pregnancyinduced Hemolysis, Elevated Liver enzymes, and Low Platelets (HELLP syndrome) may also be classified as a form of preeclampsia [4]. Preeclampsia, eclampsia, and HELLP syndrome are a significant cause of maternal and perinatal morbidity, mortality, and iatrogenic premature delivery [5], with long-term health effects for both mother and child [6, 7]. Considerable research efforts have resulted in improved understanding of the genetic basis of preeclampsia [8], exploration of numerous possible predictors of the disorder [9], and resulted in the use or nonuse of diverse treatments [10-18]. Of these possible treatments, antihypertensive medications and magnesium sulphate are widely used in

developed countries and in some developing countries [19]. Delivery of the baby, placenta, and membranes, indicated for maternal or fetal reasons, remains the only method for resolving preeclampsia, although it does not immediately remove all risks of mortality and morbidity, particularly in the early postpartum period. Thus, there is considerable understanding of the genetic, pathophysiological, and clinical manifestations of PE, effective treatments, and long-term physical effects.

There is, however, a paucity of published research on women's perceptions of their experiences of PE, which may impact on their lives well beyond delivery and the puerperium. Research in this area has largely focused on the relationship of PE to posttraumatic stress disorder (PTSD). Poel et al. [20] surveyed a single tertiary hospital's inpatients with PE and found that 18% of patients with PE required a referral to a psychologist for dysfunctional coping, and this included 3% who were diagnosed with PTSD. Van

TABLE 1: Characteristics and outcomes of respondents.

	n^*	(%)
Condition: one or more of		
Preeclampsia	53	(77.9)
Eclampsia	5	(7.4)
HELLP	26	(38.2)
Multiple conditions (included in the		
above)		
Preeclampsia and HELLP	13	(19.1%)
Preeclampsia and eclampsia	1	(1.5)
Eclampsia and HELLP	1	(1.5)
Preeclampsia, eclampsia, and HELLP	2	(2.9)
PE** experience		
One pregnancy	55	(80.9)
Two or more pregnancies	13	(19.1)
Highest level of care received		
Normal labour and postnatal care	5	(7.4)
Labour ward with additional care	24	(35.3)
Adult intensive care unit	39	(57.4)
Timing of delivery		
After 37 weeks	10	(14.7)
Between 30 weeks and 36 weeks 6 days	31	(45.6)
Before 30 weeks	27	(39.7)
Delivery earlier than planned		
No	4	(5.9)
Concern for maternal welfare	23	(33.8)
Concern for fetal welfare/fetal death	7	(10.3)
Concern for both mother and fetus	33	(48.5)
Perinatal/infant death		
Stillborn	9	(13.2)
Death within one week	4	(5.9)
Death one week to six weeks	3	(4.4)
Death six weeks to six months	1	(1.5)
Death after six months	1	(1.5)

^{*} Not all answers completed by respondents.

** Hereafter, PE used to capture all of Preeclampsia, eclampsia, and HELLP.

Pampus et al. [21] detailed three women's experiences with severe PE and highlighted the heavy burden patients with PE may have—not only a serious illness in the mother, an unexpected and potentially medicalized delivery, but also often a premature baby, all of which are hypothesised to have a trend toward association with PTSD.

The experiences of eight women with severe early onset preeclampsia were explored in a qualitative study [22]. Common themes in these families included a feeling that something was not right in the pregnancy, feeling a loss of control or "thrownness," fear for the baby's prematurity, loss, guilt, and the challenge of the illness and recovery itself. It is interesting that even though PE is actively screened for at each antenatal visit with at least a measurement of the woman's blood pressure, the diagnosis still came as a complete shock to the majority of women studied. Cowan [22] acknowledged that it is the atypical and variable nature of PE that contributes to patients having a frustrating experience with their diagnosis. Often during the initial phase when PE is evolving, women may have vague symptoms, and there may be many visits before the diagnosis is actually determined. Women who have atypical presentations in particular, such as the absence of proteinuria in HELLP syndrome, may have a delayed diagnosis and further frustration with their medical care. Antenatal hospitalisation for conditions such as preeclampsia has also been suggested to lead to maternal identity change which may have ongoing psychological consequences [23].

The consumer group, Australian Action on Pre-Eclampsia (AAPEC) [24], is a voluntary organisation set up to provide support and information to families who have experienced PE/E. It also aims to educate, inform, and advise the public and health professionals about the PE/E.

2. Materials and Methods

The AAPEC executive, including the then President (K. Conway), Medical Advisor (S. Brennecke), Midwifery Advisor (C. East) and several active members, formed a working party to develop a survey to gain a general overview of how PE was experienced by their membership and help AAPEC better meet the needs of current and future members. Further input from a critical care obstetric viewpoint (W. Pollock) was also obtained.

The key themes from the work by Cowan [22] were supplemented with themes identified by the working party, to develop relevant questions. Considerable attention was given to the inclusion of questions about the death of a member's baby, with wording developed and piloted by members to ensure appropriateness. Women whose baby had died during or following a pregnancy complicated by PE were invited to complete further questions as they chose. Questions about mothering, for example, were completed by some who lost their baby and also by those who may have subsequently had a baby. All questions were piloted among a small group of members, and their feedback was incorporated into the final survey.

