A systematic review of effective interventions for communicating with, supporting and providing information to parents of pre-term infants

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Keywords:	NEONATOLOGY, Community child health < PAEDIATRICS, Social Health

Abstract:	Objective: To identify effective communication with, supporting and providing information for parents of pre-term infants Design: Systematic review Data sources: Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS. Hand-searching of journals. Studies reviewed: 74 papers identified, 20 papers were randomised controlled trials, 16 were cohort or quasi-experimental studies, 16 were qualitative studies and 22 were other descriptive studies. Results: Interventions for supporting, communicating with, and providing information to parents that have had a premature infant are reported. Parents report feeling supported through individualised developmental and behavioural care programmes, through being taught behavioural assessment scales, and through breast feeding, kangaroo care and baby massage programmes. Parents also felt supported through organised support groups and through provision of an environment where parents can meet and support each other. Parental stress may be reduced through individual developmental care programmes, through psychotherapy, through interventions that teach emotional coping skills and active problem solving, and journal writing. Evidence reports the importance of preparing parents for the

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neonatal unit through the neonatal tour, and the importance of good communication throughout the infant admission phase and after discharge home. Providing individual web-based information about the infant, recording doctor-patient consultations, and provision of an information binder may also improve communication with parents.

The importance of thorough discharge planning throughout the infant's admission phase and the importance of home support programmes are also reported.

Conclusion: The paper reports evidence of interventions that help support, communicate with and inform parents who have had a premature infant throughout the admission phase of the infant, discharge, and returning home. A summary of interventions from the available evidence is reported.

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A systematic review of effective interventions for communicating with, supporting and providing information to parents of pre-term infants

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Abstract

Background and Objective: The birth of a pre-term infant can be an overwhelming experience of guilt, fear, and helplessness for parents. Provision of interventions to support and engage parents in the care of their infant may improve outcomes for both the parents and the infant. The objective of this systematic review is to identify effective interventions for communication with, supporting and providing information for parents of pre-term infants.

Design: Systematic searches were conducted in the electronic databases Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS. Hand-searching of reference lists and journals was conducted. Studies were included if they provided parent-reported outcomes of interventions relating to information, communication, and/or support for parents of pre-term infants prior to the birth, during care at the NICU, and after going home with their pre-term infant.

Studies reviewed: 74 papers identified, 20 papers were randomised controlled trials, 16 were cohort or quasi-experimental studies, 16 were qualitative studies and 22 were other descriptive studies.

Results: Interventions for supporting, communicating with, and providing information to parents that have had a premature infant are reported. Parents report feeling supported through individualised developmental and behavioural care programmes, through being taught behavioural assessment scales, and through breast feeding, kangaroo care and baby massage programmes. Parents also felt supported through organised support groups and through provision of an environment where parents can meet and support each other. Parental stress may be reduced through individual developmental care

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programmes, through psychotherapy, through interventions that teach emotional coping skills and active problem solving, and journal writing.

Evidence reports the importance of preparing parents for the neonatal unit through the neonatal tour, and the importance of good communication throughout the infant admission phase and after discharge home. Providing individual web-based information about the infant, recording doctor-patient consultations, and provision of an information binder may also improve communication with parents.

The importance of thorough discharge planning throughout the infant's admission phase and the importance of home support programmes are also reported.

Conclusion: The paper reports evidence of interventions that help support, communicate with and inform parents who have had a premature infant throughout the admission phase of the infant, discharge, and returning home. A summary of interventions from the available evidence is reported.

Article focus:

A systematic review to identify and synthesize evidence of effective interventions for communicating with, supporting and providing information for parents of pre-term infants.

Key messages:

- The review highlights the importance of encouraging and involving parents in the care of their pre-term infant at the neonatal unit to enhance their ability to cope with and

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improve their confidence in caring for the infant, which may also lead to improved infant outcomes and reduced length of stay at the neonatal unit.

- Interventions for supporting parents included: 1) involving parents in individualised developmental and behavioural care programmes (e.g. COPE, NIDCAP, MITP) and behavioural assessment programmes; 2) breastfeeding, kangaroo care and infant massage programmes; 3) support forums for parents; 4) interventions to alleviate parental stress; 5) preparation of parents for various stages, for example seeing their infant for the first time, preparing to go home; 6) home support programmes.

- Involving parents in the exchange of information with and between health professionals is important, with various modes of providing this information reported, for example ward rounds with doctors, discussion around infant notes, websites, and hard copy information.

Strengths and limitations of study:

Strengths

This is the first review to synthesize the evidence of interventions to support parents of pre-term infants through improved provision of information, improved communications between parents and health professionals and alleviation of stress at all stages of a parents journey through the neonatal unit. It highlights relatively inexpensive interventions that can be integrated into their pathway through the neonatal unit and going home, enhancing parental coping, and potentially improving infant outcomes and reducing the infants length of stay at the neonatal unit.

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Limitations

The quality of the evidence that this review reports is variable, and includes all types of study designs.

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Introduction

While medical advances mean that very premature neonates have an increasingly better chance of survival, the impact of this experience on the child and their parents cannot be underestimated. The birth of a pre-term infant can be an intensely stressful, confusing and difficult time for parents and families[(1)]. Approximately 80,000 pre-term infants are born in the UK each year, and 22,000 of these will be cared for in the neonatal intensive care (NICU) [(2,3)]. Evidence shows that family-centred care on the neonatal unit can reduce the length of the child's stay on the neonatal unit[(4,5,6)], reduce the rate of re-admittance to hospital[(7)], and improve the outcomes of the baby with regards to morbidity[(8)].

The Parents of Premature Babies (POPPY) study aims to develop a better understanding of the experiences of a range of parents with pre-term babies, particularly with regards to the communication, information and support they received on the NICU, ensuring that the perspectives of parents are at the heart of the study. This paper reports the results of the first phase of the POPPY study, which takes the form of a systematic review to identify effective interventions for communicating with, supporting and providing information for parents of pre-term babies.

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Methods

Systematic searches were undertaken for the period of January 1980 to October 2006 in the following databases: Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS. A combination of text terms and MeSH terms were used to maximise the volume of literature retrieved. Grey literature was sought from specialists in the field, and the following journals were hand-searched from 1990 onwards for all relevant English language articles: Neonatal Network Journal, Journal of Neonatal Nursing and Journal of Obstetric, Gynecologic, and Neonatal Nursing. Update searches were undertaken in October 2009.

Studies were included if they provided parent-reported outcomes of interventions relating to information, communication, and/or support for parents of pre-term infants prior to the birth, during care at the NICU, and after going home with their pre-term infant.

Furthermore, it was felt that the systematic review should be inclusive of all study designs as it is often not feasible or appropriate to conduct randomised control trials (RCTs) or other intervention studies on the outcomes for parents that were measured. It was deemed therefore that, despite the potential bias inherent in descriptive studies, the results of these studies nonetheless gave an important insight into parent-related interventions and should be included in this review.

The data extraction form and quality assessment for inclusion criteria were based on the guideline from the NHS Centre for Reviews and Dissemination (NHS CRD) [9] Initially, two reviewers extracted data (JB, SS) independently for 20% of papers and disagreements

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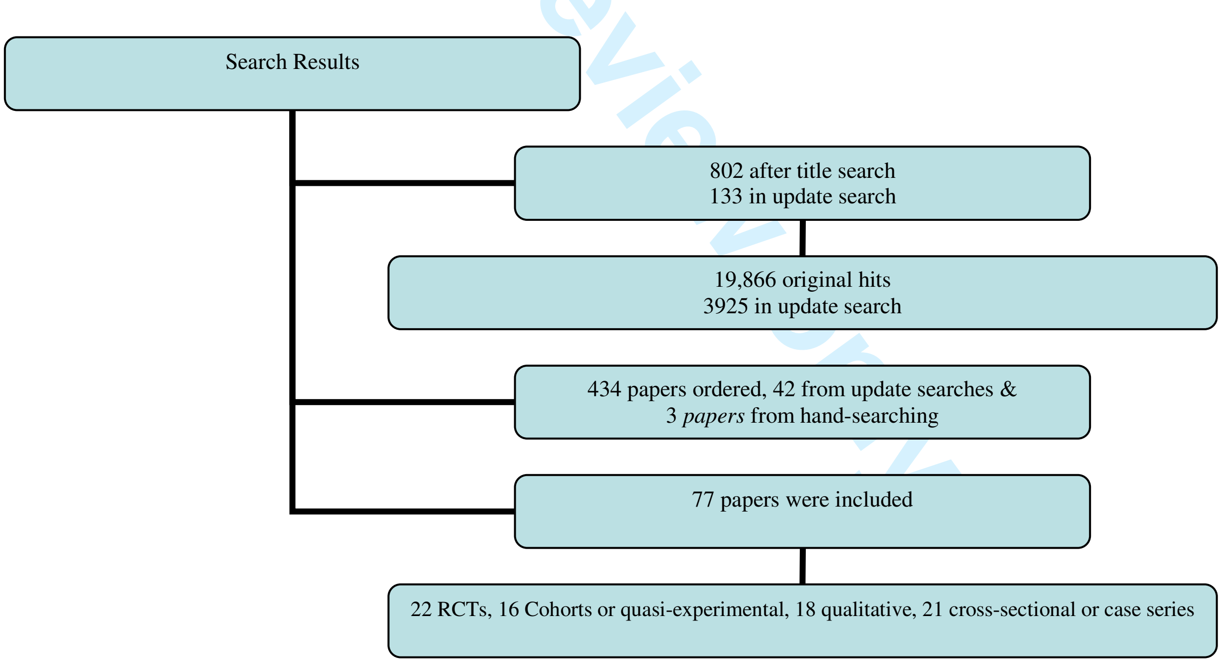
were resolved by discussion with a third reviewer. There was a high level of agreement between reviewers, so the remaining data was extracted by one reviewer and checked by a second. Any disagreements were resolved by discussion with a third reviewer. The quantitative studies covered a wide range of interventions and different methods of assessment so it was not possible to carry out a meta-analysis. A non-quantitative synthesis was conducted based on the extracted data. In the summary figure (Figure 3), the included evidence was assessed using the Scottish Intercollegiate Guidelines Assessment (SIGN) [10].

Search Results

Figure 1: The results from the literature search.



Seventy seven papers were included (four were deemed relevant in two of the sections). Papers were excluded for a number of reasons including the fact that no parent

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outcome was identified, the study was irrelevant to neonatal services offered in developed countries such as the UK (3), or the study was deemed to be inadequate after quality assessment using NHS CRD guidance. (11)

Tables 1a and 1b report the data from the randomised control trials, quasi experimental studies and cohort studies. Other evidence is reported in summary format within the text .

