CANDIDATE NUMBER: KPBF8

DISSERTATION SUPERVISOR: 
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TYPE OF DISSERTATION: 
Primary Data Collection

DISSERTATION TITLE: Are health visitors’ able to correctly describe key preterm babies’ care needs within the community?

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ABSTRACT

Background: Post hospital discharge care has been identified as a significant component in the care pathway of preterm babies (PBs), and indeed intensive home visits (IHVs) are pivotal in helping PBs achieve their developmental milestones and mitigating against the burden of diseases. Similarly, the association between knowledge and quality of care delivered to clients has been proven with significance in literature. However, very little is known of the role and knowledge of health visitors (HVs) in PBs’ care. This study aims to establish HVs’ knowledge of key PBs’ care needs within the community post hospital discharge, and whether HVs felt confident caring for PBs.

Method: A cross-sectional quantitative survey of HVs working within a central London National Health Service (NHS) Trust, using self-administered paper and online questionnaires between July and September 2015. Logistic regression analysis was applied to explore the association between knowledge and confidence, and PBs’ care needs.

Result: 102 out of 140 identified HVs completed the survey. 51.9% (n=53) of HVs reported feeling confident caring for PBs. 53.9% (n=55) of HVs correctly identified aspects of growth and development of PBs that should be based on corrected ages (CA) whilst only 17.6% (n=18) correctly identified aspects of care and development that are true about PBs. It found positive association between confidence and training (p-value=0.001) and age (p-value=0.028).
**Conclusion:** The survey found there are gaps in HVs’ knowledge of key PBs’ care needs. Future initiatives should address training needs and strengthen communication links between hospitals and community practitioners.
Acknowledgements

My profound gratitude goes to God Almighty for seeing me through this journey.

I am very grateful to my supervisors Dr. Zelee Hill and Dr. Ed Fottrell for their immeasurable support, guidance and valued experience throughout this dissertation. Zelee’s passion for preterm babies inspired the choice of this dissertation. Zelee and Ed, I could never have wished for better supervisors.

Many thanks to Mrs Heather Chester, the librarian and Cathy Hillman the academic writing support officer, for their support. Paloma Garcia-Parades, you are awesome.

I am particularly grateful to my NHS Trust for granting permission to complete this survey and for part funding this MSc. I am immensely grateful to all health visitors who participated in the survey, my valued team, colleagues and manager Angela Joyce for your support.

My mentor, Adwoa Ayensu, for suggesting UCL and being an inspiration to me and a valued friend. My friend Kelly Charles for proof reading.

To my husband Aderemi, and most importantly my daughter Ayomide, who were patient with me and were deprived of those quality times diverted to my MSc. Ayomide, I hope I inspired you that anything is possible?

My sisters and friends Christina Wuche for your immeasurable support and Kemi Ajala for always having a spare laptop for me when mine is faulty.

Finally, and not least, my utmost gratitude goes to my parents, siblings, my dear friend Panca for your invaluable support, uncle and Aunt Mr & Mrs Olaniyan and my Aunt, Mrs Adekanmbi.
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<td>IHV</td>
<td>Intensive home visit</td>
<td>PROM</td>
<td>Premature rupture of membrane</td>
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<td>PB</td>
<td>Preterm babies/ births</td>
<td>NICU</td>
<td>Neonatal intensive care</td>
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<tr>
<td>HV</td>
<td>Health visitor</td>
<td>ELBW</td>
<td>Extremely low birth weight</td>
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<tr>
<td>HVPT</td>
<td>Health visitor practice teacher</td>
<td>LBW</td>
<td>Low birth weight</td>
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<tr>
<td>CA</td>
<td>Corrected age</td>
<td>RCT</td>
<td>Randomised control trial</td>
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<tr>
<td>AA</td>
<td>Actual age</td>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>HIC</td>
<td>High income countries</td>
<td>KMC</td>
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<td>Low income countries</td>
<td>NEC</td>
<td>Necrotising enterocolitis</td>
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<td>GA</td>
<td>Gestational age</td>
<td>PNC</td>
<td>Post-natal care</td>
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<tr>
<td>BW</td>
<td>Birth weight</td>
<td>BMI</td>
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<td>OR</td>
<td>Odds ratio</td>
<td>UCL</td>
<td>University College London CPD</td>
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<tr>
<td>CPD</td>
<td>Continuing professional development</td>
<td>CI</td>
<td>Confidence interval</td>
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<td>GMDS</td>
<td>Griffiths Mental Development Scale</td>
<td>MSEL</td>
<td>Mullen Scales of Early Learning</td>
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<td>AIMS</td>
<td>Alberta Infant Motor Scale</td>
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<td>BSID</td>
<td>Bayley Scale of infant and Toddler Development II-III</td>
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<tr>
<td>ASQ</td>
<td>Ages and Stages Questionnaire</td>
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<tr>
<td>PEDI</td>
<td>Paediatric Evaluation of Disability Inventory</td>
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CHAPTER 1: BACKGROUND

1.1.1. *Health Visitors (HVs) and their role*

HVs are specialist public health nurses trained to deliver the ‘Healthy Child Programme’, a Department of Health (DH) initiative promoting the health and wellbeing of children aged zero to five (DH, 2007). HVs have diverse nursing backgrounds including adult nursing, midwifery, paediatrics and mental health. HVs work as independent and autonomous practitioners within the community with families and children, delivering specialist universal and targeted public health services around health promotion and protection. HVs tackle health issues by creating an awareness amongst parents about public health issues and programmes. HVs address social problems by providing basic parenting support, signposting to appropriate services and facilitating access to support networks to reduce social isolation (Cowley et al., 2015). HVs conduct five statutory visits including antenatal, new birth, post-natal contact (PNC), 8-12 months and 2-21/2 years’ review. However, families identified as vulnerable receive above the standard routine contacts. NICE guidelines, DH and local policy supports and endorse HV’s practice framework.

1.1.2. *Why is the care of Preterm Babies (PBs) so important?*

Premature birth (PB), birth occurring before 37 weeks’ gestation, is a major cause of child mortality and morbidity globally. It is the second highest cause of death in children under five years of age, and the most common cause of death in the first month of life (Liu et al, 2012). About fifteen million babies are born preterm every
year; the equivalent of one in ten births (World Health Organisation [WHO], 2015).
Babies born at less than 28 weeks’ gestation are referred to as extreme prematurity, 28 -32 weeks are very prematurity, and 32 -37 weeks are classified as moderate or late prematurity (WHO, 2013). About 5% of PB occur at less than 28 weeks, 15% between 28 and 31 weeks, 20% at 32-33 weeks and 60 to 70% near term (Ananth and Vintzileos, 2006).

PB is one of the main conditions in the global burden of disease due to its high mortality and considerable long-term impairments (Murray et al., 2012). In high income countries (HICs), it is the principal cause of perinatal morbidity and mortality at 5 -9% (Goldenberg et al., 2008) and in low income countries (LICs), estimated at between 15 and 24% (van den Broek et al., 2009). In England and Wales, 7.3% of live births are preterm, with rates increasing over the past twenty years due to increased mother's age, pregnancy complications, assisted fertility, and uterine distension with multiple births (Office of National Statistics [ONS], 2013). About 5% of PBs have a low birth weight (LBW) of less that 1000g compared with an average weight of 2500g for babies born at term which is thirty-seven weeks’ gestation and above (ONS, 2013).

Complications of PB includes cerebral palsy, visual, hearing and learning impairments, long-term physical problems and an increased risk of non-communicable disease throughout the life span (Rogers and Velten, 2011).
Reducing PBs is vital in reducing the increasing burden of disease and achieving sustainable development goal 3 (United Nations Development Programme, 2015).

1.1.3. Inequalities in survival rates

Inequalities and variations in death and survival rates exist in LICs and HICs. In HICs, two-thirds of PBs born before 28 weeks survive without impairments, while 10% of PBs born between 28 and 32 weeks develop considerable long-term impairments (Mohangoo et al., 2011). This is in contrast with LICs, where almost all babies born before 28 weeks die during their first day of life (Lawn et al., 2013). Deaths in LICs have been linked to lack of effective care such as warmth, breastfeeding support, antibiotics for infection and breathing support (WHO, 2013). This is because PBs are especially at risk of temperature instability, due to scarce body fat and a lack of vernix protecting their skin, thus permitting water loss and infection; hypoglycaemia and or dehydration from poor suckling reflex (Escobar et al., 2006; Kinney, 2006). Nevertheless, inexpensive and cost-effective care from trained personnel are highly effective in the reduction of death rates in PBs. Trained personnel can promote kangaroo mother care (KMC), where warmth and body temperature is maintained through skin-to-skin contact (McCall et al., 2005); and initiate feeding through either exclusive breastfeeding, parenteral nutrition or gavage feeding, for extremely PBs (Bhutta et al., 2008).
1.1.4. Causes of Preterm Births

The cause of PB is not clear. However, it is clear that any reduction in the local progesterone concentrations or in the receptors can initiate labour (Sfakianaki and Norwitz, 2006). Other precursors are either spontaneous labour with membranes intact, which is common among Caucasian women, premature rupture of membrane (PROM), common amongst black women, and induced labour or caesarean section for maternal-foetal indications (Goldenberg et al., 2008). Spontaneous preterm labour and PROM are linked to infections or inflammation of the uterus and vascular diseases (Goldenberg et al., 2008); as well as certain lifestyle choices such as tobacco use and excessive alcohol intake (Gravett et al., 2010). Microbiologists suggest that infection in the uterus accounts for 25- 40% of PBs, but rates may indeed be higher than reported as it is difficult to detect (Goldenberg et al., 2008).

Other risk factors include previous PBs, maternal ethnicity, nutritional status, low body mass index (BMI), shortened cervix, pre-eclampsia or eclampsia, intra uterine growth retardation and genetics (Goldenberg, et al., 2008; Hamilton et al., 2010). Nutritional status in pregnancy is determined by BMI and nutritional intake. Low BMI in pregnancy is linked to high risk of spontaneous PB, while obesity can be a safety factor. This is because thin women consume less vitamins and minerals, and have low serum levels of iron, folate and zinc (Hendler et al., 2005). Neggers and Goldenberg’s (2003) study showed that low concentration of serum iron decreases blood flow and increases infection; whereas obese mothers are likely to develop pre-eclampsia and diabetes which are indications for PBs (Goldenberg and Tamura, 1996).
1.1.5. Economic and financial burden of PBs

PBs attract enormous economic and societal burden due to the increasing cost of neonatal intensive care (NICU), the social burden and the long-term effect of disabilities and health problems, and the adjusted quality of life experienced by survivors and their families (Saigal and Doyle, 2008). The estimated cost to the taxpayer in England and Wales in 2006 was £2.946 billion, with an inverse relationship observed between gestational age and the average cost of survival for each child. It cost £22,885 per annum for each child surviving to eighteen years, and is substantially higher at £61,781 and £94,740 for very and extremely PBs respectively (Mangham et al., 2009).