The questions sought information about the woman's PE/E, history, timing of diagnosis of PE/E and outcomes, including level of clinical care for the mother and baby (for example, admitted to an intensive care unit). We sought to quantify women's level of knowledge, prior to diagnosis, of their potential to develop PE/E and the implications that such a condition could have for themselves and their babies, as well as their level of acceptance and understanding of the diagnosis once made. Several questions explored aspects of feeling in control of their lives and destiny, whether women considered that clinical staff believed them when they presented with symptoms and women's understanding of how sick they were. Further thematic exploration involved the implications of premature and/or emergency delivery and how women coped with separation from their baby, due to their own or their babies' health needs. We also sought information about women's sense of self-worth, mothering ability, and recovery from the illness, how they

nn%No knowledge of PE.3277.4%Felt monthol of own desiny2942.0%Felt monthol of own desiny2942.0%Felt monthol of own desiny2942.0%Felt monthol of own desiny2064.0%Felt monthol of own desiny4264.8%Felt monthol of own desiny4264.8%Felt monthol of own desiny4350.0%Did not believe the doctor or midvite1313.1%Thought it could not happen to her4360.3%Thought it was not serious or life threatening4450.0%Was frightened4362.2%As the PE continued or became more severe7683.8%Felt a sense of letting self down by becoming sick with PE5282.4%Felt ha lost control of own desity5686.2%Felt that no-one around had been through sume ceperinecs72.3%83.8%Felt that no-one around had been through sume ceperinecs7372.3%Was frightened of how bady would manage if born early5276.5%Was frightened of how bady would manage if born early5284.6%Felt that bady might die4972.1%79.4%Nus frightened of how bady would manage if born early5276.5%Was frightened of how bady would manage if born early5276.5%Was frightened of how bady would manage if born early5351.5%In the weeks, months, or yaars since the PE experience4870.6%Had professional conns			
Life perceptions and knowledge pror to diagnosis of preclampsia Life perceptions and knowledge pror to diagnosis of preclampsia No knowledge of PE Pelt unvell Pelt in control of own destiny Pelt that something was not quite right Pelt that something was not quite right Pelt that something was not quite right Pelt unvell Poly Pelt Could not happen to her Thought it could not happen to her Poly Pelt a sense offetting self down by hecoming sick with PE As arese offetting self down by hecoming sick with PF As a sense offetting self down by hecoming sick with PF As the PE continued or became more severe Pelt had lost control of own destiny Pelt hat doots for with easing unvell Pelt that doots for with the shat shape down life Pelt that doots for with easing unvell Pelt that doots for with easing unvell Pelt that doots for whet the baby/babies Pelt that doots for whet prevente expresses Pelt that doot happen the hard ys unvell Pelt affected early experiences with the baby/babies Pelt was a host chnow might righe birth early Nas frightened of how baby would manage if born early Sa a moder, was to sock Pelt that Salm should be preserve Pelt the tababy read bab were limited, because As a moder, was to sock Sa a moder, was to sock Pelt need to obtain more information about PE Sound Fired should baby have perfore Sound Fired Sa Sound PE Sound PE superised Sound PE Sound Fired Sa Sound PE Sound Fired Sound PE Sound Fired Sa Sound PE Sound PE superised Sound PE Sound Fired Sound PE superised Sound PE superised Sound PE Sound PE Sound PE Sound PE Sound		п	%
No knowledge of Pk327.4%Felt in control of own desiny2942.6%Felt muxell3551.5%Following diagnosis with PE4261.8%Following diagnosis with PE4160.3%Did not believe the doctor or midvife1319.1%Thought it was not scrious or life threatening3450.0%Was frightened4972.1%Pelt a sense of letting self down by becoming sick with PE4363.2%As the PE continued or become more severe5682.4%Felt no longer "owned" the dings that shaped own life5788.8%Did not believe the doctor or indivites about being nurvell1319.1%Felt that lost corton of own desiny5682.4%Felt that no-one around had been through sum ceperinces5077.5%New the PE afficient early experiences with the balyhabies1110.3%It was a shock to know might give birth early5377.9%Was frightened of how baby would manage if form early5276.5%Vas more worreid about the baly than about self5584.6%Felt that abours, was too sick4870.6%Baby and mother card for in different parts of hospital4760.9%Difficult to establish breastfeeding5551.5%In the weeks, months, or years since the PE experience5584.8%Hav refer needed extra healthcare compared with women whose pregnancies were normal55\$1.5%Have had extrog associa full their parts of hospital56 <td< td=""><td>Life perceptions and knowledge prior to diagnosis of preeclampsia</td><td>22</td><td>== 404</td></td<>	Life perceptions and knowledge prior to diagnosis of preeclampsia	22	== 404
ret in control of own destiny 42.0° Felt may be a so that a something was not quite right 42 control 42 contro	No knowledge of PE	32	77.4%
reti unveil or due tright due to the source of the source	Felt in control of own destiny	29	42.6%
reit mat something was not quite right 42 61.8%. Following dignosis with PE Thought it could not happen to her 41 60.3%. Did not believe the doctor or midwife 13 19.1% Thought it was not serious or life threatening 34 50.0% Was frightened 49 72.1% Felt a sense of letting self down by becoming sick with PE 43 63.2% As the PE continued or became more severe Felt had lost control of own destiny 56 82.4% Felt a sense of letting self down by becoming sick with PE 57 83.8% Did not believe the doctors/midwives about being unwell 16 22.55% Felt that doctors/midwives down to believe me that I was unwell 13 19.1% Felt that doctors/midwives down to believe me that I was unwell 13 19.1% Felt that doctors/midwives did not believe me that I was unwell 13 19.1% Felt that doctors/midwives did not believe me experiences 50 75.5% Was frightened of how baby would manage if born early 52 76.5% Was more worried about the baby than about self 55 84.6% Felt that baby might die 16 00.5% 83.8% Baby and mother cared for in different parts of hospital 39 75.4% Baby and mother cared for in different parts of hospital 47 60.1% Found there action that but the experience 25 36.8% Flut abibilis breastfeeding 53 51.5% In the weeks, months, or years since the PE experience Had professional counseling to tak about the Experience 25 36.8% Found tried ed erts halthance compared with women whose pregnancies were normal 55 81.3% Fluw that being about PE 53 77.9% Have fully recovered from the PE Had professional counseling to tak about the Experience 25 36.8% Found triats and/or family were very supportive and helpful 53 77.9% Have had very little confidence in mothering ability 16 23.5% Fluw that baby has needed extra halthere 50 77.5% Have had very little confidence in mothering ability 16 23.5% Fluw become aware that there may be a genetic link for PE, for example, own mother had PE 50 75.5% Have been avery successful mother 75 175.0% Consider that baby has needed extra halthere 75 75.5% Have bad very little confidence of PE affected later pregnan	Felt unwell	35	51.5%
Following dargnoss with Pf: Thought it could not happen to her 1 60.3% Did not believe the doctor or midwife 13 19.1% Thought it was not serious or life threatening 34 50.0% Was frightened 49 27.1.% Felt as ense of letting self down by becoming sick with PE 43 65.23% As the PE continued or became more severe Felt had lost control of own destiny 56 82.4% Felt no longer "owned" the things that shaped own life 57 88.8% Did not believe the doctors/midwives about being unwell 16 23.5% Felt that loctors/midwives about being unwell 13 19.1% Felt that doctors/midwives about being unwell 13 19.1% Felt that doctors/midwives about being unwell 53 77.9% Was frightened of how baby would manage if born early 53 77.9% Was frightened of how baby would manage if born early 53 77.9% Was more worried about the baby than about self 54 84.6% Felt that boom wight give birth carly 51 84.64% Felt that baby might die 41 60.3% Felt that baby might die 41 60.3% Felt that about self 55 84.64% Felt that baby might die 41 60.3% Felt that about self 55 84.64% Felt that baby might die 41 60.3% Felt that about self 55 84.64% Felt that baby might die 51.5% How was too sick 39 57.4% Baby and mother cared for in different parts of hospital 47 69.1% Difficult to eablish breastfeeding 51.5% Had professional counseling to talk about the experience 25 36.8% Felt there do obtain more information about PE 55 82.1% Found think and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and helpful 58 83.3% Found friends and/or family were very supportive and h	Felt that something was not quite right	42	61.8%