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Table 1: Data extraction tables

1a. Randomised controlled trials:

Author (Year Country	Study desig	Intervention	Outcome measure	No of cases	No. of contr	Statistically significant	Quality (SIGN)
Als 2003 USA	RCT	NIDCAP (Neonatal individualised Developme Care and Assessment Programme	PSI (Parental Stress In	38	38	Hospital 1: I= 35.7 (sd 21.3) C=44.9 (sd34.2) Hospital 2: I=55.8 (sd28.8) C=65.2 (sd27.5) Hospital 3: I=49.0 (sd28.6) C=55.9 (sd22.5) Group score ® = .41, p<.001 Summary: MANOVA: F=2.41, df=5.66, p<0.05	1++
Barrera 1986 Canada	RCT	Teaching developmental care	HOME Parent-infant interactic	40	40	At 4 mths and 16 mths, mothers in the Parent-Infant interventi group and full term control group were significantly better mat responsiveness and mother-infant interaction compared to the term baby control group. Manova: Maternal rseponsiveness I-7.32, FTC – 7.44, C- 6.41, f=6.78, p<0.001 Maternal involvement: I=7.23, FTC-7.16, C-6.26, f=2.70, p<0.05	1-
Browne 2005 USA	RCT	Family based intervention (Gp1: demonstratio pre-term baby behavioural cues; Gp2:viewed educational video and books about pre-term b	Nursing Child Assessn Scale (NCAFS) and Knowledge of Preterm Behavior Scale (KPIB)	Gp1: 28 Gp2:31	25	Intervention group reported significantly greater sensitive inte with pre-term babies, and significantly greater knowledge of p babies than controls at 1 month after discharge (NCAFS 45.65, 6.20vs. 47.43, 7.36 vs. 48.88, 7.41, p<0.05; m KPIB 23.32, SD 5.88 in group 1 vs. 25.90, 5.30, in group 2 vs. 5.01 in group 3, p<0.001)	1+
Cobiella 1990 USA	RCT	Two stress reduction programmes: a) Video-tape training in active problem – focussed coping strategies b) Video-tape in emotion-focussed strategies t manage anxiety	State-Trait Anxiety Inv (STAI), Depression Ac Checklist (DACL)	Gp. A – 10 Gp. B - 10	10	On post-treatment follow-up both the problem-focused and em focused treatment groups were significantly less anxious than t controls and lower levels of depression were observed for the e focused group STAI: PF-t(11)=2 71 p<0.01 EF-t2 56 p<0.02 DACL: PF – NS	1-

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						EF-t(12)=2 36, p<0.03	
Ferber 2004 Israel	RCT	Baby massage: I= to receive 15 massages 3 times per day for Gp1: mothers conduct massage Gp2: Researchers conduct massage Gp 3 controls	Coding Interactive Bel Assessment for newbo	Gp 1: 18 Gp2: 18	19	At 3 months, mothers of massaged infants were less intrusive, interactions were more reciprocal. Gp1: Dyadic reciprocity (DR) – 2.42+0.87 Maternal Intrusiveness(MI)-1.97+0.91 Gp2: DR – 2.46+0.99 MI – 1.68+0.63 Gp3: DR – 1.66+0.68 MI – 2.54+1.01 DR: F=4.69,p<0.01 MI: F=4.05,p<0.02 No significant difference in maternal sensitivity was reported.	1+
Glazebrook et 2007 UK	RCT	Nursing Child Assessment Teaching Scale (N at neonatal unit, with optional follow-up	Parental Stress Index (Home Observation for Measurement of the Environment (HOME)	99	111	No significant differences reported at discharge or at 3 months discharge.	1+
Hall 2002 Canada	RCT	Weighing infant before and after feeds to asse maternal confidence in breast feeding	Parental sense of comp scale Maternal confidence questionnaire Influence of specific re scale	30	30	No significant differences in maternal confidence or competen between weighed or not-weighed infants	1-
Huckaby 1999 USA	RCT	Photograph of baby given to mother to take w while baby on neonatal unit	Bonding Observation Checklist (BOCL) Physical Examination Observation Checklist (PEOCL)	20	20	Mothers with picture had significantly better scores on bondin measure than those without picture (p<0.001 for BOCL and p< PEOCL)	1+
Kaaresen 200	RCT	Mother-Infant Transaction Program The intervention consisted of 8 sessions shortl discharge and 4 home visits by specially traine nurses focusing on the infant's unique charact temperament, and developmental potential and interaction between the infant and the parents.	PSI	71	69 preterm 75 term	Early-intervention program reduces parenting stress in both m and fathers during the first year after a preterm birth to a level comparable to their term peers Mothers 6 mths - total stress: 16.9 (5.2 to 28.5) .005 Mothers 12mths – total stress: 13.7 (1.6 to 25.9) .03 Fathers 12 moths – total stress: 14.8 (2.1 to 27.6) .02	1+
Koh 2007 Australia	RCT	Recording doctors consultation	Information recall 10 days, 4 months, 1 y 91% of mothers in the group listened to the ta (once by day 10, twice months, and three time	93	93	At 10 days and four months, mothers in the tape group recalled significantly more information about diagnosis, treatment and outcomes than control group. 10 days:1.35 (1.08 to 1.69) p<0.007, treatment 1.35 (1.00 to 1.8 outcome 1.24 (1.05 to 1.47), p<0.009 than mothers in the c group.	1+

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			months; range 1-10).			4 months: diagnosis 1.27 (0.99 to 1.63) p<0.05, treatment 1.35 (1.00 p<0.045, and outcome 1.75 (1.27 to 2.4), p<0.004 No statistically significant differences were found between the in satisfaction with conversations (10 days), postnatal depressi anxiety scores (10 days, four and 12 months), and stress about parenting (12 months).	
Lai 2006 Taiwan	RCT	Effects of kangaroo care combined with music	State-Trait Anxiety Inv (STAI)	15	15	Music during KC also resulted in significantly lower maternal in the treatment group on day 3 of the interention (t (19.6) =−2 p<.05). Maternal state anxiety improved daily, indicating a cu dose effect (F(1.49,40.39)=5.81, p<.01). Anxiety levels in the remained unchanged	1+
Melnyk 2006 USA	RCT	Creating Opportunities for Parent Empowerm (COPE) - Information and behavioural activit about appearance and behavioural characterist preterm infants and how best to parent them.	Infant length of stay Parental Stressor Scale State-Trait Anxiety Sc (STAI) Index of Parental Beli	147 Mothers 81 Fathers	113 Mothers 73 Fathers	Mothers in the intervention group reported significantly less st less depression and anxiety at 2 months after birth. Anxiety: 28.72 (27.31-30.12) vs 30.83 (29.23-32.42)p<0.05 Depression: 5.56 (4.66-6.45) vs 7.21 (6.20-8.23)p<0.02 PSS: 3.29 (3.09-3.49) vs 3.58 (3.35-3.80), p<0.05 Parental Knowledge: 32(31.63-33.01)vs 30.50 (29.73-31.27)p There were no differences found for Fathers anxiety or depress symptoms. Infant length of stay at the NICU and at the hospital was signif lower in the intervention group (3.8 days less in NICU, 3.9 day hospital p<0.05	1++
Meyer 1994 U	RCT	Family based intervention (Psychological inte for family, teaching care and behavioural cues baby, home discharge plan)	Parental Stressor scale Maternal self esteem Inventory, Beck Depre Scale (BDS), Family Environment Scale	34	34	Intervention group reported significantly less stress (PSS) and significantly less depression (BDS) at discharge. BDI: Int: 11% vs. 44%, p<0.05; 39% vs 31% NS. PSS: Int:2.4 ± 1.0; 2.0 ±0.8 vs Con 2.4 ± 0.9; 2.6 ± 0.8 p<0.0	1+
Nurcombe 1984 USA	RCT	Behavioural Assessment Scale: Mother-Infan Transaction Programme (MITP)	Hereford Parent Attitu Survey Seashore Self Confide Rating Paired Compar Questionn-aire	37	36	Intervention group scored better on maternal adaptation (role satisfaction, attitudes to child-rearing, self confidence) than lo weight controls (F(3, 87), p<0.030. Univariate analysis: Maternal satisfaction F (2,89), 4.55, p<0.013 Maternal attitude (2,89), 4.05, p<0.021 Maternal self confidence F (1,89), 7.44, p<0.008 Full term controls scored better than combined low birth weig (F [3,87], 3.27, p=0.025).	1+

Parker-Loewe 1987 Canada	RCT	8 X 40 minute interaction coaching to encoura sensitive responding by mothers	Satisfaction with Parer Scale Knowledge of Infant Development Scale Life experiences surve Interaction rating scale	35	35	No significant difference between treatment and control group interaction or knowledge of infant development or satisfaction parenting	1-
Spiker 1993 USA	RCT	Home Support (Infant Health and Development Program (IHDP) – Home visits from discharge up to 36	Quality of assistance ir parenting pre-term bab Supportive presence fo parents of pre-term inf	271	412	Intervention group reported significantly better quality of assis ratings than control group (I: 3.6 [1.5], vs 3.3[1.5], $p<0.05$), bu significant difference on supportive presence was reported. M outcomes in this study were baby outcomes.	1-
Tessier 1998 Columbia	RCT	Effects of Kangaroo care	Mothers perception of premature babies quest	246	246	Kangaroo care significantly increased mother's sense of comp in mothering their baby (F(1481) 10.36, P .001), and was significantly increased maternal sensitivity to their baby at the neonatal unit. (F(1481) 3.71, P .05). This improved perception of their baby effect is related to a su "bonding effect" that may be understood readily by the empowering nature of the KMC intervention. The study also reported a negative effect o feelings of received support from health professionals of moth- ers practicing KMC (F 5.03, P .03). Kangaroo care significantly reduced length of stay especially i babies. Two-way analysis of variance stratifying by birth weight show the savings in hospital stays were clearly related to weight at b interaction effect (F(3480) 4.06, P .01) shows that the maxim saving in the KMC group was observed in infants weighing 15 (4.5 to 6.7 days), whereas in infants weighing 1500g, the lengt hospital stay was virtually identical in both groups	1+
Van der Pal 2007 Netherlands	RCT	NIDCAP	PSI Parents of Mother and Scale Nurse Parent Support	94	84	No significant differences were reported in Parental Stress Ind Confidence of parents, or perceived nursing support at 1 to 2 w after birth	1+

1b. Quasi- experimental and cohort Studies.

Author (Year Country	Study desig	Intervention	Outcome measure	No of cases	No. of contr	Statistically significant results	Quality (SIGN)
Byers 2003	Cohort	Co-bedding multiples in same incubator	NIDCAP infant behavi State-Trait Anxiety Inv	16	21	No significant results reported	2-

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USA			Maternal Attachment Inventory Parental satisfaction to				
Byers 2006 USA	Cohort	Family-centred care/developmental supportive ca	Questionnaire develop study to measure parer perceptions and satisfa Study mainly reports b outcomes	57	57	No differences in parent perception or satisfaction with the neonatal unit	2-
Feldman 2002 Israel	Cohort	Effects of Kangaroo care	Mother-Infant interacti Maternal depression Mothers perceptions HOME	73	73	At 37 weeks gestational age: After kangaroo care, interactions more positive, mot showed more positive affect, touch, adaptation to infant cues, infants more alertne less gaze aversion, mothers less depressed & viewed infants as less abnormal. Les maternal depression [KC mean 6.68 (5.55) vs control 9.05 (4.27), F=5.68, p<0.05 At 3 months corrected age: mothers and fathers of kangaroo care infants more sen and provided better home environment. KC Mothers provided a better home environment Manova at 3 months – HOME: (df=7,123), 2.99, p<0.01. KC fathers provided a better home environment – HOM Wilks F (df=7,110), 2.45, p<0.05. At 6 months corrected age: kangaroo care mothers more sensitive (maternal sensit KC mean 4.20 (0.64) vs control mean 3.86 (0.76, univariate 5.36, p<0.05) & infar scored higher on Bayley Mental Development Index (96.39 vs. 91.81, p<0.01) an Psychomotor Development Index (85.47 vs. 80.53, p<0.05)	2+
Finello 1998 USA	Cohort	Home Support Gp1: Home healthcare and home visitng Gp2: Home healthcare only Gp3: Home visiting only	1 week after discharge HOME CES-D FACES II 6 mths after: HOME 12 months: CES-D, FACESII HOME	? 81 in total	?	Interventions improved the home environment (at 1 month, mean HOME 27.2, SI group 1 vs. 24.2, 2.7 for group 2 vs. 30.0, 6.2 for group 3 vs. 22.7, 3.3 for group 4 p<0.001; at 6 months, 33.7, 5.9 vs. 30.2, 4.3 vs. 34.4, 4.3 vs. 28.9, 5.0, p=0.003; a months, 35.2, 5.2 vs. 31.2, 3.8 vs. 35.6, 5.3 vs. 30.5, 5.0, p=0.005). No difference groups on FACES II at 1 or 12 months, or on maternal parenting satisfaction. The was more strongly associated with reports of support from husband (p<0.001), fri support (p<0.001) and family support (p<0.001). Mean depression score at 1 mon (SD 11.59, range 0-48 on a total scale range of 0-60; 16 considered cut-off for cli depression (no differences between groups). Mean CES-D at 12 months 19.76, SI range 2-42, still indicating clinically significant levels of depression. No other significant results were reported.	2+
Jotzo 2005 Germany	Cohort	Psychological intervention to reduce stress at neo unit (One off psychological intervention to help p cope with stress)	Questionnaire: Impact of events scale Trauma experiences m	25	25	Mothers in intervention group had significantly lower traumatic impact from pret (lower overall symptoms: traumatic impact I 25.2 (SD 13.9), C 37.5 (SD 19.2), r difference 12.28 (2.74-21.82, p=0.013; lower avoidance I 7.7 (SD 5.3), C 12.4 (S mean difference 4.65 (0.67-8.69), p=0.023 and hyperarousal, I 5.9 (SD 4.7), C9. 5.7), mean difference – 3.56 (0.61 – 6.51), p=0.019; lower intrusion symptoms bu significant). Control group: 76% of mothers showed clinically significant psychol trauma at discharge vs. 36% (p<0.01) in intervention group.	2+
Kurz 2002 Austria	Cohort	Home support (Phone call and counselling of pare returning home) for parents of babies with monito	Questionnaire about m use, stress reported by	90	70	Home monitoring considered reassuring for 60% of families. After intensive coun introduced, parents liked the instruction better (74% vs. 44% very satisfied; 24%	2+