1.1.6. Post-natal care of preterm babies

In the UK, most PBs will initially be cared for in NICU, which corresponds to approximately 70,000 babies annually (Bliss, 2010). Deciding the appropriate time for PBs to be discharged home from NICU is a complex issue. Kinney (2006) asserts that PBs with LBW are at a higher risk of hospital readmission and death in their first year of life, compared with babies born after 37 weeks. Historically, PBs were only discharged home with weights above 2000g, however randomised controlled trials (RCTs) have demonstrated that they can be discharged home weighing less than 2000g, if physiologically stable (American Academy of Paediatrics [AAP], 2008). That is, they are able to support their growth through breastfeeds or formula, maintain and regulate their body temperature within the home, and possess good respiratory control or are self-ventilating (AAP, 2008). This is because PBs are particularly at risk of sudden infant death syndrome (Thompson and Mitchell, 2006).
In the UK, National Institute for Health and Care Excellence (NICE) (2013) guidelines suggest that this decision should be based primarily on guidelines and the medical condition of the child, as inappropriate or failed discharge before the child is physiologically stable, increases the likelihood of death and morbidity.

In practice, however, this may be complicated by other factors such as how ready the parents are for discharge, and the forms of care that will be required and provided at home. Preferably oral feeding should be established in hospital where specialist nurses, lactation consultants and dieticians are readily available (Avistland et al., 2006). However, babies requiring gavage feeding and other long term measures to support their growth are being discharged home. Some infants return home with tracheostomy, or respiratory support including oxygen (Edwards, 2005) and may require specialist services, such as speech therapists, occupational therapists, and dieticians.

Complex unresolved medical problems can complicate subsequent care. However, NICU staff can help parents prepare for discharge, firstly through robust parental involvement and education about the care of their babies at home. This is to assist them transition from the intensive care and close supervision and support they have been used to in hospital to none or very minimal support at home. Secondly, initiating IHVs by outreach workers post discharge can bridge this transition, because many studies have suggested the benefits of IHV in reducing cognitive and motor deficits in PBs (Parents of Premature Babies Project [POPPY], 2009).
1.2. Statement of the Problem

Although the preterm survival rate shortly post birth increased from 40% to 53% between 1995 and 2006, in most developed countries, due to advanced technology, knowledge of risk factors and several public health and medical interventions (Hamilton et al., 2010), the number of babies leaving hospital with major health issues has remained constant (Costeloe et al., 2012). Survivors are prone to long-term neural and developmental impairments, respiratory complications and lung diseases, and gastrointestinal complications (Goldenberg et al., 2008).

Community practitioners are witnessing an increase in the numbers of PBs with complex medical conditions requiring some form of special supportive technology being discharged home due to the drive for community care, pressure to reduce hospitalisation cost and high bed demands (POPPY, 2009).

It is recommended that each PB should have an appropriate follow-up plan and co-ordinated surveillance programme to monitor their growth and development (AAP, 2008), and be supported by an outreach worker, who co-ordinates and provides on-going multi-disciplinary team support at home. In reality, however, this does not usually occur. Parents can be left finding their own support and coping as they can. Oftentimes, however, this responsibility falls on the HVs (POPPY, 2009). Increasingly, HVs have become an important component of post discharge care, as hospitals are unable to provide their own outreach support. However, little is known about HVs’ knowledge and indeed their capabilities to support PBs.
DH (2011) reiterates that support in the community should be provided by a joint hospital and community team, or recognised team of community practitioners with specific neonatal training. However, most HVs are not trained neonatal nurses. This is further complicated by the lack of NICE guidelines specific to PNC of PBs within the UK to guide their practice. Most guidelines located were written in the USA. UK NICE guidelines provide general PNC for all babies. Similarly, the NHS Trust under consideration in the dissertation has no formal guidelines or specific care pathway for PBs.

The absence of specific guidelines for PBs’ care can lead to a lack of practice standardisation, leaving HVs reliant on improvisation, using their clinical judgement and drawing on their knowledge base, which may or not be relevant, up to date or indeed evidence-based. Also, access to training may or not be readily available to these HVs. This ultimately can lead to inconsistent care provided to PBs and their families. This was demonstrated in the Bliss’ (2015) report which surveyed parents of PBs in 96 neonatal units within the UK. It found only 61% (n= 59) units provided community outreach services. Units that did not provide outreach services advised that some form of support services was available through the HVs, who in some cases did not have specific neonatal training. Most parents surveyed agreed there is a need for more community support when leaving NICU, as they felt isolated without outreach support. 2 out of the 5 hospitals serving the NHS Trust where this study was conducted provided some outreach service through a neonatal nurse immediately post discharge. This was in the form of a one-off joint visit with the HV.
As HVs form part of, and in some cases the only community support, it is essential to determine their knowledge, and the source of evidence underpinning their practice and decision making in order to improve the PNC provided to PBs. It is also essential to determine whether they should be providing additional visits for PBs. A strong body of evidence suggests that IHVs are particularly helpful for PBs from disadvantaged families, who are at risk of cognitive and motor outcomes due to limited or non-existent social support, financial constraints and poor access to healthcare. These visits can help reduce, and may even improve certain maternal-child outcomes, including prematurity in high risk populations. They can also support social interaction necessary for optimising outcomes in PBs (Larson et al., 2008; Forcada-Guex et al., 2006).

In conclusion, there are three key areas where the PNC of PBs are likely to be inconsistent and will be examined in this dissertation: firstly, a lack of specific national and local guidelines for PBs’ care in the community; secondly, the training received by HVs and their knowledge of key PBs’ care needs; and lastly, lack of parental education and support post discharge.

1.3. Dissertation Design/ Overview

Prematurity is an important public health priority. The long-term consequences of prematurity vary from mild to moderate to severe disability including cerebral palsy and cognitive impairment (Costeloe et al., 2012). Although all their organs are not matured, the brain, lungs and neurological system are most susceptible to the effect
of prematurity, potentially causing increased rates of long term neurological and health issues (Rees and Inder, 2005). The gap in the specialist services required by PBs to enable them achieve their respective developmental milestones has been highlighted above. Evidence-based practice provides healthcare professionals with the necessary resources that ensure they seek the best available information that answers their fundamental questions (Heneghan et al., 2009). This suggests that to improve outcomes for PBs, practitioners need to have sufficient knowledge of the available evidence concerning IHV to be able to apply it in practice. Therefore, Chapter 2 will review the contextual/ conceptual framework around the best evidence for IHVs to determine whether HVs should be providing additional visits. Chapter 3 outlines the methodology for this study. Chapter 4 presents the observations from the self-administered questionnaire and the analysis, and it discusses how, after careful analysis, I arrived at the answer to the research question of whether HVs were able to correctly describe key PBs' care needs. Finally, Chapter 5 summarises the significant findings of this study. Findings will be detailed and summarised. However, it is not possible to consider a comparative study as no prior research in this field is available.
CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

Chapter 1 established that more PBs are surviving in the UK and the majority receive adequate care in NICU. However, there is dearth of evidence regarding their PNC, and the role HVs play in addressing certain essential needs central to their wellbeing and global development. Aylward (2005) suggests that cognitive dysfunction can be moderated by environmental factors like parental socio-economic status, and parental education delivered via IHVs. However, it is unclear whether IHV improves or does not improve cognitive and motor outcomes in PBs over time. The aim therefore is to critically examine whether there are sufficient evidence suggesting IHVs improves cognitive and motor outcomes in PBs.

This literature review will detail the search strategy, the main IHV literature findings, and indeed, its effects on cognitive and motor outcomes. It will also explore other components of IHVs and emerging themes in the literature that may be useful in the care of PBs. All eligible studies will examine and analyse the settings, research participants, methods and interventions, to identify outcomes of interventions. Finally, the findings will be presented below and a conclusion will summarise the relevant evidence-based findings and rationale for the research and purpose.

2.2. Search Strategy

Using Heneghan et al.’s (2009) reputable method for managing clinical enquiry, four concepts were identified from the research questions, including Population (PBs),
Intervention (IHV), Comparison (standard care) and Outcome (growth and development). Five databases including PubMed, Embase, CINAHL, Medline and Cochrane were used to maximise the chances of capturing the most up to date, and relevant information from 2000 until date, published in English language and involving human subjects. Although it was necessary to explore studies done in the UK to provide a local context, studies conducted outside the UK were included for comparison, in-depth analysis and to provide a global perspective. These databases were specifically chosen because they focused on nursing and medicine necessary in answering the research question.

Keywords and MESH terms are listed in Table 2.1.
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<th>Table 2.1: Database search terms</th>
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<td>Home Health Nursing</td>
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<td>Community Health</td>
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<td>Premature Birth</td>
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<td>Parent-child relations</td>
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<td>Child development</td>
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<td><strong>Keywords</strong></td>
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<tr>
<td>Cognitive</td>
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<td>Motor outcomes</td>
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<td>Nurses, Community Health</td>
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Figure 2.2 provides a summary of the search strategy. Boolean commands were performed to broaden the search by including articles that focused on either the concept of PBs AND & OR child development. A combined total of 472 potentially eligible papers were initially retrieved through database and hand searches. 307 articles were excluded after the search was combined with home visiting and its related terms utilising Boolean search ‘AND’ to narrow down and focus the search to retrieve relevant studies. 86 articles were retrieved after duplicates removed. Furthermore, advancing the search by limiting it to English language, and articles focusing on human subjects, not exceeding 10 years and excluding systematic reviews and studies without control or comparison groups and not related to community care, excluded further 72 potential articles, leaving 14 eligible articles shown below in Table 2.2. However, a major UK pilot study conducted in 1989 (The Avon project) was included as it was necessary to provide local context and perspective.
Advancing the search by limiting it to English language, articles focusing on human subjects and articles not exceeding 10 years exempting a major pilot study conducted in the UK in 1989 excluded a further 44 articles.

Articles retrieved: (n= 42)

“Further 20 articles excluded were not related to the community, were systematic reviews and without control or comparison group”

(n = 22)

“8 articles excluded when abstract screened”

Papers eligible and included in the review (n=14)
2.3. Literature Overview

The identified studies were conducted in the UK (n=3), Australia (n=2), Norway (n=3), USA (n=2), Taiwan (n=1) Netherlands (n=2) and Italy (n=1) (Appendix A). RCT was employed by all studies with quantitative approach. Quantitative approach is particularly useful in identifying prevalence rates, relationships and causal effects. However, it does not explain the differences in relationships identified by the researcher (Powell et al., 2008). RCT is a rigorous way of determining the effect of an intervention and outcome (Okeh and Ugwu, 2009).