Thought it could not happen to her4160.3%Did not believe the doctor or midwife1319.1%Thought it was not serious or life threatening3450.0%Was frightened4972.1%Felt a sense of letting self down by becoming sick with PE4365.2%As the PE continued or became more severe5682.4%Felt not longer "owned" the things that shaped own life5788.8%Did not believe the doctors/midwices about being unwell1623.5%Felt that longer "owned" the things shat shaped own life5788.8%Did not believe the doctors/midwices about being unwell1319.1%Felt that doctors/midwices about being unwell1319.1%Felt that doctors/midwices about being unwell1377.9%Was frightened of how baby would manage if form early5276.5%Was more worried about the baby than about self4160.3%Felt that baby might die4160.3%Felt that baby might die4760.1%Pedings that ability to bond with baby were limited, because3957.4%As a mother, was too sick3957.4%Baby and nother caref for in different parts of hospital4760.1%Found tit was as yoo tobain the information about PE5073.5%Haw professional counseling to talk about the experience5073.5%Have full recode extra healthcare compared with women whose pregnancies were normal5582.1%Found tit was as no tobain the information about PE50<	Following diagnosis with PE		
Did not believe the doctor or midwite1319.1%Thought it was not scious or life threatening.3450.0%Was frightened4972.1%Felt as ense of letting self down by becoming sick with PE.4363.2%As the PE continued or became more severe7281.8%Felt had lost control of own destiny5682.4%Felt no longer "owned" the things that shaped own life5783.8%Did not believe the doctors/midwives shout being unwell1623.5%Felt that a control and had been through same experiences5073.5%How the PE affected early experiences with the baby/babies778.4%It was a shock to know might give birth early5377.9%Was frightened of how baby would manage if born early5276.5%Was nightened of how baby would manage if born early5276.5%Was nore worried about the baby than about self4870.6%Felt that baby might die4160.3%Feltings that ability to bond with baby were limited, because3551.5%As a mother, was too sick3951.5%Baby and mother caref for in different parts of hospital3551.5%Difficult to establish breastfeeding3551.5%Found Liking or vrigin about PE5653.8%Found Liking or vrigin about PE5073.5%Have fold recorder form the PE experience5554.8%Full the need to obtain more information about PE5073.5%Found Liking or vrigin about 2F ex	Thought it could not happen to her	41	60.3%
Thought it was not serious or life threatening3450.0%Was fightened4972.1%Felt a sense of letting self down by becoming sick with PE4363.2%As the PE continued or became more severe5682.4%Felt hal lost control of own destiny5682.4%Felt na longer "owned" the things that shaped own life5783.8%Did not believe the doctors/midwives about being unwell1623.5%Felt that doctors/midwives about being unwell1623.5%How the PE affected early experiences with the baby/babies1119.1%It was a shock to know might give birth early5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Felt that baby might die4160.3%Felt that baby moight die3551.5%In the weeks, months, or years since the PE experience2536.8%Had professional counseling to talk about the experience2536.8%Had professional counseling to talk about the experience5073.5%Have kolk storing since the PE experience5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5588.8%Found titnak and safor family were very supportive and helpful5377.9%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found titnak and suff wer	Did not believe the doctor or midwife	13	19.1%
Was frightened4972.1%Felt a sense of letting self down by becoming sick with PE4363.2%As the PE continued or became more severe5682.4%Felt had lost control of own destiny5682.4%Felt had lost control of own destiny5682.4%Did not believe the doctors/midwives about being unwell1623.5%Felt that no-one around had been through same experiences5077.5%How the PE affected early experiences with the baby/babies71.5%It was a shock to know might give birth early5276.5%Was frightened of how hady would manage if born early5276.5%Was frightened of how hady would manage if born early5276.5%Baby more worried about the baby than about self5584.6%Felt that baby might die4060.3%Felt mat baby might die4160.3%In the weeks, months, or years since the PE experience71.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE5073.5%Found it was casy to obtain the information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found ritends and/or family eaver like ich information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5551.5%Have bed nearly like ich of PE if daughter/sister is pregnant5073.5%Have b	Thought it was not serious or life threatening	34	50.0%
Feet as ense of letting self down by becoming sick with PE4363.20Sate PE continued or became more severe5682.4%Felt had lost control of own destiny5682.4%Felt no longer "owned" the things that shaped own life5783.8%Did not believe the doctors/midwives solut being unwell1623.5%Felt that doctors/midwives did not believe me that I was unwell1319.1%Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/babies5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Feil that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%As a mother, was too sick4870.6%Baby was too sick3957.4%Baby was too sick3951.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE5551.5%Have fully recovered from the PE5551.5%Have fully recovered from the PE5155.82.1%Found it was easy to obtain the information about PE5153.5%Hour dualking or writing about PE experience2536.8%Gound talking or writing about PE experience was helpful5377.9%Have heal a strong sense of self-worth4464.7%Have heal a stron	Was frightened	49	72.1%
As the PE continued or became more severe Felt hal lost control of own destiny Felt hal lost control hal been through same experiences Felt hal doctors/midwives did not believe me that I was unwell Felt that no-one around had been through same experiences It was a shock to know might give birth early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early Was fightened of how baby would manage if born early As a mother, was too sick Baby and mother careft for in different parts of hospital Difficult to establish breastfeeding To fightened to obtain more information about PE Had professional counseling to talk about the experience Had professional counseling to talk about the experience Had professional counseling to talk about the experience was helpful Sa Was Found firends and/or family were very supportive and helpful Sa Was Have bad very little confidence in mothering ability Have bad a strong sense of self-worth Have bad very little confidence in mothering ability Have bad a strong sense of self-worth Have bad very little confidence in mothering ability Have bad very little confidence in mothering	Felt a sense of letting self down by becoming sick with PE	43	63.2%
Felt had lost control of own destiny5682.4%Felt no longer "owned" the things that shaped own life5788.8%Did not believe the doctors/midwives about being unwell1319.1%Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/balies5377.9%Was frightened of how baby would manage if born early5276.5%Was frightened of how baby would manage if born early5276.5%Was me worried about the baby than about self4160.3%Fedit that baby might die4160.3%Relings that ability to bond with baby were limited, because4870.6%Baby was too sick4870.6%Baby and mother caref for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience5384.8%Had professional counseling to talk about the experience5584.8%Found friends and/or family were very supportive and helpful5351.5%Found trinds and/or family were very supportive and helpful5353.5%Found talking or writing ability1623.5%Have been concerned about risk of PE if denayterister pregnancies5688.2%Found talking or writing ability1623.5%Have been considered their experience of PE affected later pregnancies77.5%Have been considered their experience of PE affected later pregnancies77.5%Hav	As the PE continued or became more severe		