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			use, and satisfaction			satisfied; 2% vs. 5% not satisfied, p<0.005)), were less stressed by the monitor (4 63% stressed by false alarms, p<0.05) and reacted less aggressively to monitor ala (8% vs. 24% reacted by vigorously shaking or lifting baby, p<0.05); used monitor during sleeping periods; used monitor for less time (6.1 months vs. 7.6 months, p Counselling did not reduce anxiety.	
Leonard 1989 USA	Cohort	Educational support programme for infants on ho monitors (Infant Apnea Evaluation Programmes (Gp1 – with home monitoring Gp2- no home monitoring Gp3 – healthy term babies	Symptom checklist-90 schedule of recent eve satisfaction - all in int wks after going home	Gp1-40	Gp 2- 30 Gp3 - 32	Psychological symptoms highest in parents of non-monitored premature infants (0.2845 [0 – 0.82] vs , NM – 0.4507 [0-1.3], p=0.037); particularly fathers of non-monitored infants scoring high on depression (0.6846)). Support highest in monitored infants (p=0.005) NS on family satisfaction .	2+
Lindsay 1993 USA	Cohort	Parent to Parent Peer support for parents with crit pre-term babies.	Parent report	?	?	Numerical data not reported in paper Reported benefit to parents: emotional support + Information support	2-
Ortenstrand 2001 Sweden	Cohort	Early discharge with domiciliary nursing care Domiciliary nurse made an individual care and di plan together with the parents. During these plan sessions, parent's knowledge of how to care for th term infant were checked and supplemented. The was available for home visit/ telephone consultati Monday to Friday, and at weekends parents could the neonatal ward	STAI	40	35	No differences in mothers' Trait anxiety at 1st or 2nd assessment. State (situational anxiety lower for EDG mothers at 1st assessment (EDG 30.9 [SD 6.2] vs. CG 36.6 p<0.01. Fathers showed a significant difference in trait anxiety at both 1st and 2nd study tin period (30.1 (5.8) vs 33.5 (7.7), p<0.05, but only a significant difference in state a at the 1st assessment (29.5 [5.4] vs32.8 [9.1], p<0.08. At 1 yr, no difference in recollection of anxiety in caring for the infant or in exper of mental imbalance related to the birth of the infant	2+
Penticuff 2005 USA	Cohort	Discussion around Infant progress chart	Comprehension of infa medical condition and satisfaction with collab with health professiona baby at neonatal unit	77	77	Intervention group had fewer unrealistic concerns (ANOVA): (4.32 (0.86) vs 8.56 p<0.018; less uncertainty about the infant medical condition 1.92 (0.30) vs 3.52 (0.003; had less decision conflict 45.88 (2.33) vs 59.10 (2.32), p<0.001; more satis with medical decisions process 120.20 (4.07), 104.95 (4.33), p<0.012; more satisf with decision input 33.44 (1.30) vs 30.05 (1.21), p<0.058. No significant difference was reported in satisfaction of care for the infant by HC and in satisfaction with decision made.	2++
Piecuch 1983 USA	Cohort	videophone	No. of calls made to n unit while baby at uni	17	17	Mean number of telephone calls to NICU used as proxy for interest in newborns. with access to videophone made more calls: (1.0 vs. 0.2, p< 0.05) when mothers hospitalised; (0.9 vs. 0.3, p<0.05) when mother discharged. Mothers appreciated videophone; relieved at being able to see infants; infant's condition not as bad as imagined; many talked to infant even though only viewing an image; wanted to s ups of hands and feet as well as face.	2 -
Preyde 2003 Canada	Cohort	Parent to Parent Peer Support	Parental Stressor scale Sate-Trait Anxiety Sca (Spielberger)	32	28	Intervention group better scores on all measures at 4 or 16 weeks (groups were eq at baseline), e.g. mean PSS score 1.54 (1.3-1.7) in intervention group at 4 weeks (2.7-3.1) in controls, p<0.001	2++

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						At 4 weeks mean PSS score was significantly less in the intervention group – 1.54 1.7) vs 2.93 (2.7-3.1), p<0.001. At 16 weeks mean anxiety score, mean depression score, and perceived support w significantly less in the intervention group: anxiety - 31.4 (27.2-35.4) vs 38.6 (34. p<0.05; depression - 2.20 (0.89-3.60) vs 4.88 (3.51-6.17), p<0.01; perceived supp 6.49 (6.02-6.82) vs 5.48 (5.09-5.94), p<0.01. There were no different in trait anxiety between the groups at any time period.	
Rauh 1990 USA	Cohort	Vermont Mother-Infant Transaction Programme (parents to appreciate infants unique characteristics behavioural cues, teach parents to respond to infa enhance mothers enjoyment of baby).	Maternal Role Satisfac questionnaire Self-Confidence rating Parent Attitude scale	40	41	At 6 months: significantly better intervention effects for maternal role satisfaction confidence and perception of infant temperament in intervention group; no differe maternal attitudes to child-rearing. Data not given in paper.	2-
Resnick 1988	Cohort	Educational developmental Intervention Programi home – teach parents to use: parent's voice tape, r passive range of motion, exercises) and twice-mo interventions at home by child development speci through 12 months adjusted age (e.g. language an skills enrichment exercises, cognitive developmen exercises, parenting activities)	Greenspan-Lieberman Observations System (to analyse infant-careg interactions at 6 and 12	21	20	Parent child positive verbal scores significantly higher in treatment than control g (2.91 vs. 2.08), p=0.02. Intervention group dyads had fewer negative verbal intera (0.07 vs. 0.17, p=0.03). The developmental intervention benefited the quality of the parent-infant interacti home, as well as benefiting the infant development.	2-
Ross 1984 USA	Cohort	Teaching developmental care at home to lower so economic parents	HOME Maternal Attitudes Sca Maternal development Expectationsand child attitudes survey Baby outcomes (not re here)	44	40	Intervention group reported significantly higher HOME scores (total score 38.4 vs p<0.001). No other significant differences reported	2+
Brown 1994 U	Quasi exper	Booklet, videotape and practical session. for paren broncho-pulmonary dysplasia discharged from ter care centre. Education on physical characteristics of infants or continuous low-flow oxygen & their care. Psycho development of infant, parental needs, oxygen equ CPR in NICU	Pre-test Post-test study Pre-test of knowledge immediately before an test immediately after programme; post-test r 6 weeks after discharg	18 primary care of 10 infants		Post-test scores (immediate mean = 17.33 [SD 3.91]; delayed 17.17 [4.41]) signif higher than pretest scores (14.38 [3.72], p<0.01)	2+

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Results

Interventions for supporting parents included: 1) individualised developmental and behavioural care programmes[4,11,12,13,14,15,16,17] (e.g. COPE, NIDCAP, MITP – see below); 2) behavioural assessment scales; 3) breastfeeding, kangaroo care and infant massage programmes; 4) support forums for parents; 5) the alleviation of parental stress; 6) preparing parents for seeing their infant for the first time; 7) communication and information sharing; 8) discharge planning; and 9) home support programmes.

1) Supporting parents through individualised developmental and behavioural care programmes

Figure 2: Individualised developmental and behavioural care programmes

1) COPE[4] (Creating Opportunities for Parent Empowerment) provides an educationa programme for parents at the neonatal unit on the appearance and behavioural characteristics of pre-term infants, how parents can participate in their infant's care, ar how parents can make more positive interactions with their infant.

2) NIDCAP[11,12,13] (Neonatal Individualised Developmental Care and Assessment Programme) is an intervention that stimulates pre-term infants and improves the interaction between mothers and infants

3) MITP (Mother-Infant Transaction Programme) [14,15,16] helps to enable the parents tc appreciate their infant's unique characteristics, temperament, and developmental pote

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sensitising parents to their infant's cues so that they can respond appropriately.

4) NCATS (Nursing Child Assessment Teaching Scale) NCATS (Nursing Child Assessment Teaching Scale) [17] : Examines the mother-child relationship in conjuncti with teaching mothers how to interact with the baby, teaching behavioural cues, how t play etc

NB: While the developmental care programmes are designed to improve the development of the baby, interventions give parents psychological support and practical guidance on how to care for their infants.

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Fourteen studies reported individualised developmental and behavioural care programmes, of which nine were RCTs (see Table 1a). The RCT evidence (1++ & 1+) suggested that the involvement of parents in an individualised developmental and behavioural care programme significantly reduced the maternal stress created by the NICU environment and the demands of their infant (Melnyk 2006, 1++; Kaaresen 2006, 1+; Browne 2005, 1+; Als 2003, 1++; Meyer 1994, 1+; Nurcombe 1984, 1+)[4,11,14,16,18,19]. This intervention also significantly improved the parental understanding of their infant and their interactions with their infant[4] (Melnyk 2006).

Recent RCT evidence suggested that the introduction of the NIDCAP intervention had not significantly changed levels of parental stress, confidence or nursing support. However, the outcomes were measured only 1-2 weeks after the baby was born (Van der Pal 2007, 1+)[12]. The introduction of the NCATS programme in the NICU made no significant difference to parental stress levels and maternal-infant interactions when assessed at discharge and at three months after discharge (Glazebrook et al. 2007, 1+)[20]. One RCT

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found that coaching parents on how to interact with their pre-term infant made no difference to knowledge of care, sensitivity to the infant or satisfaction in parenting compared with the control group(Parker-Loewen 1987, 1-)[21]. However, this may have been confounded by the amount of contact that the control mothers had with the researchers, as these mothers reported that they enjoyed having someone show an interest in them.

Evidence from a cohort reported that the Vermont Mother-Infant Transaction Programme (MITP) significantly improved maternal satisfaction, maternal self-confidence, and mothers' perception of their infant's temperament at six months[15]. One cohort study reported that individualised developmental care programmes appeared to make no difference to parents' perceptions of the neonatal unit or satisfaction with care, despite significantly lowering stress cues in the pre-term infants[22].

Evidence from qualitative studies provides an insight into the benefits of individualised developmental and behavioural care programmes at the neonatal unit, such as empowering parents to take care of their infants, teaching parents behavioural cues of their infants, problem-solving, and learning how to interact with their infants, resulting in a greater satisfaction with the care provided[13,23,24]. Furthermore, parents reported a reduction in stress after such programmes and said that they felt more confident in caring for their infants, which promoted parental self-reliance when returning home[24].

2) Supporting parents through use of Behavioural Assessment Scales

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No RCT evidence was reported on this intervention. Three cross-sectional studies provided insights into how to teach parents assess and interpret the behaviour of their pre-term through using the Brazelton Behavioual Assessment scales. The studies reported this intervention may improve mother-infant bonding, reduce maternal anxiety, and help mothers foster a more realistic perception of their pre-term infants[25,26,27].

3) Supporting parents through breast feeding, kangaroo care and infant massage

Four studies reported on parent outcomes of interventions around breast-feeding, of which one was a RCT, six studies reported on parent outcomes of interventions around kangaroo care (skin to skin contact with baby out of the incubator), of which 2 were RCTs, and two studies reported parent outcomes around baby massage, (see Table 1c). An RCT (1-) reported no significant difference in the mother's confidence and competence in carrying out breast feeding by weighing the infant before and after feeds[28].

Three cross-sectional studies and one case series study reported on breast feeding interventions. The studies reported that parents receiving breastfeeding support at the neonatal unit were more likely to continue breastfeeding up to a month after discharge than comparable groups. Breast-feeding education and support at the neonatal unit in the form of counselling, information (handouts and videos), practical help and group breast-feeding clinics improved the confidence of mothers in breast-feeding. An individualised discharge plan for breast feeding mothers with follow-up telephone calls or home visits appeared to maintain mothers' confidence in breastfeeding, and provide reassurance[29,30,31]

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Six studies reported parent outcomes of using kangaroo care with their pre-term infants, of which two were RCTs. The RCT evidence suggests that use of kangaroo care significantly reduces maternal anxiety around her infant, gives the mother a significantly greater sense of competence with their infant, and a significantly greater sensitivity towards her infant(Tessier 1998, 1+)[32]. Furthermore, RCT evidence suggests that music during kangaroo care resulted in significantly lower maternal anxiety (Lai 2006, 1+)[33].