Research participants were PBs recruited during birth or soon after birth. All program used eligibility criteria including gestational age (GA), birth weight (BW) particularly LBW with cut off of 1250g and less than 2500g, and one study focused on African Americans. Exclusion criteria were proximity to centres and severe brain damage or congenital disorders. Majority of the interventions utilised nurses or research nurses (n=6), others used physical therapists (n=5), physiotherapists and/ psychologists (n=3), research assistants (n=1) and psychometricians (n=1). The intervention groups received intervention on top of the standard care, with some commencing in hospital prior to discharge and up to one-year CA. Visit varied from weekly to bi-weekly, with a minimum of four sessions offered. Seven studies implemented additional interventions during hospitalisation focusing on parenting or infant development, whilst two programs included attendance at centre-based groups. The entire group received the standard care, which is standard visit to the paediatrician. The interventions aimed to improve cognitive and motor outcome in PBs.
Interventions were structured around teaching parents about developmental milestones, understanding behavioural cues and providing infant stimulation.


A range of scales can be used to monitor cognitive and motor outcomes in infant and young children. For example, the BSID-II and III monitors neuro-developmental outcomes in children up to age 3. The mental development index (MDI) monitors cognition whilst the psychomotor developmental index monitors motor development (Bos, 2013). The Griffiths scales measures development in children from birth until 2 years of age. It is commonly used by paediatricians and psychologists in the UK to measure five subscales of development, namely: locomotor, personal-social, hearing and language, eye and hand co-ordination and performance (Hogrefe, 2016). MSEL scale screens for fives aspects of development including gross and fine motor, visual
perception, expressive and receptive language from birth to sixty-eight months (Mullen, 1995). The ASQ is administered by the HVs in the UK, screens five domains of child development including communication, gross and fine motor skills, problem solving and personal-social development (Bricker et al., 1999). AIMS is a screening tool often used by physiotherapists and occupational therapists to measure motor development in infants especially PBs aged 0-18 months old at risk of motor delay (Kolobe and Bulanda, 2006). The PEDI-NL measures the child’s abilities in the three functional domains such as daily activities, mobility and social and cognitive (Hayle et al., 1992).

2.4. Literature Findings

Koldewijn et al. (2009) demonstrated improved mental and motor outcome at 6 months (p=0.000 and 0.003). All other studies documented no difference between intervention and control groups at twelve and twenty-four months for cognitive scores, except Wu et al.’s (2014) study, which found a significantly higher cognitive composite score (95% CI 0.8- 7.9; p=0.02). Although APIP (1998)'s study did not report any significant difference in cognitive scores, it found infants born <28 weeks benefited more from the intervention (95% CI 0.06- 0.83; p-value= 0.09) than those born >28 weeks (95% CI 0.25 - 0.43; P-value= 0.60). Gianni et al. (2006) and Kaaresen et al. (2008) reported that at preschool, children who received interventions scored higher than the control group on IQ measure (p-value <0.001) but at school age, no difference was noted across studies.

Koldewijn et al. (2010) reported sustained motor development at 24 months and preschool. Verkerk et al. (2011) reported only motor outcome at 31/2 years.
The most significant findings were that studies which began intervention in the hospital showed some impact on cognition in infancy, preschool and school age than the control group (Spittle et al., 2015). Accordingly, Goyal et al. (2013) assert that overall there was positive effect of IHVs on parenting outcomes at one year for PBs, with dose effect of outcome related to visit frequency.

2.5. Emerging themes:

2.5.1. Parental-Child interaction and anxieties

Several studies postulate that establishing adequate interaction for PB is very essential (Cusson, 2003). However, this may pose a great challenge for both mother and child because of the child's prematurity. PBs experience reduced ability to self-regulate, are hypersensitive to stimulation, and present with unclear behavioural cues which may be difficult for their parents to understand and respond to (Feldman and Eidelman, 2006, Pickler et al., 2010). Parents on the other hand are very anxious because they may have little or no knowledge about their child's condition, and therefore begin to question their confidence and ability to care for them. If not adequately managed, this can affect their early parenting experience, limit their ability to respond appropriately, create negative interaction pattern and consequently disruption in establishing mother-child interaction (Brandon et al., 2011). Essentially, parental interaction is usually the foundation that builds children's capacity for expressing behavioural cues, responding to play and stimulation and this requires parents that are sensitive and responsive to their child's cues. That is, parents need to be able to practice pauses during interaction to promote clarity of cues, engagement and responsiveness. These help construct social skills and secure
attachment, necessary for social, language and cognitive development (White-Traut et al., 2013; Landry and Smith, 2006).

This can be promoted through massage and touching with light feathery strokes or touch. To improve the quality of mother-child interaction, White-Traut et al.’s (2013) study supported by a nurse advocate team, targeted PBs born at 29-34 weeks who were clinically stable, using auditory, tactile (moderate touch, stroking or massage) and visual and vestibular stimulation. At 6 weeks CA, the intervention group weighed and grew length more rapidly than the control group. It also demonstrated the importance of sensory interventions and advised early incorporation into standard care for PBs including massage to support brain development.

Most studies in Appendix A as a secondary outcome measure, found that mothers in the intervention group reported significantly lower stress levels and depression than in the control group (Spittle et al., 2010; Kaaresen et al., 2008). This is particularly significant because parenting stress is linked to increased risks of behavioural problems in later childhood, and oftentimes persisting into adulthood (Kaaresen et al., 2008). Children in the intervention group had notably low sleep problem scores (p=0.01) and internalising problems (95% CI 0.28 0.93; p=0.03) (Wu et al, 2014).

2.5.2. Nutrition and growth

PBs are at risk of lower growth and length attainment in infancy and early childhood, however can catch up with their growth by mid childhood and adolescence (Farooqi et al., 2006). Studies have shown that breast milk serves as the best source of
nutrition and its protective properties protects against several diseases (Okamoto et al., 2007; Vohr et al., 2007). Breastmilk prevents against necrotising enterocolitis (NEC) often occurring in formula fed PBs around the second to third week of life. NEC is characterised by varying damage to the intestinal walls, to necrosis and perforation (Thompson and Bizzarro, 2008). However, challenges of prematurity (ineffective suck and parental concerns over insufficient milk intake) and withdrawal of close supervision and support post discharge are plausible reasons for parents giving up breastfeeding (WHO, 2001).

KMC has been proven to initiate and facilitate breastfeeding, provides warmth, reduce mortality in babies >2000 by 51% if commenced in the first week (Lawn et al., 2010). Other study reported about 80% reduction in hypothermia, increased breastfeeding, weight gain, bonding and attachment and developmental outcomes (Conde-Agudelo et al., 2011). However, it is underutilised (Lawn et al., 2010). Hake-Brooks and Anderson's (2008) study of the effect of KMC on breastfeeding duration for PBs born at 32 to 36 weeks showed that mothers in the intervention group breasted significantly longer, an average of five months compared with an average duration of two months for the control group. Also, most significantly was that no mother in the control group breastfed past seven months in comparison with the intervention group who were still breastfeeding at eighteen months. Gathwala et al.'s (2008) RCT study in India concluded that the mothers in the intervention group who practiced KMC were significantly more likely to be exclusively breastfeeding in comparison to the control group at 3 months. Accordingly, Friedman et al.'s (2004) case control study found that mothers who received breastfeeding advice in
antenatal and NICU, fed their babies up to sixty days longer than those who did not. HVs are therefore pivotal in providing parents with these information and support in the antenatal period.

The WHO (2001) recommends that babies should be exclusively breastfed for the first 6 months of life and complimentarily for 2 years. Solids should be introduced at six months' actual age (AA) and not CA as milk is no longer sufficient to meet their nutritional demands. By six months their iron supply begins to deplete and are at risk of iron deficiency anaemia. Meat, a good source of iron, can be introduced at 6 months. Although, for some medical conditions such as reflux, babies can be weaned at four months AA, but strictly under the guidance of the paediatrician and dietician. Delaying weaning can lead to delay with textures and food intake, and impact their growth and development (British Nutrition Foundation, 2015). PBs are not more predisposed or likely to develop food allergies than term babies (Liem et al., 2007).

2.5.3. Growth and development

Failure to thrive in the postnatal period is prevalent amongst LBW infants. According to Dusick et al. (2003), 89% of ELBW infants experience growth failure by 36 weeks CA, and by eighteen to twenty-two months, 40% still have their weight, length and head circumference below the 10th centile. Growth failure caused by inadequate nutrition is linked to risks of poor neurodevelopmental outcomes. Although most PBs achieve their adult statue within the normal parameters, they can be disadvantaged in their height compared to term babies (Saigal et al., 2006). Slow growth in infancy,
followed by accelerated weight gain and crossing BMI centiles in adolescence increases their risks of developing cardiovascular disease and type two diabetes (Finken, 2006). Therefore, adequate monitoring by health professionals can help detect and prevent faltering growth or excessive weight gain. Plotting anthropometric measurement in infancy should be based on CA and should continue until one year for babies born between 32-36 weeks and two years for those born before 32 weeks (Royal College of Paediatrics and Child Health, 2009). Correcting for prematurity is pivotal to obtaining an accurate assessment of the child's developmental abilities and allows the expectation of their growth and their development to be based on their CA rather than AA. The wider consensus is that it should be corrected until 2-21/2 years, which is when most PBs catch up developmentally. However, immunisations should be administered at their AA (Emory University School of Medicine, 2016).

2.6. Literature Conclusion

The findings for the benefit of IHVs for cognitive and motor outcomes were not so strong as only Koldewijn et al. reported significant cognitive outcomes at 6 months, Wu et al. at 24 months and Kaarelsen et al. at pre-school age. Conversely, the observed differences noted was no longer present at school age. Similarly, only Koldewijn et al. and Verkerk et al. reported sustained motor outcome at 24 months and preschool age. This could be due to the duration of interventions, when it was commenced and variations in the number of visits offered. It however highlighted other strong benefits of IHVs such as, improving parental-child interaction and
reducing anxieties, nutrition and growth and development to enable each PB achieve their respective developmental milestones.

Research has shown that discharge is a difficult time for parents, with outreach support post discharge perceived as invaluable, and visits from HVs with knowledge of PBs highly valued (POPPY, 2009). Parents may need immediate support from health or outreach visitors relating to the anxiety and stress of caring for a PB at home, advice adapting to the home environment, and advice on feeding and growth monitoring. In the longer term, parents may need advice on when to start complementary feeding and on types of foods to provide. An example of the importance of this information comes from a systematic review on feeding outcomes post discharge from NICU, which found that after discharge, PBs were slower in developing feeding skills, with high levels of reported feeding problems and declining rates of breastfeeding (Ross and Browne, 2013).

HVs are well placed to deliver these services especially because HVs’ contact with parents start during the antenatal period. However, discharge planning involving parents, neonatal nurses, community nurses, HVs, and where possible GPs and other relevant professionals, necessary for smooth and easy transition to home care for the parents, rarely occurs (POPPY, 2009). Oftentimes, HVs are not notified about these discharges and the basic discharge summary to furnish them with vital information about the care received and ongoing needs is unavailable (Kazmi, 2008). HVs are well-positioned to offer the necessary advice and help on health issues,
especially to those experiencing difficulty accessing services. However, research is required into how they can best serve children and families (Cowley, 2013).