Felt no longer "owned" the things that shaped own life5788.8%Did not believe the doctors/midwives about being unwell1623.5%Felt that doctors/midwives ad not believe me that I was unwell1319.1%Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/babies7179It was a shock to know might give birth early5276.5%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self4160.3%Felt that baby might die4160.3%Felt that baby might die3957.4%Baby more worried about the baby were limited, because3957.4%Baby mas too sick4870.6%Baby mat too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5377.9%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed cut a healthcare2638.2%Have had a strong sense of self-worth44	Felt had lost control of own destiny	56	82.4%
Did not believe the doctors/midwives about being unwell1623.5%Felt that doctors/midwives adi not believe me that I was unwell1319.1%Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/babies5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%As a mother, was too sick4870.6%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE3551.5%Have full recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found it was easy to obtain the information about PE5885.3%Found friends and/or family were very supportive and helpful5885.3%Found tiking or writing about PE experience was helpful5377.9%Have had atrong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Hawe the the needed extra healthcare5073.5%Have been a very successful mother<	Felt no longer "owned" the things that shaped own life	57	83.8%
Felt that doctors/midwives did not believe me that I was unwell1319.19Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/babies5377.9%It was a shock to know might give birth early5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Had professional counseling to talk about the experience2536.8%Felt the need to obtain more information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found triends and/or family were very supportive and helpful5875.9%Have had a strong sense of self-worth4464.7%Have had a strong sense of self-worth5175.9%Have had a strong sense of self-worth5276.5%Have been a very successful mother5175.9%Have been a very successful mother5175.9%Have had a strong sense of self-worth5276.5%Have been a very successful mother51 <td>Did not believe the doctors/midwives about being unwell</td> <td>16</td> <td>23.5%</td>	Did not believe the doctors/midwives about being unwell	16	23.5%
Felt that no-one around had been through same experiences5073.5%How the PE affected early experiences with the baby/babies717377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might dive1460.3%Feelt mat babity to bond with baby were limited, because4870.6%Baby was too sick3957.4%Baby was too sick3957.4%Baby was too sick3551.5%In the weeks, months, or years since the PE experience5Had professional counseling to talk about the experience5Had professional counseling to talk about the experience5Felt the need to obtain more information about PE50Found it was easy to obtain the information about PE50Found friends and/or family were very supportive and helpful58Found talking or writing about PE experience was helpful53Have hald very little confidence in mothering ability16Found talking or writing about PE experience was helpful51Have had very little confidence in mothering ability16Have had very little confidence in the first pergenancies26Make had very little confidence of PE affected later pregnancies64Have had a strong sense of self-worth51Ma beene avery successful mother51Consider that baby has needed extra healthcare64Maw beene concerned about risk of PE if daughter/sister is pregnant<	Felt that doctors/midwives did not believe me that I was unwell	13	19.1%
How the PE affected early experiences with the baby/babiesIt was a shock to know might give birth early5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE5073.5%Have full recovered from the PE5073.5%Have hald nord friends and/or family were very supportive and helpful5885.3%Found tilting or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare5073.5%Have been oncerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies4464.7%Beli	Felt that no-one around had been through same experiences	50	73.5%
It was a shock to know might give birth early5377.9%Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%Baby was too sick4970.6%Baby and nother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding5551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5585.3%Found tiking or writing about PE experience was helpful5377.9%Have held need in mothering ability1623.5%Have held need extra healthcare compared with women whose pregnancies were normal5585.3%Found tiking or writing about PE experience was helpful5377.9%Have head very little confidence in mothering ability1623.5%Have head very little confidence in mothering ability1623.5%Have been a very successful mother5175.0%Consider that baby has needed extra healthcare6688.2%Have been a concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancie	How the PE affected early experiences with the baby/babies		
Was frightened of how baby would manage if born early5276.5%Was more worried about the baby than about self5584.6%Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Had professional counseling to talk about the experience2536.8%Feut the need to obtain more information about PE5073.5%Have fully recovered from the PE5073.5%Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found it was easy to obtain the information about PE5377.9%Have felt needed extra healthcare in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%Pel increased anxiety towards future pregnancies6494.1%PE experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the	It was a shock to know might give birth early	53	77.9%
Was more worried about the baby than about self5584.6% eft that baby might die5584.6% eft.03%Feelings that ability to bond with baby were limited, because4160.3%Feelings that ability to bond with baby were limited, because3957.4% 84by and mother cared for in different parts of hospital37Baby was too sick3957.4% 69.1% Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8% 67.1%Had professional counseling to talk about the experience2536.8% 67.1%Found it was easy to obtain more information about PE3551.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1% 77.9%Have felt needed extra healthcare compared with women whose pregnancies were normal5377.9%Have had a strong sense of self-worth4464.7% 68.18% 60.14% have had a strong sense of self-worth4464.7% 64.7% 86.16% have been a very successful mother5175.0% 75.9% 75.9% 75.9% 75.9% 75.9% Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1% 94.1% 94.1% 9494.1% 94.1% 94.1%Felt increased anxiety towards future pregnancies6494.1% 94.1% 94.1% 94.1% 94.1% 94.1% 94.1%96.25.3% 94.2%How women considered their experience of PE affected later pregnancies6494.1% 94.1% 94.1% 94.1% 94.1% <td>Was frightened of how baby would manage if born early</td> <td>52</td> <td>76.5%</td>	Was frightened of how baby would manage if born early	52	76.5%
Felt that baby might die4160.3%Feelings that ability to bond with baby were limited, because4870.6%As a mother, was too sick3957.4%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience536.8%Had professional counseling to talk about the experience6697.1%Feut the need to obtain more information about PE5073.5%Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found triends and/or family were very supportive and helpful5377.9%Have head a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been concerned about risk of PE if facughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancies6494.1%PE experience influenced interval to next pregnancies5351.5%Have been avery successful mother5754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%	Was more worried about the baby than about self	55	84.6%