One cohort study, which *assessed outcomes of mothers using kangaroo care at 37 weeks, at 3 months, and at 6 months,* reported significantly better levels of mother-infant interaction, more touch, better adaptation to infant cues, and better perception of their infant at all time periods. Mothers also reported significantly less post-natal depression compared to the controls at 37 weeks[34].

One cross-sectional study reported that the majority of mothers preferred the kangaroo method, mainly because their baby was closer to them. Touch was important to mothers, as it induced feelings of well-being and fulfilment in parents[35].

In the qualitative studies, parents described how kangaroo care helped them to get to know their infant, increased their confidence, and made them feel that their infant needed them[36]; parents reported that their mood was improved, that they perceived their infant differently and felt a stronger sense of identifying with their infant[37].

Two studies reported on parent outcomes of baby massage on pre-term infants, of which one was an RCT (see Table 1d). RCT evidence reported that at three months, mothers of massaged infants felt significantly less intrusive *towards caring for their baby,* interactions were more reciprocal, and treated infants were more socially involved

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compared to controls[38]. One cross-sectional study also reported improved maternal-infant interactions[39].

4) Support forums for parents

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No RCT evidence was reported for these interventions. Nine studies reported the benefits of participating in support groups set up within the NICU, either run by staff at the neonatal unit or by parents who have experienced having a pre-term infant themselves. Evidence from cohort studies reported that parent-led peer support groups at the NICU led to mothers in the intervention group having significantly less stress at four weeks and 16 weeks after support was initiated at the neonatal unit[40,41]. Mothers of critically ill pre-term infants had significantly better maternal mood states, maternal-infant relationships, and home environments in the intervention group compared to the control group[42]

Evidence from a qualitative study gave insights into how a health professional led support group assisted parents to gain perspective, feel supported, and learn practical information about how to interact with their baby[43]. Qualitative evidence also reports that parent-to-parent support groups provided parents with information, emotional support, and strength[44]. Cross-sectional studies and case series studies reported on how health professional led support groups also helped to relieve anxiety, gave an opportunity to communicate with staff, and gain confidence in their parenting skills[45,46,47]. Another case series study reported how a support programme run by parents gave parents space to

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express their worries and concerns and provided comfort in talking to 'experienced' parents[48].

5) Alleviating parent stress

Seven studies report interventions that attempt to alleviate the adverse psycho-social consequences of having a pre-term infant, of which four were RCTs. RCT evidence is reported in the individualised developmental behavioural programme section for the stress reduction benefits of COPE, NIDCAP, and MITP[4,11,14,16] (Melnyk 2006; Kaaresen 2006; Ali 2003; Nurcombe 1984). Other RCT evidence reports that the use of videotape in strategies that focus on coping with emotions and active problem solving significantly reduced maternal stress (Cobiella 1990, 1-)[49].

Evidence from a cohort study reported that the use of one-off psychological interventions to teach relaxation and coping mechanisms to normalise their experience, as well as emotional and practical support significantly reduced the traumatic impact for parents compared to controls[50]. Two case series studies gave insights into the use of journal writing for documenting feelings, thoughts, milestones and involvement in care; the use of psychotherapy to offer support and insight at a time of crisis was also found to reduce stress[51,52].

6) Preparing parents for seeing their infant the neonatal unit for the first time

Two studies reported evidence for different ways of preparing parents for seeing their pre-term infant for the first time, of which one was an RCT[53,54]. The RCT evidence

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reported that giving parents a photograph of their pre-term infant provides a positive effect by improving bonding with their infant (Huckabay 1999, 1+)[53].

The qualitative study gave an insight into how a tour of the neonatal unit prior to having a pre-term infant (when a pregnancy at high risk of premature labour was diagnosed) may decrease parent's fears, inspire hope in their infant's prognosis, and give parents reassurance about the care offered at the NICU[54]. However, some parents found the appearance of the babies and the technology overwhelming, and some expressed concerns that the tour was not supported by staff on the neonatal unit.

7) Interventions for communication and information sharing

Eight studies assessed interventions to improve the issues of communication at the neonatal unit, of which one was a RCT[55]. The RCT evidence reported that taping parent-doctor consultations improved the recall of parents of the consultation[55]. The trial found that mothers who received audiotapes of their consultation recalled significantly more information about the diagnosis, treatment, and outcome of their children than women in the control group at ten days and at four months.

Evidence from a cohort study reported that discussions between health professionals and parents around their infant's progress chart resulted in the intervention group having significantly fewer unrealistic concerns, less uncertainty about the medical condition of the

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infant, less conflict and a greater satisfaction with regards to shared decision-making[56]. Another cohort study reported that parents had significantly greater contact with the NICU *during the infant's admission* and reported a sense of relief at seeing their infant when they had access to the neonatal unit via a videophone[57].

Qualitative evidence investigated the perception of parents regarding the methods of effective and ineffective communication at the NICU. Parents perceived that the most effective communication with nurses was through discourse management (nurses asking questions and encouraging parents to ask questions), caring and reassuring communication, and communication as equal partners in the care of the infant. Ineffective communication was perceived as when the information given was inconsistent, staff did not check if parents understood the information, and if questions were not allowed[58]. Furthermore, qualitative evidence reported that 'chat' or 'social talk' between nurses and parents had a positive influence on mothers' confidence, their sense of control, and their feeling of connection with their baby[59].

Cross-sectional studies provided an insight into the methods of improving communication between parents of pre-term infants and health professionals. The use of a web-based programme (BabyLink) to provide individualised information to parents helped communicate complex issue, and parents reported that it helped to humanise the experience of the neonatal unit[60]. Furthermore, a study reported that the use of BabyLink improved the overall satisfaction of the family with care at the neonatal unit and actually reduced the length of stay at the neonatal unit[6]. Parents reported that they found the tape-recorded consultations with doctors helpful to process the information, as well as being comforting and supportive[61].

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Five studies reported evidence on the information needs of parents, none of which provided RCT level evidence. One pre-test/post-test study concluded that information and training for specific practical care of their infant on oxygen therapy could significantly improve the relevant knowledge of parents, and reduced their distress when entering the transition period of returning home[62].

Three qualitative studies described an information binder that provided relevant information about medical and practical issues relating to the NICU. Parents could add information to the folder. The information binder empowered parents to take an active interest in acquiring relevant information about their infant and improved parents understanding and ability to participate in decision-making. Furthermore, the information binder increased parent's confidence in caring for their infant, and gave them hope of progress for their infant[63, 64]. Prioritising information through a "card sort" (cards which state information topics for parents who have had a pre-term infant) was reported by a qualitative study as being a less intimidating way for parents to access important and timely information [65]. This study reported that parents' highest priorities were infant cardiopulmonary resuscitation (CPR), infant illness and development; information with a moderate priority were feeding, giving medication, and hygiene; and information topics that were given the lowest priority included getting help at home and the use of car seats. One cross-sectional study reported that the neonatal nurses were the best source of information at the NICU[66].

8) Discharge planning

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Six studies reported on discharge programmes, of which one reported RCT level evidence (Barrera 1986, 1-)[67]. RCT evidence suggests that a parent-infant discharge programme within a therapeutic problem-solving model significantly improved parent interactions with their infants, and parents were significantly more engaged with their infants after returning home compared with the parents who did not go through a discharge programme[67].

One cohort study assessed an early discharge programme with an individualised care and discharge plan, followed by domiciliary nursing care, and reported significantly less anxiety in mothers in the intervention group at discharge[68]. No significant differences in the experiences of parents with regards to their infant's emotional well-being and breast feeding issues were reported. The levels of anxiety did not appear to be different between groups of parents who did not receive a formal discharge programme at one year after discharge from the neonatal unit[68].

The qualitative studies gave insights into how discharge planning provided support for parents. One study conducted a discharge programme that comprised of an educational programme during the period of hospitalisation for parents with pre-term infants, a visit and orientation about the neonatal unit by the family's health visitor, a multidisciplinary and cross-sector discharge conference, and the publication of relevant booklets for parents and health care providers[69]. The parents found that most of the intervention initiatives contributed to a feeling of overall increased support and met their needs, including improving their confidence in caring for their pre-term infant and ensuring the well-being of their child following discharge. Families valued the support and guidance they received from the co-ordinating health visitor, and valued having a named contact

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nurse throughout their stay at the neonatal unit and at home, which demonstrated the importance of continuity of care. All participants in this study felt secure when they returned home.

One qualitative study assessed the perceptions of parents of pre-term infants regarding an early discharge and home-care programme[70]. The study concluded that parents of children who were discharged early may feel more positive about coming home as early as possible from the hospital, as this may help parents to feel like a 'normal' family and not to have to share their infant with the nurses and other health professionals on the neonatal unit. However, parents in this study appreciated the 24 hour accessibility of the staff on the neonatal unit for support and knowledge.

Two further qualitative studies reports a Care by Parent discharge programme and describes how the mother can stay in the same room or in a room close to her pre-term infant, assuming all of the aspects of care but with help at hand if needed [71,72]. Mothers reported that it gave them the opportunity to test reality and bridge the gap between hospital and home, so gaining confidence in taking their infant home, and it helped mothers to feel like a proper family, and promoted their "ownership" of the infant.

9) Home support programmes

Ten studies reported the outcomes of parents who participated in home intervention programmes, of which two were RCTs. RCT evidence reported that home support programmes, where parents are visited and given emotional and practical support regularly for the first year and for up to three years afterwards, lead to significantly reduced parental stress levels, a greater positive effect on maternal behaviour and greater

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interactions with their pre-term infant. However, the intervention was not significantly associated with improved maternal coping (Spiker 1993, 1-)[73]. RCT evidence also reports that regular home support programmes that last for up to a year made mothers significantly more responsive to their infant and meant that they were able to provide more appropriate and varied stimulations for the infant (Barrera 1986, 1-)[67].

Evidence from a cohort study where parents were visited regularly and taught care-taking skills, games and exercises reported a significantly better home environment for the family. However, there was no difference found between the intervention group and the control group with regards to maternal coping[74]. Evidence from a cohort study also assessed the support and psychological impact of an Infants Apnea Evaluation Programme (IAEP) for infants on home monitors and reported that monitoring itself significantly reduced anxiety. The structured support programme was found to be supportive by parents[75]. A similar cohort study introduced a home counselling programme for parents who used home monitoring. Parents were significantly less stressed by the presence of the monitor and by false alarms, and reacted less aggressively to monitor alarms. Parents in the structured support programme used the monitor less, and mainly during sleeping periods[76]. One cohort conducted an educational developmental programme at home twice monthly using a parent’s voice tape, baby massage, and a passive range of motion and exercise. The programme resulted in a significant improvement in parent-infant interaction at six months and 12 months after discharge, as well as benefiting the infant[77].

Evidence from a cohort study reported that a home healthcare programme and home visiting programme significantly improved the home environment of the intervention

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groups compared to the control groups at one month and 12 months[5]. However, there were no significant differences between groups with regard to family experiences and parental satisfaction.

Evidence from one cross-sectional study and two case series studies give insights into the effect of home support programmes. Specific to the UK, the community neonatal service (CNS) was valued positively in providing support and continuity of care for parents who needed a high level of support (e.g. experiencing depression and bonding struggles with their infant, infant sleeping issues and feeding problems) [78]. One study assessed the impact of an intensive care co-ordinator who provided home visits for providing teaching, guidance and support to parents[79]. The study reported that the intensive care co-ordinator made families feel comfortable, offering emotional and practical support, and taught parents the necessary skills for parenting the pre-term infant. Another similar study assessed a neonatal integrated home care programme where neonatal nurses taught specific infant care needs and provided emotional support to parents. Parents reported that the programme helped them to bring their pre-term infants home earlier, provided nurse help, support, instruction and encouragement [80].

Discussion

The aim of this systematic review focused on identifying interventions that were effective in supporting, informing and communicating with parents who have had a pre-term infant. The scope of this review was very broad, and the searches were therefore developed to be inclusive. This resulted in the search being sensitive, but not specific.