2.7. Research Rationale

Despite the wealth of evidence that exists around the complex need of PBs and the ongoing support required to enable them achieve their cognitive and developmental milestones, little is known about the knowledge and capabilities of HVs in relation to the key care needs of PBs’. Accordingly, there is dearth of literature in this field. Therefore, this research sought to explore HVs knowledge of key PBs’ care needs within the community.

2.8. Research Question

Are HVs able to correctly describe key PBs’ care needs within the community post hospital discharge?

2.9. Research Objectives

1. Describe HVs’ training, knowledge and confidence in relation to PBs’ care and developmental milestones.

2. Describe practices in notifying HVs about PBs’ discharge and whether discharge summary was received by HVs.

3. Describe HVs knowledge of local and national policies.
4. Determine the relationship between knowledge and confidence and;

i) age

ii) speciality,

iii) years of experience

iv) number of PBs seen by HVs.

v) training.
CHAPTER 3: METHODOLOGY

This chapter describes the research methodology of this study, method of sample selection, designing of the survey instrument and data collection. It provides an explanation of the statistical tool used to analyse the data. The data collected form much of the substance of chapter four, and the recommendations can be found in Chapter five.

3.1. Study design

This is a prospective cross-sectional survey using self-administered paper and on-line questionnaires.

3.2. Developing the research instrument

The research instrument utilised was a self-administered questionnaire (Appendix B). A self-completed questionnaire was chosen as is was less expensive and offers respondents greater anonymity by avoiding face to face contact due to the sensitive nature of the research questions.

As there was no existing survey instrument, a new one was designed after a thorough literature review (Figure 2.2) and it reflected the aims and objectives of the study. The questions were designed to be quick and easy to complete, and elicit relevant responses from respondents to ensure the research questions were answered as intended. It contained twelve structured questions insightful to the
research question, including a range of socio-demographic variables: age, sex, job, experience and the key outcome variable which is the knowledge and confidence of HVs (Table 3.1). To avoid constructing a complex and lengthy questionnaire, a tick box mix of dichotomous, multiple choice and a few free text questions was used.

<table>
<thead>
<tr>
<th>Table 3.1: Key Outcome variables- Knowledge and Confidence</th>
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</table>

For Questions 7, the two correct answers are ‘growth monitoring' and 'developmental milestones'. For questions 8, ‘they should continue skin-to skin' and ‘should be touched with a light feathery stroke’.
3.3. Demographic characteristics of Study Population

All HVs working within an NHS Trust in central London were identified as prospective respondents. Managers not holding clinical caseload were excluded from the study.

3.4. Arranging research access

Through my work as a HV within the Trust, I was able to obtain the emailing list of all HVs within the Trust from the employee workforce department. An initial email was sent out to all HVs informing them about the proposed survey. This was further discussed at the HVs' forum to provide better information and to encourage active engagement and participation. The forum is held monthly and it is avenue for all HVs and school nurses working within the Trust to meet and share experiences, innovations, evidence-based learning and discuss topics of common interests. Forums are an excellent way of creating social connections and disseminating good practices. Although not compulsory to attend, it is advisable to. Some HVs are however unable to attend because of other routine and urgent commitments linked to the role. The idea of first administering the surveys at the forum was to collect the bulk of the data there, then to capture those that were absent via the online survey.

3.5. Ethics

Following the agreement of the research topic with the research supervisor, ethics approval was obtained from University College London's (UCL) ethics committee. A further ethics application was made to the Trust and permission was granted to
proceed with the survey. To maintain confidentiality of HVs, the name of the Trust and the copy of the ethics permission will be withheld.

3.6. Collecting the data

Self-administrated questionnaires were distributed to all HVs working for the Trust between August and September, 2015. The initial survey was administered via pen and paper at the HVs forum and only eighteen HVs completed the survey. Unfortunately, the numbers were low due to the restructuring and consultation occurring at that time. Information letter explaining confidentiality and anonymity and the purpose of the research was administered alongside the survey. They were only requested to sign but a few HVs wrote their names on the survey.

A further eighty-four surveys were completed online using Google Forms during working hours, thus maximising the return with minimal inconvenience to respondents. Google Forms is a way of collecting information and feedback including surveys, using Google Chrome web store app. It allows you create and design surveys online and responses are immediately collected in a spreadsheet online. Respondents were then invited to complete the survey via the link sent through their work email. The first part provided information about confidentiality, the nature and purpose of the research to enable them consent without coercion. To avoid incomplete surveys, respondents could not proceed with submitting their survey if they had not answered all questions. Weekly reminder via emails and close liaison with team leads to encourage their staff complete the survey was used to increase the number of respondents.
Although it was important to gauge the knowledge and confidence of HVs in order to gather information to improve PNC for PBs, in tandem, the self-administered paper and online questionnaires were designed to be confidential and voluntary. The first question on the survey was consenting to proceed with the survey or exit. HVs were informed that they would not receive individual feedback but would receive joint feedback when data analysis is completed.

3.7. Data Management

The survey completed online in Google Forms was downloaded and saved in an Excel format. The hand filled questionnaires were manually entered into the downloaded Excel sheet and unique identifiable numbers awarded. The hand completed questionnaires were collated and filed separately to ensure confidentiality and accountability even after the research was completed. There was no personally identifiable data on the online questionnaire.

3.8. Data Cleaning, Reduction and Analysis

The data reduction involved examining the data for correctness and completeness to minimise error, and coding. Only two HVs qualified within the last year, therefore the decision was made to recode years of experience as 0 - 5, 6- 10 and over 10 years for analysis purposes. There were 9 specialist HVs and 22 HV practice teachers (HVPTs). Due to the low numbers of specialist HVs, it is plausible for analysis purpose to combine this category with HVPTs which is also another speciality. However, these categories were kept separate because the HVPT's role is
particularly useful as they are responsible for facilitating student HVs learning and signing them off as being proficient within practice. In essence, they are the gatekeepers of the profession.

Questions 7, 8 and 10 (Table 3.1) were dichotomised as the intention was to determine whether HVs had sufficient knowledge of key PBs’ care needs or not, and agreed to being confident or not to provide care and support to PBs and their families post discharge. This meant that those who answered only one correctly or all incorrectly were grouped as insufficient knowledge and those who answered both answers correctly, were grouped as sufficient knowledge. Binary coding was used in the analysis, 0 for insufficient knowledge and 1 for sufficient knowledge. Similarly, confidence was coded using binary intervals which is whether HVs felt confident or not. Strongly agree and agree were coded as 0 and neither agree nor disagree, disagree and strongly disagree was coded as 1.

The data analysis involved describing the data to view the distribution of the variables, coding and utilising STATA version 12.1 (StataCorp 2011) software to perform statistical analysis of the descriptive study (Chapter 4). Simple descriptive analysis was employed to get a sense of the nature of responses and emerging themes. Pearson’s Chi-squared test and Fischer’s exact explored for correlation between variables and the primary outcome which is knowledge and confidence. Logistic regression analysis was employed to explore the associations between the
dependent variables and the independent variables and to determine the forms of this relationship.

A range of variables such as age, years of experience and specialty, closely linked to knowledge and confidence were identified early on in the literature review as potential confounders. A multivariable adjusted model controlled for potential confounding. The logistic regression sought to explore whether age, specialty and years of experience (dependent variables) are confounders in the relationship between knowledge and confidence (independent variables) (refer to appendix C for Stata command).
CHAPTER 4: RESULTS

4.1. Introduction

The aim of this chapter is to present the data gathered from the self-administered survey instrument, analysis and findings in a meaningful way to facilitate the discussions around the interpretation and implications for practice which will be presented in chapter 5.

This chapter at the outset provides a background to respondent's characteristics, followed by a descriptive analysis incorporating cross tabulation analysis, and finally, a summary of the data using logistic regression analysis.

4.2. Response Rate

Out of the potential 140 HVs identified to complete the questionnaire, only 102 completed the survey within the defined time frame. This constitutes a 73% response rate. All compulsory questions posed to the respondents were answered and the responses are presented below. Descriptive statistics of the baseline characteristics of respondents such as the age, sex, years of experience, speciality, training received, the number of PBs cared for within the last two years and babies that were breastfed is presented in Table 4.1 below. Nothing is known about non-respondents and their reason for not completing the survey.
4.3. Study Population

Only 3.9% (n=4) of respondents were male, and just over half of the respondents (55.9%, n=57) were 46 years and over. Over two-thirds of respondents were HVs (69.6%, n=71) and more than half of HVs (55.9%, n=57) had over 10 years work experience. Only 1.9% (n=2) qualified within the last year. Just under half of respondents (45.1%, n=46) reported receiving training on caring for PBs post discharge as part of their general and specialist training, and more than half of the respondents (54.9%, n=56) reported no training at all. Only 13.7% (n=14) had not cared for PBs within the last 2 years and were therefore allowed to exit the survey at this point. 86.3% (n=88) of respondents who answered yes proceeded to complete the survey (Table 4.1).

Figure 4.2 below shows that almost all respondents, (97.1%, n=99) desired further training and support around PBs. The significant training need identified was around growth and development of PBs, weaning and breastfeeding PBs.
Table 4.1: Baseline characteristics of respondents and descriptive statistics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td>Female</td>
<td>98</td>
<td>96.1</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
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<tr>
<td>20-30 years</td>
<td>22</td>
<td>21.6</td>
</tr>
<tr>
<td>31-45 years</td>
<td>23</td>
<td>22.5</td>
</tr>
<tr>
<td>&gt;46 years</td>
<td>57</td>
<td>55.9</td>
</tr>
<tr>
<td><strong>Specialty</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Visitor</td>
<td>71</td>
<td>69.6</td>
</tr>
<tr>
<td>Specialist Health Visitor</td>
<td>9</td>
<td>8.8</td>
</tr>
<tr>
<td>Health Visitor Practice Teacher</td>
<td>22</td>
<td>21.6</td>
</tr>
<tr>
<td><strong>Experience</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within the last year</td>
<td>2</td>
<td>1.9</td>
</tr>
<tr>
<td>1-5 years</td>
<td>35</td>
<td>34.3</td>
</tr>
<tr>
<td>6-10 years</td>
<td>8</td>
<td>7.8</td>
</tr>
<tr>
<td>Over 10 years</td>
<td>57</td>
<td>55.9</td>
</tr>
<tr>
<td><strong>Training Received</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>56</td>
<td>54.9</td>
</tr>
<tr>
<td>Yes, as part of general training</td>
<td>35</td>
<td>34.3</td>
</tr>
<tr>
<td>Yes, as part of specialist training</td>
<td>11</td>
<td>10.8</td>
</tr>
<tr>
<td><strong>Number of PBs seen within last 2 yrs.</strong></td>
<td>Total= 604</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>14</td>
<td>13.7</td>
</tr>
<tr>
<td>1-5</td>
<td>47</td>
<td>46.1</td>
</tr>
<tr>
<td>&gt;6</td>
<td>41</td>
<td>40.2</td>
</tr>
<tr>
<td>Breastfed</td>
<td>332</td>
<td>54.9</td>
</tr>
</tbody>
</table>
4.3.1. HVs aware of guidelines?