Feelings that ability to bond with baby were limited, because4870.6%Baby was too sick4870.6%Baby and mother cared for in different parts of hospital3957.4%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found taking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had very little confidence or PE affected later pregnancies were normal5175.0%Consider that baby has needed extra healthcare2638.2%Have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been concerned about risk of PE if facughter/sister is pregnant5276.5%How women considered thiter experience of PE affected later pregnancies4464.7%PE experience influenced interval to next pregnancy3754.4%PE experience influenced interval to next pregnancy3754.4%PE objorner of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)49<	Felt that baby might die	41	60.3%
As a mother, was too sick4870.6%Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE5073.5%Have fully recovered from the PE5073.5%Have fully recovered from the PE5073.5%Have full recovered from the PE5073.5%Have had very little confidence in mothering ability1623.5%Have had very little confidence in mothering ability1623.5%Have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been a very successful mother5276.5%Have been a very succes of PE affected later pregnancies6494.1%PE experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%70.6%How was born (e.g., by Cesarean Section)3348.5%	Feelings that ability to bond with baby were limited, because		
Baby was too sick3957.4%Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE5073.5%Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have been a very successful mother5175.0%Consider that bay has needed extra healthcare2638.2%Have been a very successful mother5175.5%Have been a very successful mother5175.0%Consider that bay has needed extra healthcare6494.1%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Choice	As a mother, was too sick	48	70.6%
Baby and mother cared for in different parts of hospital4769.1%Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Had professional counseling to talk about the experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE3551.5%Have full recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found triends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of forspital4070.6%Level of medical care during pregnancy48 <td< td=""><td>Baby was too sick</td><td>39</td><td>57.4%</td></td<>	Baby was too sick	39	57.4%
Difficult to establish breastfeeding3551.5%In the weeks, months, or years since the PE experience2536.8%Had professional counseling to talk about the experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have bee concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%Level of medical care during pregnancy4870.6%70.6%How baby was born (e.g., by Cesarean Section)3348.5%	Baby and mother cared for in different parts of hospital	47	69.1%
In the weeks, months, or years since the PE experience Had professional counseling to talk about the experience Felt the need to obtain more information about PE Found it was easy to obtain the information about PE Found it was easy to obtain the information about PE Have fully recovered from the PE So Have full needed extra healthcare compared with women whose pregnancies were normal Found friends and/or family were very supportive and helpful Found talking or writing about PE experience was helpful Found talking or writing about PE experience was helpful Have had very little confidence in mothering ability Have had very little confidence in mothering ability Have had a strong sense of self-worth Believe have been a very successful mother Consider that baby has needed extra healthcare Have become aware that there may be a genetic link for PE, for example, own mother had PE Have been axies to <u>SPE if daughter/sister is pregnant</u> Felt increased anxiety towards future pregnancies Felt increased anxiety towards future pregnancy Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic) 40 Choice of nospital Level of medical care during pregnancy How baby was born (e.g., by Cesarean Section) 33 48.5%	Difficult to establish breastfeeding	35	51.5%
Had professional counseling to talk about the experience2536.8%Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE3551.5%Have fully recovered from the PE5073.5%Have fully recovered from the PE5073.5%Found fit needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of nospital4070.6%Level of medical care during pregnancy4340.6%How baby was born (e.g., by Cesarean Section)3348.5%	In the weeks, months, or years since the PE experience		
Felt the need to obtain more information about PE6697.1%Found it was easy to obtain the information about PE3551.5%Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been concerned about risk of PE if daughter/sister is pregnant5273.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Had professional counseling to talk about the experience	25	36.8%
Found it was easy to obtain the information about PE3551.5%Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%How baby was born (e.g., by Cesarean Section)3348.5%	Felt the need to obtain more information about PE	66	97.1%
Have fully recovered from the PE5073.5%Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Found it was easy to obtain the information about PE	35	51.5%
Have felt needed extra healthcare compared with women whose pregnancies were normal5582.1%Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have fully recovered from the PE	50	73.5%
Found friends and/or family were very supportive and helpful5885.3%Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have felt needed extra healthcare compared with women whose pregnancies were normal	55	82.1%
Found talking or writing about PE experience was helpful5377.9%Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4970.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Found friends and/or family were very supportive and helpful	58	85.3%
Have had very little confidence in mothering ability1623.5%Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Found talking or writing about PE experience was helpful	53	77.9%
Have had a strong sense of self-worth4464.7%Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have had very little confidence in mothering ability	16	23.5%
Believe have been a very successful mother5175.0%Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have had a strong sense of self-worth	44	64.7%
Consider that baby has needed extra healthcare2638.2%Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Believe have been a very successful mother	51	75.0%
Have become aware that there may be a genetic link for PE, for example, own mother had PE5073.5%Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Consider that baby has needed extra healthcare	26	38.2%
Have been concerned about risk of PE if daughter/sister is pregnant5276.5%How women considered their experience of PE affected later pregnancies6494.1%Felt increased anxiety towards future pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have become aware that there may be a genetic link for PE, for example, own mother had PE	50	73.5%
How women considered their experience of PE affected later pregnancies6494.1%Felt increased anxiety towards future pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Have been concerned about risk of PE if daughter/sister is pregnant	52	76.5%
Felt increased anxiety towards future pregnancies6494.1%PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	How women considered their experience of PE affected later pregnancies		
PE experience influenced interval to next pregnancy3754.4%Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Felt increased anxiety towards future pregnancies	64	94.1%
Enjoyment of the pregnancy4261.8%Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	PE experience influenced interval to next pregnancy	37	54.4%
Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)4972.1%Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Enjoyment of the pregnancy	42	61.8%
Choice of hospital4070.6%Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Choice of primary caregiver (e.g., Midwife, General Practitioner, Specialist Obstetrician, Hospital Clinic)	49	72.1%
Level of medical care during pregnancy4870.6%How baby was born (e.g., by Cesarean Section)3348.5%	Choice of hospital	40	70.6%
How baby was born (e.g., by Cesarean Section) 33 48.5%	Level of medical care during pregnancy	48	70.6%
	How baby was born (e.g., by Cesarean Section)	33	48.5%