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The majority of studies included in this review are from the USA, which may affect the generalisation of interventions in neonatal units today and the ability of such studies to be applied in a British practice setting would need to be considered. While this review identified a range of interventions that can help parents, certain groups were under-represented in the study samples, including amongst others minority ethnic groups, individuals from lower social classes and young parents. Further research on which interventions are helpful to these groups is needed.

Despite the limitations of the evidence-base, this systematic review highlights interventions for providing improved support, information and communication to parents of a pre-term infant. These interventions are summarised in Figure 2.

This study has identified a range of interventions that can produce beneficial outcomes for parents in relation to communication, information and support. Important messages have come through this research, which healthcare professionals and neonatal units should consider. Some units may have already utilised some of these interventions, but we would urge them to use the POPPY study results to review current practice and consider whether unit and professional practice requires adaptation or change. Changing practice can be difficult and a number of key elements are required, including evidence, an understanding of the context of care and a way of facilitating this evidence into practice[81]. We also acknowledge that part of the context is a complex range of workforce issues that limits what neonatal units can achieve, despite their best efforts. The focus on developing patient-centred care within the NHS in the UK also applies to neonatal units and should include parent-focused care as an extension of this concept[82].

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Many of the interventions that have been identified in this study could be described as being building blocks for a family-centred model of care in the UK setting, which embraces the mother and father or significant others in the medical care of their infant. Such interventions act through establishing key actions and interventions that emphasise the importance of communicating with, supporting and informing the family. Furthermore, our review demonstrated that such family-centred interventions resulted in shorter stays at the neonatal units, less re-hospitalisation of pre-term infants and better long-term outcome with regards to morbidity in this group of infants[4]. This contributes to a strong argument that highlights the potential for family-centred care to be made more cost-effective, more acceptable to parents, and in some cases offer important clinical benefits.

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Ethics Approval:

Ethics approval was gained for the study through MREC, South East Ethics Research Unit (ref: 06/MRE 01/6)

Funder: This study was funded by the Big Lottery

Guarantor: The University of Warwick, Coventry, CV7 4AL is the guarantor of this study

WHAT IS ALREADY KNOWN ON THIS TOPIC It has long been recognised that family-centred care at the neonatal unit is beneficial not just fo parents of premature infants, but for the infants themselves. While the importance of family cer care is known, neonatal units are unsure which are the most effective family- centred care interventions to support, communicate with, and provide information to these parents
WHAT THIS STUDY ADDS

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The evidence from the systematic review provides a summary pathway of family-centred care interventions to assist in providing support, information and communication with parents of premature infants throughout their stay at the neonatal unit and after discharge home.

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4. Have you acted as an expert witness on the subject of your study, review, editorial, or letter? No

5. Do you have any other competing financial interests? If so, please specify. No

Contributorship statement

JB conducted the systematic review, sat on the advisory group and steering group for the study, synthesized the evidence and wrote the drafts of the paper.

SS was the principal investigator of the study, obtaining funding for the study, sat on the advisory group and steering groups for the study, over saw all stages of the study, assisted in the identification and quality assessment of the evidence, and assisted in the writing of the first draft of the paper.

MN was the fund holder, sat on the advisory group and steering group of the study and commented on the synthesis of the evidence and draft papers.

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NJ was the patient representative on this study. She was integral in the development of this project, in the development of the proposal, sat on the advisory group and the steering group, and commented on the synthesis of the data and the drafts of the paper

LT was integral in the development of this project, in the development of the proposal, sat on the advisory group and the steering group, and commented on the synthesis of the data and the drafts of the paper

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Figures and Tables

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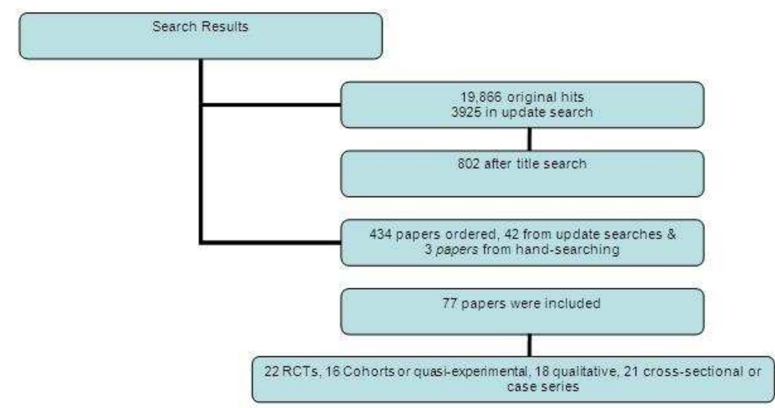

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Figure 2: Individualised developmental and behavioural care programmes

1) COPE[4] (Creating Opportunities for Parent Empowerment) provides an educational programme for parents at the neonatal unit on the appearance and behavioural characteristics of pre-term infants, how parents can participate in their infant's care, and how parents can make more positive interactions with their infant.

2) NIDCAP[11,12,13] (Neonatal Individualised Developmental Care and Assessment Programme) is an intervention that stimulates pre-term infants and improves the interaction between mothers and infants

3) MITP (Mother-Infant Transaction Programme)[14,15,16] helps to enable the parents to appreciate their infant's unique characteristics, temperament, and developmental potential, sensitising parents to their infant's cues so that they can respond appropriately.

4) NCATS (Nursing Child Assessment Teaching Scale) NCATS (Nursing Child Assessment Teaching Scale)[17] : Examines the mother-child relationship in conjunction with teaching mothers how to interact with the baby, teaching behavioural cues, how to play etc

NB: While the developmental care programmes are designed to improve the development of the baby, these interventions give parents psychological support and practical guidance on how to care for their infants.

only

Tour of Neonatal
unit to prepare Parents (3)

Pre-Neonatal
If high risk
pregnancy
is diagnosed

At the Neonatal Unit

Information of what to
expect - to prepare parents (3)

SIGN level of evidence used to grade evidence e.g. (3), or (1+) as described in SIGN table

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Summary of POPPY Systematic Review – Interventions at the Neonatal Unit

Provide Information

- Parent Information Binder - 'one day at a time' (3)
  - Provide relevant, timely information to parents when they require it and store in binder. Also helpful to take with them if transferred to another hospital
- Prioritising info needs in parent circle (3)
  - Using card sort to assess most important information needs, support needs and communication preferences of parents.
- Provide information leaflets on specific conditions relevant to individual parents (3)
- Information Needs (R)
  - Sensitivity to behavioural cues
  - Infant development and behaviour
  - Caring for the baby

Support Groups

- Parent lead (buddy parent programme)(2++)
- Nurse lead (3)

Improve Communication

- Record consultations with doctors (or provide results in writing) (1++)
- Involve Parents in discussions around Infant Progress Chart (2++)
- Video-phone link to unit (2-)
- Baby Link – website information – general and specific to parents (3)

Family-centred care at the Neonatal Unit

Discharge Planning

Teaching Parents:

Educate parents about behavioural cues and developmental aspects of baby to improve interaction with baby and knowledge of baby (COPE, NIDCAP and MITP) (1+)

- Behavioural Assessment Scales
  - Brazelton Behavioural Assessment Scale (3)

  Education videos and books to teach parents about behavioural cues and development shifts of their premature baby (1+)

- Individualised developmentally supportive family centred care interventions, including emotional and practical factors (1+)

Individualised developmental and care Programmes

- COPE (Creating opportunities for Parent empowerment)(1+)
- NIDCAP (Neonatal individualised Developmental Care and Assessment Programme) (1+)
- Mother – Infant Transaction Programme (1+)

- Kangaroo care (1+)
- Baby massage (1)
- Breast feeding (3)

(ie to improve confidence and competence in caring and bonding with baby)

Stress Education Programme

- COPE (Creating opportunities for Parent empowerment) (1+)
- NIDCAP (Neonatal individualised Developmental Care and Assessment Programme) (1+)
- Mother – Infant Transaction Programme (1+)
- Video tape training: active problem solving focussed coping strategy (1+)
- One off stress reduction programme (2+)
- Journal Writing (3)
- Counselling / Psychotherapy (3)

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Summary of POPPY Systematic Review - Interventions at Discharge

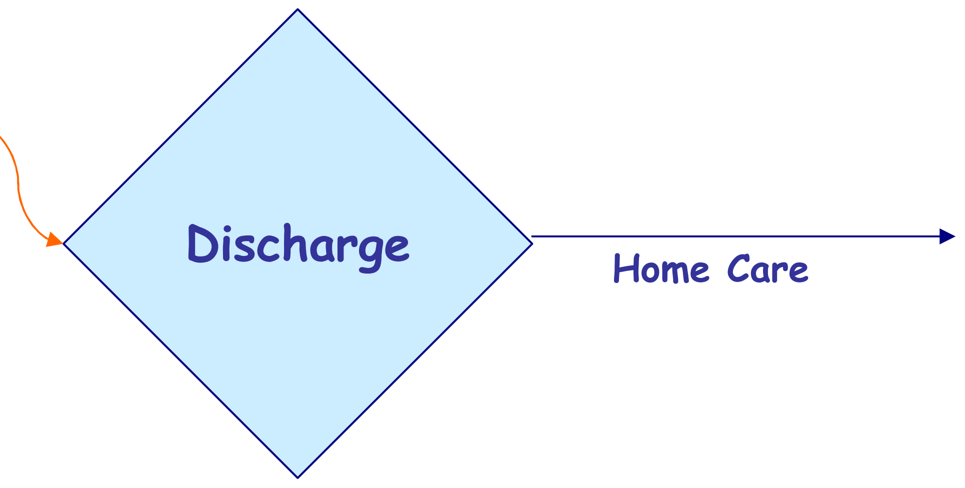
Discharge Planning Programme
(Reduce stress of returning home, improve parent-baby interactions, improve home environment for baby)

1. Parent – Infant interventions (to improve parent – infant interactions and improve the home environment) (1+)

2. Early discharge with domiciliary nursing (2+)

3. Educational programme for Parents; visit and orientation from a Health Visitor linked to the unit; multidisciplinary and cross-sector discharge conference; provision of appropriate booklets / leaflets for Parents. (3)

4. Care by Parent discharge programme – mothers / parents stay overnight with their infant in the same room and assumes all care for the baby, but help is available if needed. (3)



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Summary of POPPY Systematic Review – Interventions for Home Care Programmes

Community Neonatal Service

Community neonatal nurses assist parents in practical and emotional issues at home as required. Telephone Service available to parents to call when needed. Aimed at high risk parents (3)

Home Care

Structured home-visiting programme

(E.g. teaching caretaking skills, games and exercises to do with baby, coping skills for parents)

Examples:

Spiker / Klebanov – 3 Visits per month in year 1; 1.5 visits per month in years 2 and 3 (1+)

Barrera: 1-2 visits a week for 4 months; then every other week for 5-8 months and monthly for last 3 months of the year (1+)

Ross: 2 visits a month for first 3 months, then 1 visit a month up to 12 months (2+)

Isaacs: 2 visits a month for first 3 months, then 1 visit a month up to 12 months (3)

Home-monitoring Programme (2+)

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SIGN Level of evidence

- 1++ = High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
- 1+ = Well-conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
- 1–Meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias*
- 2++ = High-quality systematic reviews of case–control or cohort studies High-quality case–control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal
- 2+ = Well-conducted case–control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal
- 2– = Case–control or cohort studies with a high risk of confounding bias, or chance and a significant risk that the relationship is not causal*
- 3 = Non-analytic studies (for example, case reports, case series)
- 4 = Expert opinion, formal consensus
- R= non-systematic review

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A systematic review of interventions for communicating with, supporting and providing information to parents of pre-term infants

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A systematic review of interventions for communicating with, supporting and providing information to parents of pre-term infants

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Abstract

Background and Objective: The birth of a pre-term infant can be an overwhelming experience of guilt, fear, and helplessness for parents. Provision of interventions to support and engage parents in the care of their infant may improve outcomes for both the parents and the infant. The objective of this systematic review is to identify and map out effective interventions for communication with, supporting and providing information for parents of pre-term infants.