In response to the question regarding existence of guidelines specifically for PBs, just under one quarter of HVs (23.5%, n=24) correctly answered that the trust did not have guidelines on the care of PBs (Figure 4.3).
4.3.2. HVs notified of birth and discharge summary received?

Figures 4.4 and 4.5 below shows that the majority of notification came from NICU (63.6%, n=56) and less than one quarter of respondents (19.3%, n=17) reported receiving all discharge notes.
4.3.3. HVs confident caring for PBs?

In response to the question posed to HVs as to whether they felt confident caring for PBs, just over 50% (51.9%, n=53) of respondents in Figure 4.6 below reported feeling confident caring for PBs.
4.3.4. Additional support provided by HVs

HVIs mainly provided additional growth monitoring, breastfeeding support and emotional support to PBs and their families, as shown in figure 4.7 below.

![Figure 4.7: Support provided to PBs by HVs](image)

4.4. Descriptive statistics

In relation to the question on knowledge of adjusted age for PBs, just over half of respondents, (53.9%, n=55) correctly identified areas that should be based on CA of a child. Similarly, in relation to knowledge on aspects of care and development that are true about PBs, less than one quarter of respondents (17.6%, n=18) correctly identified this in 4.8 below.
4.5. Test for trend across categories

Table 4.9 presents a summary of the chi-square analysis and fishers exact for the correlation between the trend in knowledge and confidence, and age, years of
experience, specialty, median numbers of PBs cared for and training received. The result demonstrates only a positive correlation between confidence and training as p-value=0.001.

4.9: Cross tabulation for trend/ Chi-square and Fisher’s analysis

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>n</th>
<th>%</th>
<th>Test for Trend</th>
<th>Knowledge of adjusted age for PBs</th>
<th>n</th>
<th>%</th>
<th>Test for Trend</th>
<th>Knowledge of aspects of care and development that are true about PBs</th>
<th>n</th>
<th>%</th>
<th>Test for Trend</th>
<th>Fisher’s exact</th>
<th>Fischer’s exact</th>
<th>P-value (P=)</th>
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<tbody>
<tr>
<td>Age</td>
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<tr>
<td>20-30 years</td>
<td>12</td>
<td>21.8</td>
<td>0.4603</td>
<td>04</td>
<td>22.2</td>
<td>0.0058</td>
<td>7</td>
<td>13.2</td>
<td>5.3295</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>31-45 years</td>
<td>11</td>
<td>20.0</td>
<td>P= 0.794</td>
<td>04</td>
<td>22.2</td>
<td>P=0.997</td>
<td>15</td>
<td>28.3</td>
<td>P= 0.070</td>
<td></td>
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<tr>
<td>&gt;46 years</td>
<td>32</td>
<td>58.2</td>
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<td>10</td>
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<tr>
<td>HV</td>
<td>39</td>
<td>70.9</td>
<td></td>
<td>13</td>
<td>72.2</td>
<td>Fisher’s exact=0.450</td>
<td>34</td>
<td>64.2</td>
<td>1.7200</td>
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<tr>
<td>Specialist HV</td>
<td>03</td>
<td>5.4</td>
<td></td>
<td>01</td>
<td>5.6</td>
<td></td>
<td>5</td>
<td>9.4</td>
<td>P= 0.423</td>
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<tr>
<td>HV Practice Teacher</td>
<td>13</td>
<td>23.6</td>
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<td>04</td>
<td>22.2</td>
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<td>14</td>
<td>26.4</td>
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<tr>
<td>Experience</td>
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<tr>
<td>&gt; 5 years</td>
<td>17</td>
<td>30.9</td>
<td>2.4908</td>
<td>07</td>
<td>38.8</td>
<td>Fisher’s exact=1.000</td>
<td>15</td>
<td>28.3</td>
<td>4.0333</td>
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<tr>
<td>6-10 years</td>
<td>06</td>
<td>10.9</td>
<td>P= 0.288</td>
<td>01</td>
<td>5.6</td>
<td></td>
<td>06</td>
<td>11.3</td>
<td>P= 0.133</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>32</td>
<td>58.2</td>
<td></td>
<td>10</td>
<td>55.6</td>
<td></td>
<td>32</td>
<td>60.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PBs</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>0</td>
<td>7</td>
<td>12.7</td>
<td>0.5926</td>
<td>0</td>
<td>0.0</td>
<td>3.5956</td>
<td>05</td>
<td>9.4</td>
<td>2.2058</td>
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<td></td>
<td></td>
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<td>1-5</td>
<td>24</td>
<td>43.6</td>
<td>P= 0.744</td>
<td>09</td>
<td>50.0</td>
<td>P=0.166</td>
<td>24</td>
<td>45.3</td>
<td>P= 0.332</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>&gt;6</td>
<td>24</td>
<td>43.6</td>
<td></td>
<td>09</td>
<td>50.0</td>
<td></td>
<td>24</td>
<td>45.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Training No</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Yes</td>
<td>30</td>
<td>54.5</td>
<td>0.0061</td>
<td>09</td>
<td>50</td>
<td>0.2121</td>
<td>21</td>
<td>39.6</td>
<td>10.4026</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>25</td>
<td>45.5</td>
<td>P= 0.938</td>
<td>09</td>
<td>50</td>
<td>P= 0.645</td>
<td>32</td>
<td>80.4</td>
<td>P= 0.001</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
4.6. Logistic regression results

4.6.1. Single-variable crude result

In relation to question 7 on knowledge of adjusted age for PBs (Table 4.10), it found positive associations between knowledge and years of experience. HVs with 6-10 years and over 10 years' experience were 253% 3.53(0.63, 19.83) and 50% 1.50(0.65, 3.46) more likely to have sufficient knowledge than the reference category which is those with 1-5 years' experience. In contrast, logistic regression showed no significant difference across all category score as p= >0.05.

In relation to question 8 about the knowledge of care and development that are true about PBs (Table 4.10), positive associations were not observed and the logistic regression was not significant across all category score.

Age, speciality, years of experience, and training were shown to be positively associated with confidence. However, only age and training were found to be statistically significant as p=0.02 and 0.002 respectively (Table 4.10).
Table 4.10: Single-variable unadjusted results for knowledge and confidence, and age, specialty, years of experience, and median number of PBs cared for and training.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Knowledge of care and development that are true about PBs</th>
<th>OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10 years</td>
<td>1.05 (0.65 - 1.69)</td>
<td>0.335</td>
<td></td>
</tr>
<tr>
<td>10-20 years</td>
<td>3.10 (1.19 - 8.03)</td>
<td>0.152</td>
<td></td>
</tr>
<tr>
<td>&gt;20 years</td>
<td>1.05 (0.65 - 1.69)</td>
<td>0.335</td>
<td></td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HV</td>
<td>0.41 (0.95 - 1.77)</td>
<td>0.233</td>
<td></td>
</tr>
<tr>
<td>HVPT</td>
<td>1.18 (0.45 - 3.13)</td>
<td>0.731</td>
<td></td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;6 years</td>
<td>0.67 (0.24 - 1.87)</td>
<td>0.499</td>
<td></td>
</tr>
<tr>
<td>6-10 years</td>
<td>1.50 (0.65 - 3.46)</td>
<td>0.335</td>
<td></td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>0.67 (0.24 - 1.87)</td>
<td>0.499</td>
<td></td>
</tr>
<tr>
<td>Years of experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5 years</td>
<td>0.99 (0.12 - 7.29)</td>
<td>0.969</td>
<td></td>
</tr>
<tr>
<td>5-10 years</td>
<td>1.50 (0.65 - 3.46)</td>
<td>0.335</td>
<td></td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>0.99 (0.12 - 7.29)</td>
<td>0.969</td>
<td></td>
</tr>
<tr>
<td>Knowledge of aspects of care and confidence</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.6.2. Multivariable adjusted model result

<table>
<thead>
<tr>
<th>Training</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0.002</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0.496</td>
<td>0.936</td>
</tr>
</tbody>
</table>

Training: Omitted. 100% HVs with 0 PB were categorized as knowledge and confidence and excluded from the regression.

<table>
<thead>
<tr>
<th>Specialty</th>
<th>0-5</th>
<th>6-10</th>
<th>11-20</th>
<th>21-30</th>
<th>31-40</th>
<th>40-60</th>
<th>60+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.483</td>
<td>0.483</td>
<td>0.483</td>
<td>0.483</td>
<td>0.483</td>
<td>0.483</td>
<td>0.483</td>
</tr>
<tr>
<td>Specialty</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
</tbody>
</table>

Note: Omitted. 100% HVs with 0 PB were categorized as knowledge and confidence and excluded from the regression.

Overall, age, specialty, and years of experience were not significantly associated with both outcome variables after adjusting for other factors (Table 4.11). Although, the OR of 4.52 (95% CI 0.47 - 2.26) for HVs with 6-10 years suggests they were 3.5 times likely to have sufficient knowledge and confidence than other categories, the p-value suggests this was not statistically significant. The lack of significance may be due to sample size. Although the CI was wide, it suggests there was a trend towards higher OR with 6-10 years of experience.
## Table 4.11: Multivariable adjusted model result for knowledge and confidence, and age, specialty and years of experience

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Knowledge of adjusted age for PBs</th>
<th>Knowledge of aspects of care and PBs</th>
<th>Knowledge of disabilities for PBs</th>
<th>Knowledge of adjusted age for PBs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>p-value</td>
<td>OR (95% CI)</td>
<td>p-value</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30 years</td>
<td>0.031 (0.017-0.508)</td>
<td>0.38 (0.22-0.67)</td>
<td>0.870</td>
<td>0.56 (0.15-2.09)</td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>0.057 (0.034-0.946)</td>
<td>0.35 (0.14-0.87)</td>
<td>0.777</td>
<td>0.53 (0.08-3.36)</td>
</tr>
<tr>
<td>Specialty</td>
<td>HV</td>
<td>HVPT</td>
<td>HVPT</td>
<td></td>
</tr>
<tr>
<td>HV Specialist</td>
<td>0.40 (0.07-2.36)</td>
<td>1.02 (0.33-2.94)</td>
<td>1.00 (0.33-2.94)</td>
<td></td>
</tr>
<tr>
<td>HVPT</td>
<td>0.98 (0.33-2.94)</td>
<td>1.00 (0.33-2.94)</td>
<td>1.00 (0.33-2.94)</td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>&gt;5 years</td>
<td>&gt;5 years</td>
<td>&gt;5 years</td>
<td></td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>4.52 (0.57-37.67)</td>
<td>2.36 (0.42-13.26)</td>
<td>0.389</td>
<td>0.503</td>
</tr>
<tr>
<td>5-10 years</td>
<td>0.54 (0.05-6.23)</td>
<td>0.51 (0.02-1.32)</td>
<td>0.503</td>
<td>0.503</td>
</tr>
<tr>
<td>10+ years</td>
<td>0.26 (0.06-1.17)</td>
<td>0.25 (0.06-1.17)</td>
<td>0.25 (0.06-1.17)</td>
<td>0.25 (0.06-1.17)</td>
</tr>
<tr>
<td>Specialty</td>
<td>HV</td>
<td>HVPT</td>
<td>HVPT</td>
<td></td>
</tr>
<tr>
<td>HV</td>
<td>0.53 (0.06-4.86)</td>
<td>1.01 (0.25-3.99)</td>
<td>1.01 (0.25-3.99)</td>
<td></td>
</tr>
<tr>
<td>HVPT</td>
<td>0.53 (0.06-4.86)</td>
<td>1.01 (0.25-3.99)</td>
<td>1.01 (0.25-3.99)</td>
<td></td>
</tr>
<tr>
<td>Knowledge of aspects of care and PBs that are about PBDs</td>
<td>0.895</td>
<td>0.837</td>
<td>0.895</td>
<td>0.837</td>
</tr>
<tr>
<td>Knowledge of disabilities for PBs</td>
<td>0.121</td>
<td>0.328</td>
<td>0.121</td>
<td>0.328</td>
</tr>
<tr>
<td>Knowledge of adjusted age for PBs</td>
<td>0.177</td>
<td>0.493</td>
<td>0.177</td>
<td>0.493</td>
</tr>
</tbody>
</table>