TABLE 2: Women's reported perceptions of their PE* experience.

 * "PE" used to capture all of preeclampsia, eclampsia, and HELLP.

	n	%
Felt scared of losing the partner/relative/friend	49	76.6%
Felt scared that the partner/relative/friend may lose the baby	45	70.3%
Felt the need to advocate for the partner/relative/friend and baby	39	60.9%
Thought that most women have babies at 40 weeks with many problems	44	68.8%
Never expected the pregnancy to end like this	46	100.0%
Had never heard of preeclampsia before this	48	75.0%
Had heard a little about problems in pregnancy	51	79.7%
Never felt that pregnancy problems would happen to someone they knew	41	64.1%
Could see this coming because noticed the partner/relative/friend was unwell leading up to this	16	25.0%
Did not know what to do to help	46	71.9%
Felt was able to support partner/relative/friend as planned	40	58.8%

TABLE 3: The PE experience from the perspective of the women's partners, family member, or close friends.

perceived their experience had affected or might influence their decisions and care for future pregnancies, as well as what information they would have found beneficial before and following the development of PE/E. Response options included "strongly agree," "agree," "disagree," "strongly disagree," or "undecided"; "none," "a little," "very little," "not at all," "undecided," as appropriate. Results were summarized in order to simplify them and highlight the more meaningful findings, for example, "strongly agree" and "agree," or "disagree" plus "strongly disagree," as appropriate for each question.

A section of the survey was devoted to exploring the perceptions of one of each woman's social contacts, including, as selected by each woman, her partner, close family member or friend. We sought to elicit how these confidants felt about the likelihood that PE/E could develop, specifically for someone they know, fear about outcomes, including death of the woman and/or her baby and feeling that they may or may not have known what to do to help.

The surveys, with an accompanying information sheet and reply paid envelope for return, were posted to each of the 112 AAPEC members. A follow-up survey was posted approximately six weeks later, to enhance the response rate. No identifying data were noted on the survey and a unique identifier was allocated to all returned surveys. Consent was implied by return of the survey, and the project was approved by the Royal Women's Hospital Human Research Ethics Committee.

Data were entered onto a database and analysed using descriptive statistics (Microsoft Access, Microsoft Excel, Microsoft Corp, Redmond, WA; SPSS version 16.0 software, SPPS Inc, Chicago, IL, USA).

3. Results

Surveys were returned by 68 women (61% response rate) and from 64 partners, close relatives, or friends (57% response rate). Characteristics, outcomes, and responses are provided in Tables 1 and 2. Respondents reported experiencing preeclampsia (n = 53), eclampsia (n = 5), and/or HELLP syndrome (n = 26) within a median of four years prior to the survey (range 1 to 47 years). Many felt that "something was not quite right" and, once diagnosed, that this could not be happening to them. Although only 19% did not believe the initial diagnosis, 51% of respondents thought that PE was not serious or life threatening (Table 2). Fifty eight women had given birth prematurely (between 30 weeks and 36 weeks 6 days, n = 31; before 30 weeks, n = 27), and eighteen babies had died (Table 1). Most women whose babies had died noted that they felt well supported by hospital staff (n = 14). Women felt that their experience with PE had a substantial effect on their anxiety towards future pregnancies and the level of medical care for subsequent pregnancies.