Design: Systematic searches were conducted in the electronic databases Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS. Hand-searching of reference lists and journals was conducted. Studies were included if they provided parent-reported outcomes of interventions relating to information, communication, and/or support for parents of pre-term infants prior to the birth, during care at the NICU, and after going home with their pre-term infant. Titles and abstracts were read for relevance and papers judged to meet inclusion criteria were included. Papers were data extracted, quality assessed and a narrative summary was conducted in line with the York Centre for Reviews and Dissemination guidelines.

Studies reviewed: 72 papers identified, 19 papers were randomised controlled trials, 16 were cohort or quasi-experimental studies, 37 were non-intervention studies.

Results: Interventions for supporting, communicating with, and providing information to parents that have had a premature infant are reported. Parents report

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feeling supported through individualised developmental and behavioural care programmes, through being taught behavioural assessment scales, and through breast feeding, kangaroo care and baby massage programmes. Parents also felt supported through organised support groups and through provision of an environment where parents can meet and support each other. Parental stress may be reduced through individual developmental care programmes, through psychotherapy, through interventions that teach emotional coping skills and active problem solving, and journal writing.

Evidence reports the importance of preparing parents for the neonatal unit through the neonatal tour, and the importance of good communication throughout the infant admission phase and after discharge home. Providing individual web-based information about the infant, recording doctor-patient consultations, and provision of an information binder may also improve communication with parents.

The importance of thorough discharge planning throughout the infant's admission phase and the importance of home support programmes are also reported.

Conclusion: The paper reports evidence of interventions that help support, communicate with and inform parents who have had a premature infant throughout the admission phase of the infant, discharge, and returning home. The level of evidence reported is mixed, and this should be taken into account when developing policy. A summary of interventions from the available evidence is reported.

Article focus:

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A systematic mapping review to identify and synthesize evidence of effective interventions for communicating with, supporting and providing information for parents of pre-term infants.

Key messages:

- The review highlights the importance of encouraging and involving parents in the care of their pre-term infant at the neonatal unit to enhance their ability to cope with and improve their confidence in caring for the infant, which may also lead to improved infant outcomes and reduced length of stay at the neonatal unit.

- Interventions for supporting parents included: 1) involving parents in individualised developmental and behavioural care programmes (e.g. COPE, NIDCAP, MITP) and behavioural assessment programmes; 2) breastfeeding, kangaroo care and infant massage programmes; 3) support forums for parents; 4) interventions to alleviate parental stress; 5) preparation of parents for various stages, for example seeing their infant for the first time, preparing to go home; 6) home support programmes.

- Involving parents in the exchange of information with and between health professionals is important, with various modes of providing this information reported, for example ward rounds with doctors, discussion around infant notes, websites, and hard copy information.

Strengths and limitations of study:

Strengths

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This is the first review to synthesize the evidence of interventions to support parents of pre-term infants through improved provision of information, improved communications between parents and health professionals and alleviation of stress at all stages of a parents journey through the neonatal unit. It highlights relatively inexpensive interventions that can be integrated into their pathway through the neonatal unit and going home, enhancing parental coping, and potentially improving infant outcomes and reducing the infants length of stay at the neonatal unit.

Limitations

The quality of the evidence that this review reports is variable, and includes all types of study designs.

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Introduction

While medical advances mean that very premature neonates have an increasingly better chance of survival, the impact of this experience on the child and their parents cannot be underestimated. The birth of a pre-term infant can be an intensely stressful, confusing and difficult time for parents and families[(1)]. Parents can have feelings of fear about their infant's condition or doubt in their ability to care for the child. Parents may also experience anger or grief, or they may blame themselves and experience intense guilt. Once mothers have returned home, hospital visits to see their baby can be difficult if coping with other siblings and travelling long distances to the neonatal unit[(2)]. It is therefore not surprising that mothers of pre-term babies experience significantly higher levels of post-natal depression than mothers of healthy full-term infants[(3)]. Fathers, who are often the main source of comfort and support for their wives, report feeling powerless to help, and often feel isolated from their infant as the health professionals focus on the infant and mother[(4)].

Furthermore, while going home with their infant can be a time of joy and relief for these parents, bringing home a fragile infant and caring for them on your own for the first time can be a worrying time, causing additional stress for the parents.

Reducing parent stress and introducing interventions to improve parents confidence and ability to care for their premature infant at the neonatal unit and after

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returning home can improve outcomes for parents and their child, reduce the length of stay at the neonatal unit[5,6] and reduce the re-admittance to hospital[7].

The Parents of Premature Babies (POPPY) study aims to develop a better understanding of the experiences of a range of parents with pre-term babies, particularly with regards to the communication, information and support they received on the NICU, ensuring that the perspectives of parents are at the heart of the study[8]. This paper reports the results of the first phase of the POPPY study, which takes the form of a systematic review to identify effective interventions for communicating with, supporting and providing information for parents of pre-term babies.

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Methods

Systematic searches were undertaken for the period of January 1980 to October 2006 in the following databases: Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS (see table 1 for search strategy). A combination of text terms and MeSH terms were used to maximise the volume of literature retrieved. Grey literature was sought from specialists in the field, and the following journals were hand-searched from 1990 onwards for all relevant English language articles: Neonatal Network Journal, Journal of Neonatal Nursing and Journal of Obstetric, Gynecologic, and Neonatal Nursing. Update searches were undertaken in October 2009.

Studies were included if they met the inclusion criteria:

- Outcomes reported by parents who have had a premature infant (i.e. ≤36 weeks gestation).
- Provided parent-reported outcomes of interventions relating to information provision at the neonatal unit and after discharge.
- Provided parent-reported outcomes of interventions relating to communication with health professionals at the neonatal unit and after discharge.
- Provided parent-reported outcomes of interventions relating to provision of support at the neonatal unit and after discharge.
- Design of study was: RCTs, Quasi experimental, cohort, case-control, cross-sectional, case series, case reports, or qualitative
- Studies were relevant to that of developed countries

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- Passed quality assessment
- Published between January 1980 to October 2009
- English language

Studies were excluded in the met the exclusion criteria

- Reported parent-reported outcomes of parents who had a sick full-term infant at the neonatal unit.
- Outcomes were not reported by parents (e.g. evaluation of parent intervention by health professionals)
- Editorials or opinions
- Study was fatally flawed
- Not English Language
- Published before Jan 1980

It was felt that the systematic review should be inclusive of all study designs as it is often not feasible or appropriate to conduct randomised control trials (RCTs) or other intervention studies on the outcomes for parents that were measured. We therefore set out to conduct a more realist review. A realist review is not a method or formula, but a logic of enquiry that is inherently pluralist and flexible, encompassing all types of study types. It seeks not to judge but to explain, and is driven by the question 'What works for whom in what circumstances and in what respects?' We wanted to identify what works for parents who have had a premature infant and at what part of their experience at the neonatal unit and after returning home. In practical terms,

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the realist reviewer identifies and evaluates the programme theories that implicitly or explicitly underlie families of interventions.

It was deemed therefore that, despite the potential bias inherent in descriptive studies, the results of these studies nonetheless gave an important insight into parent-related interventions and should be included in this review.

The data extraction form and quality assessment for inclusion criteria were based on the guideline from the NHS Centre for Reviews and Dissemination (NHS CRD) [(9)] Initially, two reviewers extracted data (JB, SS) independently for 20% of papers and disagreements were resolved by discussion with a third reviewer. There was a high level of agreement between reviewers, so the remaining data was extracted by one reviewer and checked by a second. Any disagreements were resolved by discussion with a third reviewer. The quantitative studies covered a wide range of interventions and different methods of assessment so it was not possible to carry out a meta-analysis. A non-quantitative synthesis was conducted based on the extracted data. In the summary figure (Figure 2), the included evidence was assessed using the Scottish Intercollegiate Guidelines Assessment (SIGN) [(10)].

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Search Results

Figure 1: The results from the literature search.

Seventy two papers were included (four were deemed relevant in two of the sections). Papers were excluded for a number of reasons including the fact that no parent outcome was identified, the study was irrelevant to neonatal services offered in developed countries such as the UK (3), or the study was deemed to be fatally flawed (11)

Tables 2a and 2b report the data from the randomised control trials, quasi experimental studies and cohort studies. Non-intervention studies are reported in table 2c.

Results

Interventions for supporting parents included: 1) individualised developmental and behavioural care programmes[4,11,12,13,14,15,16,17] (e.g. COPE, NIDCAP, MITP – see below); 2) behavioural assessment scales; 3) breastfeeding, kangaroo care and infant massage programmes; 4) support forums for parents; 5) the alleviation of parental stress; 6) preparing parents for seeing their infant for the first time; 7) communication and information sharing; 8) discharge planning; and 9) home support programmes.

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1) Supporting parents through individualised developmental and behavioural care programmes

Figure 2: Individualised developmental and behavioural care programmes

Fourteen studies reported individualised developmental and behavioural care programmes, of which nine were RCTs (see Table 1a). The RCT evidence (1++ & 1+) suggested that the involvement of parents in an individualised developmental and behavioural care programme significantly reduced the maternal stress created by the NICU environment and the demands of their infant [4,11,14,16,18,19]. This intervention also significantly improved the parental understanding of their infant and their interactions with their infant[4].

Recent RCT evidence suggested that the introduction of the NIDCAP intervention had not significantly changed levels of parental stress, confidence or nursing support. However, the outcomes were measured only 1-2 weeks after the baby was born (Van der Pal 2007, 1+)[12]. The introduction of the NCATS programme in the NICU made no significant difference to parental stress levels and maternal-infant interactions when assessed at discharge and at three months after discharge (Glazebrook et al. 2007, 1+)[20]. One RCT found that coaching parents on how to interact with their pre-term infant made no difference to knowledge of care, sensitivity to the infant or satisfaction in parenting compared with the control group(Parker-Loewen 1987, 1-)[21]. However, this may have been confounded by the amount of contact that the control mothers had with the researchers, as these mothers reported that they enjoyed having someone show an interest in them.

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Evidence from a cohort reported that the Vermont Mother-Infant Transaction Programme (MITP) significantly improved maternal satisfaction, maternal self-confidence, and mothers' perception of their infant's temperament at six months[15]. One cohort study reported that individualised developmental care programmes appeared to make no difference to parents' perceptions of the neonatal unit or satisfaction with care, despite significantly lowering stress cues in the pre-term infants[22].

Evidence from qualitative studies provides an insight into the benefits of individualised developmental and behavioural care programmes at the neonatal unit, such as empowering parents to take care of their infants, teaching parents behavioural cues of their infants, problem-solving, and learning how to interact with their infants, resulting in a greater satisfaction with the care provided[13,23,24]. Furthermore, parents reported a reduction in stress after such programmes and said that they felt more confident in caring for their infants, which promoted parental self-reliance when returning home[24].

2) Supporting parents through use of Behavioural Assessment Scales

No RCT evidence was reported on this intervention. Three cross-sectional studies provided insights into how to teach parents assess and interpret the behaviour of their pre-term through using the Brazelton Behavioual Assessment scales. The studies reported this intervention may improve mother-infant bonding,

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reduce maternal anxiety, and help mothers foster a more realistic perception of their pre-term infants[25,26,27].

3) Supporting parents through breast feeding, kangaroo care and infant massage

Four studies reported on parent outcomes of interventions around breast-feeding, of which one was a RCT, six studies reported on parent outcomes of interventions around kangaroo care (skin to skin contact with baby out of the incubator), of which 2 were RCTs, and two studies reported parent outcomes around baby massage, (see Table 1c). An RCT (1-) reported no significant difference in the mother's confidence and competence in carrying out breast feeding by weighing the infant before and after feeds[28].

Three cross-sectional studies and one case series study reported on breast feeding interventions. The studies reported that parents receiving breastfeeding support at the neonatal unit were more likely to continue breastfeeding up to a month after discharge than comparable groups. Breast-feeding education and support at the neonatal unit in the form of counselling, information (handouts and videos), practical help and group breast-feeding clinics improved the confidence of mothers in breast-feeding. An individualised discharge plan for breast feeding mothers with follow-up telephone calls or home visits appeared to maintain mothers' confidence in breastfeeding, and provide reassurance[29,30,31]

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Six studies reported parent outcomes of using kangaroo care with their pre-term infants, of which two were RCTs. The RCT evidence (1+) suggests that use of kangaroo care significantly reduces maternal anxiety around her infant, gives the mother a significantly greater sense of competence with their infant, and a significantly greater sensitivity towards her infant[32]. Furthermore, RCT evidence (1+) suggests that music during kangaroo care resulted in significantly lower maternal anxiety [33].