**Note:** PBDs = Physical, Developmental, and Emotional Disorders
CHAPTER 5: DISCUSSION

5.1. Introduction

This cross-sectional quantitative study set out to determine whether HVs can correctly describe key PBs’ care needs and the support required from them by mothers of PBs within the community. It also sought to construct statistical models to explain the relationships between knowledge and confidence, and age; specialism; years of experience; training; and whether the median number of PBs cared for by HVs correlated with confidence. Key findings discussed here suggest that training is essential to improving HVs knowledge and confidence in caring for PBs.

5.2. Key Findings

The major finding of the descriptive data as described in figure 4.8 was that HVs knowledge was found to be inconsistent and was not always robust. Although 53.9% (n=55) rightly identified the two right answers in relation to question 7 on CA for growth and development of PBs, 46.1% (n=45) did not. In contrast, less than one quarter of HVs (17.6% n=18) correctly identified the two right answers on aspects of care and development that are true about PBs, whilst 82.4% (n=84) could not. This calls into question how well trained and prepared they are, and how they receive guidance regarding care in practice. This has great implications for practice because parents of PBs might receive inconsistent advice which might lead to confusion and affect their ability to trust and follow professional advice. This is consistent with the Bliss’ (2015) report, that HVs were lacking in neonatal training. Bhardwa (2014) at the Institute of Health Visiting highlighted continuing professional development
(CPD) in online form, easy to use and access, with built in evaluation as essential for HVs. Similarly, Cowley (2013) concurred that the government should invest more in educating HVs especially in CPD, focusing on their essential roles and skills. This survey, however, suggests that HVs are aware of their training needs as expressed through the survey, they require additional training particularly around breastfeeding, weaning, growth and developmental milestones, bonding and emotional support for PBs (Figure 4.2).

Table 4.9 suggests that the older age category, 46 years and over, appear to be more knowledgeable and confident. The observed result could be due to the fact that those aged 46 and over (55.9%, n=57) are the largest category. This correlates with a recent work force data compiled by NHS Employers (2015) and DH (2011) asserting that health visiting is an ageing workforce. In contrast, the logistic regression found the 31-45 year olds were more confident (Table 4.10).

Table 4.9 also seems to suggest that HVs were more knowledgeable and confident. However, it is worth noting that about two-thirds of respondents (69.6%, n=71) were HVs. In contrast, the logistic regression (Table 4.10) showed HVPT were more knowledgeable and confident.

Similarly, HVs with over ten years’ experience appeared to be more knowledgeable and confident (Table 4.9). Benner (1982) citing the ‘Dreyfus Model of Skill Acquisition’ said skills acquisition is a paradigm where a ‘novice’ moves through five
levels of proficiencies of skills to become an ‘expert’. The novice starts off with little or no experience or professional discretion through to acquiring experience and developing enormous intuitive grasp of a situation, using deep understanding to connect and a holistic approach to solve problems. However, it is worth noting that this category makes up over half (55.9%, n=57) of respondents. In contrast, the logistic regression found HVs’ with 6-10 years’ experience were more knowledgeable and confident (Table 4.10).

The result highlights the presence of some sorts of good practice as HVs provided various forms of care to PBs, particularly around additional growth monitoring, weaning, breastfeeding, reflux, skin-to-skin, massage and emotional support to parents (Figure 4.7). The care provided to each individual PB varied depending on their respective needs. Whilst some required additional growth monitoring, others did not, especially if they were discharged with a healthy weight and were reaching developmental milestones.

Interestingly, neither the Trust nor NICE has specific guidelines for the PNC of PBs post hospital discharge. However, 16.7% (n=17) mentioned that the Trust had guidelines. This raises questions around HVs awareness of local and national policies and guidelines, and ultimately the overarching principles underpinning practice. This is particularly worrying, despite the increasing number of PBs globally and in the UK, there is no national guideline regarding PNC within the community to support the role of the HVs. It highlights the need for employers to standardise care
for PBs locally, and for NICE to produce guidelines specifically tailored to meet the needs of these vulnerable ones. Ploeg et al. (2007) affirm that having practice guideline is an essential and useful tool necessary for closing the research-evidence gap.

There were inconsistencies with the way HVs were notified of discharges. The survey found most births were notified via the midwife and NICU. Most concerning was the fact that 80.7% (n=71) of HVs received only some or did not receive any discharge notes post discharge. Discharge notes are particularly useful especially where minimal or no communication existed between both parties whilst babies were hospitalized. They promote client safety as they provide a good source of information on the needs of the child and further support required (Kind and Smith, 2008). This particular area raises concerns of a disconnect between acute and primary care especially where there is no outreach service to support families post discharge. This echoes Francis (2013) mid-Staffordshire’s report about failings from poor standards and the absence of many checks and balances that could have averted significant failings.

The statistical analysis found association between confidence and age and training (Table 4.10). Chi-squared (p=0.001) and the p-value of the unadjusted logistic regression (p=0.028 and 0.002) were statistically significant. This aligns with the descriptive data that showed 51.9% (n=53) of HVs said they felt confident caring for PBs and 45.1% (n=46) HVs had received training. This demonstrates that training
improved their knowledge and confidence, thus influencing the quality of care provided to PBs. Pike et al.’s (2011) cross-sectional study demonstrated that staff’s safeguarding training contributed to a 20% increase in knowledge, and that being confident enabled participants to link their knowledge with safeguarding processes.

The unadjusted logistic regression for categorical data (Table 4.10) revealed marginal trends suggesting positive associations between (i) the trend in knowledge of adjusted age for PBs and years of experience; and (ii) trend in confidence and age, years of experience and specialism. However, it is notable that this trend was not found to be statistically significant, possibly due to small sample size which may have allowed the nuances of the data to be lost. The use of categorical data rather than numerical data could also have been a factor. Although, the statistical analysis of numerical data is more powerful and often simpler (UCL, 2015), using categorical variables made it quick and easy for HVs who are often busy and under pressure to achieve their key performance index, to complete this survey.

To avoid the direct or inverse correlation with both the dependent and independent variable, and the likelihood of obtaining a false correlation, age, years of experience and specialty were adjusted for confounding. The logistic regression for the adjusted model result showed that the trend in the OR observed in the crude analysis (Table 4.10) was no longer present when adjusted for confounding (Table 4.11).

The summary of respondent’s characteristics presented in Table 4.1 showed the wide gender disparity (Female, 96.08% and Male, 3.92%) observed in the sample.
This can be explained by the disparity in the total numbers of male and female in the profession nationally. Nelson and Belcher (2006) explained that the predominance of females in nursing profession is linked to discrimination and stereotypes which prevent men from making the decision to study nursing.

5.3. Strength of the study

The composite data provided a range of insight into the research topic as no study comparing HVs knowledge has been previously conducted. The study addressed gaps in the literature regarding the knowledge of HVs of PBs’ care needs and compared how the median number of PBs cared for correlates with confidence.

A mixed method approach would have been preferable. However, a quantitative study was chosen because of the confidential and sensitive nature of the information likely to be volunteered. Similarly, a quantitative survey is suited and sufficient for surveying more HVs and obtaining an overall illustration of the extent of the problem. It is also a formal and systematic process of generating numerical data that can be converted into numbers, to be presented in an objective form (Burns and Grove, 2008). Quantitative research is suitable in answering the specific research question which can help formulate facts and show patterns in the study (Shields and Twycross, 2003).

The sampling method used was less biased because including all HVs working in the organisation ensured that the sample broadly represented HVs working within
central London. The sample size used was adequate as 92 was the minimum requirement if using simple random sampling.

The multi-varied adjusted regressions showed the researcher thought about possible confounders during planning. The multiple logistic regression model allowed associations to be measured independently. Using age, years of experience and specialism score as possible confounding variables can be argued to be advantageous, permitting scarce prejudice in the analysis (Turrell et al., 2009). The single-variable logistic regression model allowed associations to be measured independently.

The relatively good response rate of 73% was encouraging as one of the pitfalls of online survey is low response rate. The researcher’s professional experience and understanding of the topic was a great strength.

5.4. Limitations

The survey instrument was not tested for reliability and validity, in particular for measuring knowledge, due to time constraint and the unavailability of previous surveys and instruments in this field. Given more time in the future, a more sensitive questionnaire testing the strengths of the answers, rather than the answers alone would be recommended. The data showed the number of children who were having
some breastmilk and not those that were exclusively breastfed. This was due to the researcher trying not to deviate from the research question.

Small numbers in some categories made basic level of analysis sometimes challenging but this was managed by merging categories together. A potential limitation is firstly, that generalising findings to the wider HV population in the UK would not be viable, as data was collected within one Trust. Secondly, the small sample size was largely beyond my control, due to limited timescale to conduct the survey, manpower and constraints obtaining ethics permission from several NHS Trusts. Thirdly, this survey was intended to be anonymous, therefore, it was impossible to tell who had not completed to approach to complete the survey. Albeit, the study remains very relevant in the context of the survey.

A further study is recommended, ideally with a mixed methods design, to minimise recall bias and enable inferential statistics to be made. The dichotomous and multiple choice answer options in this survey could be regarded as being subjective and may not have captured in-depth or spontaneous responses which could inadvertently be a source of bias. However, they are easy to code and process, and enabled comparison across respondents (Kumar, 2005).

Although, nothing is known about non-respondents, a completion rate of almost 73% makes the responses unlikely to be too different.
Although this topic is close to the researcher’s heart, the researcher was able to stand back and took care not to participate in the study. The data collection method also limited researcher’s potential bias.