Partners/friends/relatives expressed fear that the woman and/or her baby could have died, that they had no prior awareness of PE, and that they did not know what to do to help (Table 3).

4. Discussion

The PE experience had a substantial effect on women, their confidants, and their babies in the index pregnancy. The diagnosis was a shock to many respondents, and there were elements of denial of the severity of the condition until after the event. Prior to the diagnosis of PE, many women may have never experienced a significant illness and had been expecting a routine, normal pregnancy. Many of the experiences recounted by the women were emotionally intense and can be interpreted in the context of anxiety, depression, and posttraumatic stress disorder [21, 25]. Several of the known risk factors for PTDS were elicited, including feelings of loss of control over their situation and obstetric procedures, commonly induction or caesarean section at an earlier time point than expected had the pregnancy been normal and, for some, extremely premature [21, 25]. For other women, the emotional intensity of the experience may not have equated with a diagnosis of PTSD, but our findings indicated that it was no less important for the individual woman and her support network.

The experiences of women whose babies are cared for in the neonatal intensive care nursery, including those born preterm, have some similarities, particularly issues of bonding when the infant is too small or too sick to be breastfed or handled. The provision of emotional support to the mother is often rated very well in the intensive care setting [26] and forms an important component of processing the feelings engendered by the experience [27]. Women in our survey reported that their experience with bonding was not only limited by the baby's health but also their own, with some women being in intensive care settings themselves. Further exploration of women's experiences using qualitative methodologies may provide additional insights to identify and promote interventions to assist with this.

The PE experience affected how women approached future pregnancies, as well as the level of medical care and choice of hospital for the subsequent pregnancy and birth. This has implications for the provision of antenatal and birthing services for the small percentage that may experience PE in a subsequent pregnancy [28]. Australia's population is largely clustered around the major cities, with concurrent centralisation of specialty healthcare facilities in these cities. Women requiring more intense surveillance throughout pregnancy who reside in regional centres may have been transferred to tertiary facilities in their index PE pregnancy, including the baby requiring neonatal intensive care in a tertiary setting. These women may need to relocate to be near a specialty healthcare facility for at least some of their subsequent pregnancy including possible induction of labour [26]. Such a move has major social and financial implications for the woman and her family-removing the woman from her social context at a time when her emotional needs are as important as her physical needs, and those of her baby only serve to perpetuate the cycle of morbidity and the potential for nonresolution of posttraumatic stress disorder if that is a feature for her. Studies of paternal experiences supporting their partner during pregnancy and childbirth have identified themes of feeling helpless, lacking knowledge, and potentially altering their relationship with their partner [29]. The experiences reported by the respondent's partner, close friend, or family member mimic those of the social networks of critical care patients, including the need to work through the shock of receiving the news, uncertainty surrounding the potential outcome for mother and baby, provision of adequate information, and involvement in decision making and moving on [30, 31].

Access to information about PE was viewed as very important. The origins of AAPEC [24] lie in women's perceived need to access information at a time when internetbased sites and hard copy publications were less prolific than they are now (personal communication, 13 October 2010). Although numerous sites can now be accessed with a simple online search, the quality and readability of information need to be appropriate for women with varying levels of health literacy [32].

This survey examined the experiences of PE within the AAPEC membership, with a reasonable response rate of 61%. Women who seek membership of such a consumer organisation and who respond to this type of survey may not

be representative of all women who experience PE, and more research is required to examine the impact of PE on women and their confidants in the broader maternity services sector.

5. Conclusion

The responses to this survey from women and their partners, close relatives, or friends indicated that the experience of PE was viewed as very important to all and traumatic to many. The provision of information and support was valued prior to and at the time of diagnosis and needed to be revisited during ongoing care. Referral to consumer groups such as AAPEC [24] may be beneficial. Further research may consider the experiences of women and their confidants closer to the time of the PE experience.

Acknowledgments

C. East (The University of Melbourne, Australia), K. Conway (Australian Action on Pre-Eclampsia, Australia), W. Pollock (Mercy Hospital for Women, Australia), N. Frawley (Royal Women's Hospital, Australia), and S. Brennecke (The University of Melbourne, Australia) are all on behalf of the Australian Action on Pre-Eclampsia, Carlton South, VIC 3053, Australia.

References

- S. A. Lowe, M. A. Brown, G. A. Dekker et al., "Guidelines for the management of hypertensive disorders of pregnancy 2008," *Australian and New Zealand Journal of Obstetrics and Gynaecology*, vol. 49, no. 3, pp. 242–246, 2009.
- [2] L. Duley, "Pre-eclampsia, eclampsia, and hypertension," *Clinical Evidence*, vol. 2008, p. 1402, 2008.
- [3] L. Duley, "The global impact of pre-eclampsia and eclampsia," Seminars in Perinatology, vol. 33, no. 3, pp. 130–137, 2009.
- [4] M. Habli, N. Eftekhari, E. Wiebracht et al., "Long-term maternal and subsequent pregnancy outcomes 5 years after hemolysis, elevated liver enzymes, and low platelets (HELLP) syndrome," *American Journal of Obstetrics and Gynecology*, vol. 201, no. 4, pp. 385.e1–385.e5, 2009.
- [5] C. Nelson-Piercy, *Handbook of Obstetric Medicine*, Informa Healthcare, London, UK, 2006.
- [6] C. M. Anderson, "Preeclampsia: exposing future cardiovascular risk in mothers and their children," *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, vol. 36, no. 1, pp. 3–8, 2007.
- [7] C. S. Wu, E. A. Nohr, B. H. Bech, M. Vestergaard, J. M. Catov, and J. Olsen, "Health of children born to mothers who had preeclampsia: a population-based cohort study," *American Journal of Obstetrics and Gynecology*, vol. 201, no. 3, pp. 269.e261–269.e210, 2009.
- [8] M. P. Johnson, L. T. Roten, T. D. Dyer et al., "The *ERAP2* gene is associated with preeclampsia in Australian and Norwegian populations," *Human Genetics*, vol. 126, no. 5, pp. 655–666, 2009.
- [9] C. A. Meads, J. S. Cnossen, S. Meher et al., "Methods of prediction and prevention of pre-eclampsia: systematic reviews of accuracy and effectiveness literature with economic modelling," *Health Technology Assessment*, vol. 12, no. 6, pp. 1–249, 2008.