One cohort study, which assessed outcomes of mothers using kangaroo care at 37 weeks, at 3 months, and at 6 months, reported significantly better levels of mother-infant interaction, more touch, better adaptation to infant cues, and better perception of their infant at all time periods. Mothers also reported significantly less post-natal depression compared to the controls at 37 weeks[34].

One cross-sectional study reported that the majority of mothers preferred the kangaroo method, mainly because their baby was closer to them. Touch was important to mothers, as it induced feelings of well-being and fulfilment in parents[35].

In the qualitative studies, parents described how kangaroo care helped them to get to know their infant, increased their confidence, and made them feel that their infant needed them[36]; parents reported that their mood was improved, that they perceived their infant differently and felt a stronger sense of identifying with their infant[37].

Two studies reported on parent outcomes of baby massage on pre-term infants, of which one was an RCT (see Table 1d). RCT evidence (1+) reported that

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at three months, mothers of massaged infants felt significantly less intrusive towards caring for their baby, interactions were more reciprocal, and treated infants were more socially involved compared to controls[38]. One cross-sectional study also reported improved maternal-infant interactions[39].

4) Support forums for parents

No RCT evidence was reported for these interventions. Nine studies reported the benefits of participating in support groups set up within the NICU, either run by staff at the neonatal unit or by parents who have experienced having a pre-term infant themselves. Evidence from cohort studies reported that parent-led peer support groups at the NICU led to mothers in the intervention group having significantly less stress at four weeks and 16 weeks after support was initiated at the neonatal unit[40,41]. Mothers of critically ill pre-term infants had significantly better maternal mood states, maternal-infant relationships, and home environments in the intervention group compared to the control group[42]

Evidence from a qualitative study gave insights into how a health professional led support group assisted parents to gain perspective, feel supported, and learn practical information about how to interact with their baby[43]. Qualitative evidence also reports that parent-to-parent support groups provided parents with information, emotional support, and strength[44]. Cross-sectional studies and case series studies reported on how health professional led support groups also helped to relieve

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anxiety, gave an opportunity to communicate with staff, and gain confidence in their parenting skills[45,46,47]. Another case series study reported how a support programme run by parents gave parents space to express their worries and concerns and provided comfort in talking to ‘experienced’ parents[48].

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5) Alleviating parent stress

Seven studies report interventions that attempt to alleviate the adverse psycho-social consequences of having a pre-term infant, of which four were RCTs. RCT evidence (1+ - 1++) is reported in the individualised developmental behavioural programme section for the stress reduction benefits of COPE, NIDCAP, and MITP[4,11,14,16]. Other RCT evidence (1-) reports that the use of videotape in strategies that focus on coping with emotions and active problem solving significantly reduced maternal stress [49].

Evidence from a cohort study reported that the use of one-off psychological interventions to teach relaxation and coping mechanisms to normalise their experience, as well as emotional and practical support significantly reduced the traumatic impact for parents compared to controls[50]. Two case series studies gave insights into the use of journal writing for documenting feelings, thoughts, milestones and involvement in care; the use of psychotherapy to offer support and insight at a time of crisis was also found to reduce stress[51,52].

6) Preparing parents for seeing their infant the neonatal unit for the first time

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Two studies reported evidence for different ways of preparing parents for seeing their pre-term infant for the first time, of which one was an RCT[53,54]. The RCT evidence (1+) reported that giving parents a photograph of their pre-term infant provides a positive effect by improving bonding with their infant[53].

The qualitative study gave an insight into how a tour of the neonatal unit prior to having a pre-term infant (when a pregnancy at high risk of premature labour was diagnosed) may decrease parent's fears, inspire hope in their infant's prognosis, and give parents reassurance about the care offered at the NICU[54]. However, some parents found the appearance of the babies and the technology overwhelming, and some expressed concerns that the tour was not supported by staff on the neonatal unit.

7) Interventions for communication and information sharing

Eight studies assessed interventions to improve the issues of communication at the neonatal unit, of which one was a RCT[55]. The RCT evidence (1+) reported that taping parent-doctor consultations improved the recall of parents of the consultation[55]. The trial found that mothers who received audiotapes of their consultation recalled significantly more information about the diagnosis, treatment, and outcome of their children than women in the control group at ten days and at four months.

Evidence from a cohort study reported that discussions between health professionals and parents around their infant's progress chart resulted in the intervention group having significantly fewer unrealistic concerns, less uncertainty

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about the medical condition of the infant, less conflict and a greater satisfaction with regards to shared decision-making[56]. Another cohort study reported that parents had significantly greater contact with the NICU during the infant's admission and reported a sense of relief at seeing their infant when they had access to the neonatal unit via a videophone[57].

Qualitative evidence investigated the perception of parents regarding the methods of effective and ineffective communication at the NICU. Parents perceived that the most effective communication with nurses was through discourse management (nurses asking questions and encouraging parents to ask questions), caring and reassuring communication, and communication as equal partners in the care of the infant. Ineffective communication was perceived as when the information given was inconsistent, staff did not check if parents understood the information, and if questions were not allowed[58]. Furthermore, qualitative evidence reported that 'chat' or 'social talk' between nurses and parents had a positive influence on mothers' confidence, their sense of control, and their feeling of connection with their baby[59].

Cross-sectional studies provided an insight into the methods of improving communication between parents of pre-term infants and health professionals. The use of a web-based programme (BabyLink *)* to provide individualised information to parents helped communicate complex issue, and parents reported that it helped to humanise the experience of the neonatal unit[60]. Furthermore, a study reported that the use of BabyLink improved the overall satisfaction of the family with care at the neonatal unit and actually reduced the length of stay at the neonatal unit[6]. Parents

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reported that they found the tape-recorded consultations with doctors helpful to process the information, as well as being comforting and supportive[61].

Five studies reported evidence on the information needs of parents, none of which provided RCT level evidence. One pre-test/post-test study concluded that information and training for specific practical care of their infant on oxygen therapy could significantly improve the relevant knowledge of parents, and reduced their distress when entering the transition period of returning home[62].

Three qualitative studies described an information binder that provided relevant information about medical and practical issues relating to the NICU. Parents could add information to the folder. The information binder empowered parents to take an active interest in acquiring relevant information about their infant and improved parents understanding and ability to participate in decision-making. Furthermore, the information binder increased parent's confidence in caring for their infant, and gave them hope of progress for their infant[63, 64]. Prioritising information through a "card sort" (cards which state information topics for parents who have had a pre-term infant) was reported by a qualitative study as being a less intimidating way for parents to access important and timely information [65]. This study reported that parents' highest priorities were infant cardiopulmonary resuscitation (CPR), infant illness and development; information with a moderate priority were feeding, giving medication, and hygiene; and information topics that were given the lowest priority included getting help at home and the use of car seats. One cross-sectional study reported that the neonatal nurses were the best source of information at the NICU[66].

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8) Discharge planning

Six studies reported on discharge programmes, of which one reported RCT level evidence[(67)]. RCT evidence (1-) suggests that a parent-infant discharge programme within a therapeutic problem-solving model significantly improved parent interactions with their infants, and parents were significantly more engaged with their infants after returning home compared with the parents who did not go through a discharge programme[(67)].

One cohort study assessed an early discharge programme with an individualised care and discharge plan, followed by domiciliary nursing care, and reported significantly less anxiety in mothers in the intervention group at discharge[(68)]. No significant differences in the experiences of parents with regards to their infant's emotional well-being and breast feeding issues were reported. The levels of anxiety did not appear to be different between groups of parents who did not receive a formal discharge programme at one year after discharge from the neonatal unit[(68)].

The qualitative studies gave insights into how discharge planning provided support for parents. One study conducted a discharge programme that comprised of an educational programme during the period of hospitalisation for parents with pre-term infants, a visit and orientation about the neonatal unit by the family's health visitor, a multidisciplinary and cross-sector discharge conference, and the publication of relevant booklets for parents and health care providers[(69)]. The

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parents found that most of the intervention initiatives contributed to a feeling of overall increased support and met their needs, including improving their confidence in caring for their pre-term infant and ensuring the well-being of their child following discharge. Families valued the support and guidance they received from the co-ordinating health visitor, and valued having a named contact nurse throughout their stay at the neonatal unit and at home, which demonstrated the importance of continuity of care. All participants in this study felt secure when they returned home.

One qualitative study assessed the perceptions of parents of pre-term infants regarding an early discharge and home-care programme[70]. The study concluded that parents of children who were discharged early may feel more positive about coming home as early as possible from the hospital, as this may help parents to feel like a 'normal' family and not to have to share their infant with the nurses and other health professionals on the neonatal unit. However, parents in this study appreciated the 24 hour accessibility of the staff on the neonatal unit for support and knowledge.

Two further qualitative studies reports a Care by Parent discharge programme and describes how the mother can stay in the same room or in a room close to her pre-term infant, assuming all of the aspects of care but with help at hand if needed [71,72]. Mothers reported that it gave them the opportunity to test reality and bridge the gap between hospital and home, so gaining confidence in taking their infant home, and it helped mothers to feel like a proper family, and promoted their "ownership" of the infant.

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9) Home support programmes

Ten studies reported the outcomes of parents who participated in home intervention programmes, of which two were RCTs. RCT evidence (1-) reported that home support programmes, where parents are visited and given emotional and practical support regularly for the first year and for up to three years afterwards, lead to significantly reduced parental stress levels, a greater positive effect on maternal behaviour and greater interactions with their pre-term infant. However, the intervention was not significantly associated with improved maternal coping[(73)]. RCT evidence also reports that regular home support programmes that last for up to a year made mothers significantly more responsive to their infant and meant that they were able to provide more appropriate and varied stimulations for the infant[(67)].

Evidence from a cohort study where parents were visited regularly and taught care-taking skills, games and exercises reported a significantly better home environment for the family. However, there was no difference found between the intervention group and the control group with regards to maternal coping[(74)]. Evidence from a cohort study also assessed the support and psychological impact of an Infants Apnea Evaluation Programme (IAEP) for infants on home monitors and reported that monitoring itself significantly reduced anxiety. The structured support programme was found to be supportive by parents[(75)]. A similar cohort study introduced a home counselling programme for parents who used home monitoring. Parents were significantly less stressed by the presence of the monitor and by false alarms, and reacted less aggressively to monitor alarms. Parents in the structured support programme used the monitor less, and mainly during sleeping periods[(76)]. One cohort conducted an educational developmental programme at home twice

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monthly using a parent's voice tape, baby massage, and a passive range of motion and exercise. The programme resulted in a significant improvement in parent-infant interaction at six months and 12 months after discharge, as well as benefiting the infant[77].

Evidence from a cohort study reported that a home healthcare programme and home visiting programme significantly improved the home environment of the intervention groups compared to the control groups at one month and 12 months[5]. However, there were no significant differences between groups with regard to family experiences and parental satisfaction.

Evidence from one cross-sectional study and two case series studies give insights into the effect of home support programmes. Specific to the UK, the community neonatal service (CNS) was valued positively in providing support and continuity of care for parents who needed a high level of support (e.g. experiencing depression and bonding struggles with their infant, infant sleeping issues and feeding problems) [78]. One study assessed the impact of an intensive care co-ordinator who provided home visits for providing teaching, guidance and support to parents[79]. The study reported that the intensive care co-ordinator made families feel comfortable, offering emotional and practical support, and taught parents the necessary skills for parenting the pre-term infant. Another similar study assessed a neonatal integrated home care programme where neonatal nurses taught specific infant care needs and provided emotional support to parents. Parents reported that the programme helped them to bring their pre-term infants home earlier, provided nurse help, support, instruction and encouragement [80].

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Discussion

The aim of this systematic review focused on identifying interventions that were effective in supporting, informing and communicating with parents who have had a pre-term infant. This study has identified a range of interventions that can produce beneficial outcomes for parents in relation to communication, information and support.

RCT evidence reports that developmental and behavioural care programmes such as COPE and MITP significantly reduce stress and depression in mothers of premature infants, significantly increase mothers' knowledge of her infant's condition and care (COPE) and significantly improved mothers attitude and confidence in caring for their infant (MITP). COPE and MITP performed better than other such programmes because they were developed to improve both mother and infant outcomes, whereas other developmental programmes focussed more on infant outcomes. Such interactive learning programmes appear to be more successful at reducing mother's stress and improving mother's knowledge than stand alone coaching sessions for parents.