5.5. Conclusion

This study provided invaluable insight into the knowledge of HVs. Overall, there is sufficient evidence suggesting gaps in HVs knowledge and the need for improvement. Identification of the gaps in HVs’ knowledge and practice are significant, as they can inform clinicians to further their knowledge and in turn, enable them improve services provided to PBs. It highlighted the importance of neonatal training for HVs to improve the care they provide to their vulnerable clients and families.

Chapter 2 established some benefits of IHVs to PBs. Accordingly, Cameron et al. (2005) found that early screening of PBs can reduce incidence of motor delay. In tandem, Amess et al.’s (2010) study reported that developmental assessment conducted by HVs are useful in measuring outcomes in PBs.

It raised the issue of disconnect between hospital and community services as 80.7%(n=71) did not receive all discharge notes and inconsistencies existed in the way hospital discharges were notified. There should be a standardised discharge notification process to avoid children being missed. Other barriers to HVs delivering
quality and effective care include the absence of standardised care pathway for PBs and NICE guidelines, to ensure uniformity of evidence-based practices across the HV service.

In spite of the limitation of the study, the research findings contribute to the paucity of evidence of the benefits of IHV to PBs and whether HVs are able to correctly describe PBs’ key care needs. It highlighted the gap in the knowledge of HVs around the key care needs of PBs and offers recommendations below to help improve quality in practice.

**Key messages/recommendations:**

- Training for HVs should focus on PBs and their developmental need.
- Improved communication and liaison between hospital and community to ensure complete notification is received and HVs are promptly notified of discharges.
- Clearer discharge notification pathway and channel.
- Targeted IHVs for PBs conducted by outreach workers or HVs.
- Standardised PNC pathway and guidelines for PBs.
- NICE to consider writing specific post-natal guideline for PBs.

**Word count excluding abstract: 9753**

Abstract (249)
Reference Lists


Ross, E.S. and Browne, J.V. (2013) Feeding Outcomes in Preterm Infants After Discharge from the Neonatal Intensive Care Unit (NICU): A Systematic Review. Newborn & Infant Nursing Reviews, 13(2), pp.87–93


StataCorp. (2011) *Stata Statistical Software: Release 12*. College Station, TX: StataCorp LP.


<table>
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<th>Study Design</th>
<th>Author/Date</th>
<th>Sample</th>
<th>Objective</th>
<th>Intervention Received</th>
<th>Main Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCT</td>
<td>Spittle et al. (2010)</td>
<td>120 PBs were assigned randomly into intervention (n=61) and control groups (n=59).</td>
<td>(1) To determine the effects of preventative care at home on child development and parent-child relationship, infant development and mental health; (2) To determine the effects of preventative care at home on child development and parental mental health.</td>
<td>Preventative care programme consisting of 9 home visits lasting up to 1.5-2 hours long over 1-year period from a physiotherapist and psychologist focusing on parent-infant child relationship, infant development and parental mental health.</td>
<td>At 2 years CA (96%) n=115: Although cognitive, language or motor composite scores between both groups was not statistically significant, children in the intervention group scored better for externalizing and dysregulation behaviours and higher competence scores than the control group.</td>
</tr>
<tr>
<td>Quantitative</td>
<td>CBIP (n=57), HBIP (n=58) and UC (n=50)</td>
<td>Computer generated randomisation based on GA from 3 to 7 years.</td>
<td>Based on GA from 3 to 7 years.</td>
<td>Extensive base-line perinatal data obtained from medical records and parent questionnaire. BSITD-III and child behaviour checklist for ages 1.5 to 5 years.</td>
<td>CBIP (n=57), HBIP (n=58) and UC (n=50): Group differences in cognitive and motor scores between both groups did not differ in 2 to 7 years.</td>
</tr>
<tr>
<td>Study Details</td>
<td>Intervention (n=69)</td>
<td>Control (n=67)</td>
<td>Comparison</td>
<td>Sample Size</td>
<td>Randomisation</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Kaaresen et al. (2008)</td>
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<tr>
<td>Stratified RCT.</td>
<td></td>
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<tr>
<td>To examine the effects of an early intervention program on cognitive, motor and behavioural outcomes among low birth weight children at 2 years CA.</td>
<td></td>
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<tr>
<td>Inclusion criteria - Infants born at &lt;37 weeks weighing &lt;1500g. Exclusion criteria - congenital abnormalities or severe neonatal disease.</td>
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<tr>
<td>Randomisation of infants born at &lt;2000g at North Norway Hospital.</td>
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<tr>
<td>BSID-II, Bayley’s, Developmental and Child behaviour checklists.</td>
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<tr>
<td>No difference in the cognitive and motor outcomes in the intervention and control group at 2 years CA.</td>
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<tr>
<td>Wu et al. (2014)</td>
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<tr>
<td>Stratified RCT.</td>
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</tr>
<tr>
<td>To determine the effects of a clinic-based intervention program and usual care on clinic-based and hospital-based intervention program on cognitive, motor and behavioural outcomes among low birth weight children at 2 years CA.</td>
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<tr>
<td>Inclusion criteria - Infants born at &lt;37 weeks weighing &lt;1500g. Exclusion criteria - congenital abnormalities or severe neonatal disease.</td>
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<tr>
<td>Randomisation of infants born at &lt;37 weeks weighing &lt;1500g at Northern Taiwan Hospitals.</td>
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<tr>
<td>BSID-II, Bayley’s, Developmental and Child behaviour checklists.</td>
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</tr>
<tr>
<td>No difference in the cognitive and motor outcomes in the intervention and control group at 2 years CA.</td>
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</tbody>
</table>
A second study was conducted between 3 and 5 years. Intervention (n=72) and control (n=74) groups were compared using the Wechsler Preschool and Primary Scale of Intelligence—Revised at 3 and 5 years and McCarthy Scales of Children’s Abilities and Grooved Pegboard. Parent education group and parent-adviser group were compared using Fisher’s exact test. All 3209 PBs born at 32 weeks or less between 1990 and 1993. Randomised into portage (n=111), parent adviser (n=99) and control received the standard follow up (n=99).

The effectiveness of a home based developmental education programme in very preterm children. Blinded stratified randomisation with exclusion criteria—English not being first language and not resident in Bristol. Stratified by GA (<28 weeks, >28 weeks), hospital of care and families with multiple births. Strata: English not being first language and not resident in Bristol. Interviews with parents using GMDS. Interviews with parents using parent-adviser group at 6 months and 24 months in Portage developed parent-child relationship. Parent group received Portage is a home visit educational programme with multiple bricks. Research nurse trained in Portage delivered Portage to the Portage group, non-directional counselling for the parent-adviser group at home. Visit was weekly for first 2 months then bi-weekly with Portage. No developmental benefit from long-term family support. However, small improvement in developmental scores at 2 years CA was observed in children in the Portage group compared to the control group. Portage was particularly beneficial in children with birth weight <1250g and those with identified lesions on cerebral ultrasound scans. The intervention group produced a similar effect on child development as the parent-adviser group. However, there was no difference between the groups for motor scores with Portage. Wechsler Preschool and Primary Scale of Intelligence scores of Cerebral Ultrasound revealed no cerebral lesions. The Avon Premature Infant Program (APIP) (1998).
<table>
<thead>
<tr>
<th>Study</th>
<th>Quantitative Study</th>
<th>Cameron et al. (2005)</th>
<th>A single centre RCT. 72 very preterm with VLBW were randomly assigned to intervention (n=34) and control group (n=38). To investigate the effects of a physical therapy intervention programme against standard follow up on motor outcomes in preterm infants with VLBW.</th>
<th>No difference between intervention and control group in motor development or social-emotional, cognitive, behavioural relation to motor and social-emotional development of preterm infants.</th>
<th>Armstrong, D., et al. (2018)</th>
<th>A single centre RCT. 20 very preterm with VLBW were randomly assigned to intervention (n=21) and control group (n=18). To evaluate the effects of a modified developmental intervention programme on motor development in preterm infants.</th>
<th>No difference between intervention and control group in motor development.</th>
</tr>
</thead>
</table>
### Study 1: Quantitative Study.

**A single centre RCT.**

**Dusing et al.** (2015).

- 10 PBs. Intervention (n=5) and Control (n=5).
- To determine the feasibility of completing a clinical trial of supporting play exploration and early development intervention (SPEEDI) for PBs.

#### Inclusion criteria:
- Gestational age <34 weeks.
- Medically stable.
- Lived within 30 minutes of the hospital in the USA.
- For multiple births, one infant was randomly selected to participate.

#### Exclusion criteria:
- Genetic syndrome or musculoskeletal deformity.

#### BSITD-III to assess cognition at 6 months, and to test for motor performance.

#### Results:
- Although not statistically significant, the trends in all outcome measures suggest that SPEEDI has the potential to influence development beyond the end of the intervention period.
- Intervention group showed significantly higher scores in higher scores in reasoning, subscales, and hand-coordination and personal-social, eye-reaching subscales.

### Study 2: Quantitative Study.


- 38 PBs with birth weight <1250 were randomly assigned into intervention group (n=18) and control group (n=18).
- To determine the effect of an early post-discharge developmental intervention on neurodevelopmental outcomes at 36 months in VLBW infants.

#### Inclusion criteria:
- Singleton baby, and formula fed born in a North Italian hospital.

#### Exclusion criteria:
- Congenital heart conditions, genetic conditions and brain abnormality shown on MRI.

#### GMDS and related subscale at 12, 24 and 36 months.

#### Results:
- At 12 and 24 months CA, no difference was seen in both groups.
- At 36 months’ AA, children in the intervention group showed significantly higher scores in personal-social, eye-hand coordination and reasoning subscales.
### Quantitative Study

**Stratified RCT**

Koldewijn et al. (2009)

176 PBs from two level three and five city hospitals with NICU in Amsterdam were assigned randomly to intervention group (n=86) and control group (n=90).

To determine whether the Infant Behavioural Assessment and Intervention Program (IBAIP), improved developmental and neurobehavioral outcomes in VLBW infants.

Randomisation with inclusion criteria of GA <32 weeks and/or birth weight <1500g. Exclusion criteria include mothers with drug use or severe physical and mental illness, infants with severe congenital abnormalities and non-Dutch speech.

**BSID-II.**

Neurobehavioral functioning was evaluated using the Infant Behavioural Assessment (IBA) at baseline and at 6 months CA. Sustained motor development at 2 years.

The IBAIP improved the mental, motor, and behavioural outcomes of VLBW infants at 6 months CA (p=0.000).

Johnson et al. (2011)

233 PBs from 6 neonatal units in the UK. Randomised to intervention group (n=112) and control group (n=121).

To determine the outcomes in VLBW neurodevelopmental and behavioural programs. Improved intervention group (IBAIP) improved outcomes compared to the usual care. Exclusion criteria were illness not compatible with life and resident outside catchment area.

**BSID-II.**

Weekly Parent Baby Interaction Programme (PBIP) sessions delivered to mothers during NICU stay and up to a maximum of 6 sessions post discharge. Control group had no contact.

PBIP did not have any effect on infants' cognitive or motor development scores at 2 years CA.