- [10] L. Duley and D. Henderson-Smart, "Magnesium sulphate versus phenytoin for eclampsia," *Cochrane Database of Systematic Reviews*, no. 2, article CD000128, 2000.
- [11] L. Duley and D. Henderson-Smart, "Magnesium sulphate versus diazepam for eclampsia," *Cochrane Database of Systematic Reviews*, no. 2, article CD000127, 2000.
- [12] L. Duley, D. J. Henderson-Smart, S. Meher, and J. F. King, "Antiplatelet agents for preventing pre-eclampsia and its complications," *Cochrane Database of Systematic Reviews*, no. 2, article CD004659, 2007.
- [13] L. Duley, H. E. Matar, M. Q. Almerie, and D. R. Hall, "Alternative magnesium sulphate regimens for women with preeclampsia and eclampsia," *Cochrane Database of Systematic Reviews*, no. 4, article CD007388, 2008.
- [14] G. J. Hofmeyr, A. Roodt, A. N. Atallah, and L. Duley, "Calcium supplementation to prevent pre-eclampsia—a systematic review," *South African Medical Journal*, vol. 93, no. 3, pp. 224–228, 2003.
- [15] S. Meher and L. Duley, "Progesterone for preventing preeclampsia and its complications," *Cochrane Database of Systematic Reviews*, no. 4, article CD006175, 2006.
- [16] S. Meher and L. Duley, "Garlic for preventing pre-eclampsia and its complications," *Cochrane Database of Systematic Reviews*, vol. 3, article CD006065, 2006.
- [17] S. Meher and L. Duley, "Exercise or other physical activity for preventing pre-eclampsia and its complications," *Cochrane Database of Systematic Reviews*, no. 2, article CD005942, 2006.
- [18] S. Meher and L. Duley, "Rest during pregnancy for preventing pre-eclampsia and its complications in women with normal blood pressure," *Cochrane Database of Systematic Reviews*, no. 2, article CD005939, 2006.
- [19] M. Aaserud, S. Lewin, S. Innvaer et al., "Translating research into policy and practice in developing countries: a case study of magnesium sulphate for pre-eclampsia," *BMC Health Services Research*, vol. 5, article 68, 2005.
- [20] Y. H. M. Poel, P. Swinkels, and J. I. P. De Vries, "Psychological treatment of women with psychological complaints after preeclampsia," *Journal of Psychosomatic Obstetrics and Gynecol*ogy, vol. 30, no. 1, pp. 65–72, 2009.
- [21] M. G. Van Pampus, H. Wolf, W. C. M. Weijmar Schultz, J. Neeleman, and J. G. Aarnoudse, "Posttraumatic stress disorder following preeclampsia and HELLP syndrome," *Journal of Psychosomatic Obstetrics and Gynecology*, vol. 25, no. 3-4, pp. 183–187, 2004.
- [22] J. Cowan, Women's Experience of Severe Early Onset Pre-Eclampsia: A Hermeneutic Analysis, Auckland University of Technology, Auckland, New Zealand, 2005.
- [23] M. Markovic, L. Manderson, H. Schaper, and S. Brennecke, "Maternal identity change as a consequence of antenatal hospitalization," *Health Care for Women International*, vol. 27, no. 9, pp. 762–776, 2006.
- [24] Australian Action on Pre-eclampsia, 2010, http://www.aapec .org.au.
- [25] E. Olde, O. Van Der Hart, R. Kleber, and M. Van Son, "Posttraumatic stress following childbirth: a review," *Clinical Psychology Review*, vol. 26, no. 1, pp. 1–16, 2006.
- [26] M. Nicolaou, R. Rosewell, N. Marlow, and C. Glazebrook, "Mothers' experiences of interacting with their premature infants," *Journal of Reproductive and Infant Psychology*, vol. 27, no. 2, pp. 182–194, 2009.
- [27] B. S. Eriksson and G. Pehrsson, "Evaluation of psycho-social support to parents with an infant born preterm," *Journal of Child Health Care*, vol. 6, no. 1, pp. 19–33, 2002.

- [28] S. D. McDonald, C. Best, and K. Lam, "The recurrence risk of severe de novo pre-eclampsia in singleton pregnancies: a population-based cohort," *British Journal of Obstetrics and Gynaecology*, vol. 116, no. 12, pp. 1578–1584, 2009.
- [29] S. Hanson, L. P. Hunter, J. R. Bormann, and E. J. Sobo, "Paternal fears of childbirth: a literature review," *Journal of Perinatal Education*, vol. 18, pp. 12–20, 2009.
- [30] A. Keenan and L. Joseph, "The needs of family members of severe traumatic brain injured patients during critical and acute care: a qualitative study," *Canadian Journal of Neuroscience Nursing*, vol. 32, no. 3, pp. 25–35, 2010.
- [31] H. U. Rothen, K. H. Stricker, and D. K. Heyland, "Family satisfaction with critical care: measurements and messages," *Current Opinion in Critical Care*, vol. 16, pp. 623–631, 2010.
- [32] C. Shieh and J. A. Halstead, "Understanding the impact of health literacy on women's health," *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, vol. 38, no. 5, pp. 601–612, 2009.