**PEDI-NL.**

Developmental Inventory of Physical, Social, and Cognitive Development was conducted by 6 experienced physical therapists at 6 months CA. Randomisation was conducted.

**IBAIP**

Randomisation was conducted by experienced physical therapists at 6 months CA. Randomisation was conducted.
<table>
<thead>
<tr>
<th>Intervention</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ELBW group</td>
<td>Received standard care.</td>
</tr>
<tr>
<td>Intervention group</td>
<td>Received standard care.</td>
</tr>
</tbody>
</table>

**RCT** (2009) Teti et al.

**Quantitative Analysis**

- **Participants:**
  - ELBW infants bi-monthly assessed at 4, 6, 9, 12 and 18 months of age.
  - ELBW infants of African American mothers who are > 18 years of age.
  - ELBW infants of African American and their extremely low birth weight mothers.

- **Intervention:**
  - 8 sessions delivered over 20-week post discharge.
  - Intervention consists of:
    - A psychoeducational video,
    - Serial administration of the Brazelton Neonatal Behavioural Assessment Scale,
    - Maternally administered infant massage by research assistant.

- **Outcomes:**
  - ELBW in the intervention group showed significantly higher cognitive scores than the control group, but no intervention effect was observed among heavier PBs.

- **Study Design:**
  - Quantitative study.

- **Randomisation:**
  - Randomisation with inclusion criteria of ELBW infants of African American mothers.
  - Exclusion criteria were positive to toxicology screen or children with chromosomal abnormalities and mothers who are > 18 years of age.

- **Evaluation:**
  - To evaluate the efficacy of an early intervention program targeting African American mothers and their extremely low birth weight infants at 3 to 4 months of age from four NICUs.

- **Instruments:**
  - BSID-II.

- **Results:**
  - ELBW infants of African American mothers who are > 18 years of age.
Appendix B: Questionnaire

Informed Consent Form for in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: Are health visitors’ able to correctly describe key preterm babies’ care needs within the community?

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 2982/003

Thank you for your interest in taking part in this research. Before you agree to take part please read the information sheet provided

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant’s Statement

I

• have read the notes written above and the Information Sheet, and understand what the study involves.
• understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
• consent to the processing of my personal information for the purposes of this research study.
• understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
• agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed: ___________________________ Date: ___________________________
**SURVEY ON THE KEY PRETERM BABIES CARE NEEDS WITHIN THE COMMUNITY**

Thank you for taking time off from your busy schedule and agreeing to participate in this short self-completed survey. I am an MSc. student with the University College London and I exploring the role of health visitors in the care of preterm infants. All data will be collected and stored in accordance with the Data Protection Act 1998 and information given is anonymous and confidential. I really appreciate your honest answers.

Please tick the most appropriate responses.

<p>| | | |</p>
<table>
<thead>
<tr>
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</thead>
</table>
| 1 | What is your gender? | ☐ Female  
☐ Male |
| 2 | How old are you? | ☐ 20 to 30 years  
☐ 31 to 45 years  
☐ 46 years and over |
| 3 | When did you qualify as a health visitor? | ☐ Within the last year  
☐ Between 1 to 5 years ago  
☐ Between 6 to 10 years ago  
☐ Over 10 years ago |
| 4 | Are you a Health Visitor, a Specialist Health Visitor or a Health Visitor practice teacher? | ☐ Health Visitor  
☐ Specialist Health Visitor  
☐ Health Visitor practice teacher |
| 5 | Does your trust have guidelines for the care of preterm babies post discharge? | ☐ Yes  
☐ No  
☐ Don’t know |
| 6 | Have you received any training on caring for preterm babies post discharge? | ☐ Yes, specialist course/training  
☐ Yes, as part of my general training  
☐ No |
| 7 | Which of the following do you think are done based on corrected age? (tick all that apply) | ☐ Starting weaning  
☐ Immunization schedule  
☐ Growth monitoring  
☐ Developmental milestones |
| 8 | Please tick the statements about preterm babies that you believe are true. | ☐ Are more likely to suffer from food allergies  
☐ Can be weaned at 4 months corrected age  
☐ Can be weaned at 8 months’ actual age  
☐ Should catch up their growth by one year  
☐ Should catch up developmentally by one year  
☐ Should be introduced to meat later than term babies  
☐ Should continue skin-to-skin care post discharge  
☐ Are more likely to need formula than term babies  
☐ Should be touched with a light, feathery stroke |
| 9 | Please tick any areas that you feel you need more training or support on in relation to pre-term care: | ☐ Breastfeeding pre-terms  
☐ Weaning pre-terms  
☐ Catch up growth in pre-terms  
☐ Development of pre-terms  
☐ Other: Specify |
| 10 | Think about the following statement and tick the most appropriate answer: “I feel well able to provide care and support for preterm babies and their families post discharge” | ☐ Strongly Agree  
☐ Agree  
☐ Neither agree nor disagree  
☐ Disagree  
☐ Strongly Disagree |
| 11 | How many pre-term babies have you visited in the last two years? (If none you may end the interview here) | ☐ (Enter 00 if none) |
| 12 | Thinking of these preterm babies, how were you notified about them? (tick all that apply) | ☐ Midwife  
☐ GP |
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Were you provided with their discharge notes?</td>
<td>Yes, all, Yes, some, No</td>
</tr>
<tr>
<td>14</td>
<td>How many were breastfed at your first visit?</td>
<td>□ (Enter 00 if none)</td>
</tr>
<tr>
<td>15</td>
<td>Which of the following services/support did you provide for them? (tick all that apply)</td>
<td>Additional growth monitoring, Advice on weaning, Support for breastfeeding, Support for formula feeding, Advice about reflux, Advice about hygiene, Advice about play, Advice about skin to skin care, Advice about massage, Emotional support, Other: Specify_________</td>
</tr>
</tbody>
</table>

**Appendix C: Stata to-do file command**

```stata
clear
cd "\ad.ucl.ac.uk\home\sejjade\Documents\import excel using Final_102_COMPLETE1_Main.xls, first clear
save Final_102_COMPLETE1.dta
describe
count	tab Sex	tab Age
histogram Age_Score, normal title("Respondent Age")
tab Sex Age_Score, row
//labelling
label define Age 0 "20 to 30 years old" 1 "31 to 45 years old" 2 "46 years and over"
label values Age_Score Age	tab Age_Score	tab Age_Score, nolab	tab Job
```
//labelling
label define Specialty 0 "Health visitor" 1 "Specialist health visitor" 2 "Health visitor practice teacher"
label values Specialty_Score Specialty
tab Specialty_Score
tab Specialty_Score, nolab
tab Experience

//labelling
label define Exp 0 "Less than 5 years" 1 "6 to 10 years" 2 "over 10 years"
label values Exp_Score Exp
tab Exp_Score
tab Exp_Score, nolab
tab Specialty_Score Exp_Score, row
tab Training

// labelling
label define Training 0 "no" 1 "Yes, as part of my general training Yes, specialist course/ training"
label values Training_Score Training
tab Training_Score
tab Training_Score, nolab
tab Guidelines

// labelling
label define Guidelines 0 "no" 1 "Yes" 2 "Don't know"
label values Guidelines_Score Guidelines
tab Guidelines_Score
tab Guidelines_Score, nolab
tab Training_Support
tab BF, missing
tab WP, missing
tab GR, missing
tab DV, missing
tab Oxygen, missing

tab Refresher, missing

tab Bonding, missing

tab DP_APP_Treatment, missing

tab Emotional, missing

tab PT_Experience, missing

tab Notification

// labelling

label define Notification 0 "Midwife" 1 "GP" 2 "NICU" 3 "Parent/ family" 4 "HUB/ Child information hub/ new birth notification" 5 "Not notified at all"

label values Notif_Score Notification

tab Notif_Score

tab Notif_Score, nolab

tab Discharge_Notes

// labelling

label define Discharge_Notes 0 "No" 1 "Yes some" 2 "Yes all"

label values Disc_Scores Discharge_Notes

tab Disc_Scores

tab Disc_Scores, nolab

tab Support_Providance

tab AGM, missing

tab AW, missing

tab SB, missing

tab SF, missing

tab AR, missing

tab AH, missing

tab AP, missing

tab AS, missing

tab AM, missing

tab ES, missing
// Confidence
tab Confidence

// Labelling
label define Confidence 0 "Disagree/ Neither Agree Nor disagree" 1 "Agree/ Strongly Agree"
label values Confidence Score Confidence

// Preterm Babies

// Breastfeeding

//Use logistic for categorical data
xi: logistic Confidence_Score i.Age_Score
xi: logistic Confidence_Score i.Specialty_Score
xi: logistic Confidence_Score i.Exp_Score
xi: logistic Confidence_Score i.Pre_Bab
xi: logistic Confidence_Score i.Training_Score
logistic //Use logistic regression, because the data is categorical
logistic Confidence_Score i.Age_Score i.Specialty_Score i.Exp_Score

// Knowledge 1
tab Knowledge1
tab SW, missing
tab IS, missing
tab GM, missing
tab DM, missing
tab Knowledge1_Score
//labelling
label define Know 0 "No Knowledge" 1 "High Knowledge"
label values Knowledge1_Score Know
tab Knowledge1_Score
tab Knowledge1_Score, nolab
//Classical analysis (cross-tabulations, chi-square)
tag2 Knowledge1_Score Age_Score Exp_Score, first chi
tag Knowledge1_Score Specialty_Score, exact
tag2 Knowledge1_Score Pre_Bab Training_Score, first chi
//Use logistic for categorical data
xi: logistic Knowledge1_Score i.Age_Score
xi: logistic Knowledge1_Score i.Specialty_Score
xi: logistic Knowledge1_Score i.Exp_Score
xi: logistic Knowledge1_Score i.Pre_Bab

xi: logistic Knowledge1_Score i.Training_Score

logistic Regression //Use logistic regression for categorical data

logistic Knowledge1_Score i.Age_Score i.Specialty_Score i.Exp_Score

//Knowledge2

tab A1, missing

tab A2, missing

tab A3, missing

tab A4, missing

tab A5, missing

tab A6, missing

tab A7, missing

tab A8, missing

tab A9, missing

tab Knowledge2_Score

//labelling

label values Knowledge2_Score Know

tab Knowledge2_Score

tab Knowledge2_Score, nolab

//Classical analysis (cross-tabulations, chi-square)

tab Knowledge2_Score Age_Score, chi

tab Knowledge2_Score Specialty_Score, exact

tab Knowledge2_Score Exp_Score, exact

tab2 Knowledge2_Score Pre_Bab Training_Score, first chi

//Use logistic for categorical data

xi: logistic Knowledge2_Score i.Age_Score
xi: logistic Knowledge2_Score i.Specialty_Score
xi: logistic Knowledge2_Score i.Exp_Score
xi: logistic Knowledge2_Score i.Pre_Bab
xi: logistic Knowledge2_Score i.Training_Score

logistic Regression //Use logistic regression, because the data is categorical
logistic Knowledge2_Score i.Age_Score