Other RCT evidence reported that skin to skin care and baby massage significantly improved the mother-infant interaction and increased the mother's sense of competence in handling their infant. These are inexpensive interventions that can be introduced relatively easily to most NICUs.

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Perhaps more controversial RCT evidence reports that recording parent's consultations with their doctors significantly improved the parent's recall of diagnosis, treatment and outcomes of their infant. However, in our growing litigious society, doctors may be reluctant to do this.

Cohort evidence reports the benefits of several interventions including discussions around the infant progress chart, parent support groups at the neonatal unit and home support programmes once the infant has been discharged. The non-intervention studies further added to the review by bring a wider breadth of information around the beneficial experiences of developmental care programmes, educational interventions, preparation for visiting the neonatal unit, and interventions to reduce parent's stress, that might not have been reported within an RCT design.

Important messages have come through this research, which healthcare professionals and neonatal units should consider. Some neonatal units may have already utilised some of these interventions, but we would urge them to use the results of this systematic review to re-evaluate current practice around parents of premature infants and consider whether unit and professional practice requires adaptation or change. Changing practice can be difficult and a number of key elements are required, including evidence, an understanding of the context of care and a way of facilitating this evidence into practice[81]. We also acknowledge that part of the context is a complex range of workforce issues that limits what neonatal units can achieve, despite their best efforts. The focus on developing patient-

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centred care within the NHS in the UK also applies to neonatal units and should include parent-focused care as an extension of this concept[82].

Many of the interventions that have been identified in this study could be described as being building blocks for a family-centred model of care in the UK setting, which embraces the mother and father or significant others in the medical care of their infant. Such interventions act through establishing key actions and interventions that emphasise the importance of communicating with, supporting and informing the family. Furthermore, our review demonstrated that such family-centred interventions resulted in shorter stays at the neonatal units, less re-hospitalisation of pre-term infants and better long-term outcome with regards to morbidity in this group of infants[4]. This contributes to a strong argument that highlights the potential for family-centred care to be made more cost-effective, more acceptable to parents, and in some cases offer important clinical benefits.

The scope of this review was very broad, and the searches were therefore developed to be inclusive. This resulted in the search being sensitive, but not specific. Furthermore, this systematic review includes intervention studies and non-intervention studies. It is implicit that the non-interventional studies will bring bias to the evidence base. We have therefore stratified the summary of results into RCTs and non RCTs, with the non-RCTs being stratified further within observational designs by study design (ie., cohort, case-control, cross-sectional, etc). It was important to include the non-interventional studies as much of the literature around parents' views and experiences does not lend itself to the RCT design. Being inclusive of studies

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benefits the evidence base by bringing together 'experience' studies in a systematic way gaining a greater breadth of perspectives and a deeper understanding of issues from the point of view of those targeted by the interventions.

The Scottish intercollegiate group network (SIGN) grading system used in this review is intended to place greater weight on the quality of evidence, and to emphasise that the body of evidence should be considered as a whole, and not rely on a single study. It is also intended to allow more weight to be given to recommendations supported by the good quality observational studies where RCTs are not available for practical or ethical reasons, as shown in figure 4.

The majority of studies included in this review are from the USA, which may affect the generalisation of interventions in neonatal units today and the ability of such studies to be applied in a UK practice setting would need to be considered. While this review identified a range of interventions that can help parents, certain groups were under-represented in the study samples, including amongst others minority ethnic groups, individuals from lower social classes and young parents. Further good quality research within a UK setting, and research on under-represented groups of parents at the neonatal units is needed.

Despite the limitations of the evidence-base, this systematic review highlights interventions for providing improved support, information and communication to parents of a pre-term infant. These interventions are summarised in Figure 3.

Figure 4 Scottish Intercollegiate Guideline Network (SIGN) Levels of Evidence

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Table 1:

Search terms:

INTERVENTION MEDLINE 1951-2006 Search carried out 23 JAN 2006		1. SEARCH: INFORMATION-DISSEMINATION#.DE. 2. SEARCH: INFORMATION OR INFORM$ OR INFORMATION ADJ SEEKING ADJ BEHAVIOUR OR INFORMATION ADJ NEEDS OR PATIENT ADJ INFORMATION OR (PARENT ADJ INFORMATION).AB. 3. SEARCH: ACCESS-TO-INFORMATION#.DE. 4. SEARCH: (INFORMATION ADJ RESOURCES).AB. 5. SEARCH: PATIENT-EDUCATION#.DE. OR PATIENT-EDUCATION-HANDOUT-PUBLICATION-TYPE#.DE. 6. SEARCH: PATIENT-CARE-TEAM#.DE. 7. SEARCH: COLLABORATI$ OR JOINT ADJ WORKING OR TEAM.AB. 8. SEARCH: COMMUNICATION#.W..DE. OR COMMUNICATION-BARRIERS#.DE. 9. SEARCH: COMMUNICATION.AB. 10. SEARCH: (INFORMATION ADJ SERVICE).AB. 11. SEARCH: EARLY-INTERVENTION-EDUCATION#.DE. 12. SEARCH: SELF-HELP-GROUPS#.DE. 13. SEARCH: SOCIAL-SUPPORT#.DE. 14. SEARCH: HELPING-BEHAVIOR#.DE. 15. SEARCH: HELP ADJ SEEKING ADJ BEHAVIOUR OR HELP.AB. 16. SEARCH: SELF ADJ HELP OR (SELF ADJ HELP ADJ GROUPS).AB. 17. SEARCH: ADVICE OR ADVISE OR ADVISORY.AB. 18. SEARCH: INTERNET#.W..DE. 19. SEARCH: COUNSELING#.W..DE. OR DIRECTIVE-COUNSELING#.DE. 20. SEARCH: COGNITIVE-THERAPY#.DE. OR THERAPY-COMPUTER-ASSISTED#.DE. OR NONDIRECTIVE-THERAPY#.DE. 21. SEARCH: PSYCHOTHERAPY#.W..DE. OR PSYCHOTHERAPY-BRIEF#.DE. 22. SEARCH: INTERNET OR WEB OR COUNSELING OR THERAP$ OR PYSCHOTHERAPY.AB. 23. SEARCH: HEALTH-EDUCATION#.DE. 24. SEARCH: HEALTH ADJ EDUCATION OR

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		PATIENT ADJ EDUCATION OR (PARENT$ ADJ EDUCATION).AB.
		25. SEARCH: HEALTH ADJ EDUCATION OR PATIENT ADJ EDUCATION OR PARENT ADJ EDUCATION OR PARENTAL ADJ EDUCATION OR (PARENTS ADJ EDUCATION).AB.
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		27. SEARCH: LEAFLET OR BOOKLET OR POSTER OR PAMPHLET OR INFORMATION ADJ SHEET OR FREQUENTLY ADJ ASKED ADJ QUESTIONS OR DVD OR CD OR VIDEO OR CDROM OR COMPUTER.AB.
		28. SEARCH: RESOURCE-GUIDES-PUBLICATION-TYPE#.DE.
		29. SEARCH: AUDIOVISUAL-AIDS#.DE.
		30. SEARCH: EDUCATIONAL-TECHNOLOGY#.DE.
		31. SEARCH: 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30
		32. SEARCH: COMMUNITY-INSTITUTIONAL-RELATIONS#.DE.
		33. SEARCH: (HOME ADJ VISIT).AB.
		34. SEARCH: GUIDE OR GUIDANCE.AB.
		35. SEARCH: 32 OR 33 OR 34
		36. SEARCH: 31 OR 35
		37. SEARCH: INFANT-PREMATURE#.DE.
		38. SEARCH: INFANT-LOW-BIRTH-WEIGHT#.DE.
		39. SEARCH: INFANT-VERY-LOW-BIRTH-WEIGHT#.DE.
		40. SEARCH: INTENSIVE-CARE-NEONATAL#.DE.
		41. SEARCH: INTENSIVE-CARE-UNITS-NEONATAL#.DE.
		42. SEARCH: (SPECIAL ADJ CARE ADJ BABY ADJ UNIT).AB.
		43. SEARCH: SPECIAL ADJ CARE NEAR BABY.AB.
		44. SEARCH: (PRETERM OR PREMATURE) NEAR (BABY OR BIRTH OR INFANT OR CHILD).AB.
		45. SEARCH: EARLY NEAR (BABY OR BIRTH OR INFANT OR CHILD).AB.
		46. SEARCH: 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45

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		51. SEARCH: CAREGIVERS#.W..DE.
		52. SEARCH: MATERNITY NEXT PATIENT
		53. SEARCH: FAMILY.AB.
		54. SEARCH: 48 OR 49 OR 50 OR 51 OR 52 OR 53
		55. SEARCH: 47 AND 54
		56. SEARCH: 48 OR 49 OR 50 OR 51 OR 52
		57. SEARCH: INFORMATION OR INFORM$ OR INFORMATION ADJ SEEKING ADJ BEHAVIOUR OR INFORMATION ADJ NEEDS OR (PARENT ADJ INFORMATION).AB.
		58. SEARCH: INFORMATION OR INFORM.AB.
		59. SEARCH: 1 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 58
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Table 2: Data extraction tables

2a. Randomised controlled trials:

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Glazebrook et al 2007 UK	RCT	Nursing Child Assessment Teaching Scale (NCATS) at neonatal unit, with optional follow-up	Parental Stress Index (PSI) Home Observation for Measurement of the Environment (HOME)	99	111	No significant differences reported at discharge or at 3 months after discharge.	1+
Koh 2007 Australia	RCT	Recording doctors consultation	Information recall 91% of mothers in the tape group listened to the tape (once by day 10, twice by four months, and three times by 12 months; range 1-10).	93	93	At 10 days and four months, mothers in the tape group recalled significantly more information about diagnosis, treatment and outcomes than control group. Recall at 10 days:1.35 (1.08 to 1.69) p<0.007, treatment 1.35 (1.00 to 1.84) and outcome 1.24 (1.05 to 1.47), p<0.009 than mothers in the control group. Recall at 4 months: diagnosis 1.27 (0.99 to 1.63) p<0.05, treatment 1.35 (1.00 to 1.84) p<0.045, and outcome 1.75 (1.27 to 2.4), p<0.004 No statistically significant differences were found between the groups in satisfaction with conversations (10 days), postnatal depression and anxiety scores (10 days, four and 12 months), and stress about parenting (12 months).	1+
Van der Pal 2007 Netherlands	RCT	NIDCAP	PSI Parents of Mother and Baby Scale Nurse Parent Support Tool	94	84	No significant differences were reported in Parental Stress Index, Confidence of parents, or perceived nursing support at 1 to 2 weeks after birth	1+
Kaaresen 2006	RCT	Mother-Infant Transaction Program The intervention consisted of 8 sessions shortly	PSI	71	69 preterm	Early-intervention program reduces parenting stress in both mothers and fathers during the first year after a preterm birth	1+

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		before discharge and 4 home visits by specially trained nurses focusing on the infant's unique characteristics, temperament, and developmental potential and the interaction between the infant and the parents.			75 term	to a level comparable to their term peers Mothers 6 mths - total stress: 16.9 (5.2 to 28.5) .005 Mothers 12mths – total stress: 13.7 (1.6 to 25.9) .03 Fathers 12 moths – total stress: 14.8 (2.1 to 27.6) .02	
Lai 2006 Taiwan	RCT	Effects of kangaroo care combined with music	State-Trait Anxiety Inventory (STAI)	15	15	Music during KC also resulted in significantly lower maternal anxiety in the treatment group on day 3 of the interention (t (19.6) =–2.14, p<.05). Maternal state anxiety improved daily, indicating a cumulative dose effect (F(1.49,40.39)=5.81, p<.01). Anxiety levels in the control remained unchanged	1+
Melnyk 2006 USA	RCT	Creating Opportunities for Parent Empowerment (COPE) - Information and behavioural activities about appearance and behavioural characteristics of preterm infants and how best to parent them.	Infant length of stay Parental Stressor Scale (PSS) State-Trait Anxiety Scale (STAI) Index of Parental Belief Scale	147 Mothers 81 Fathers	113 Mothers 73 Fathers	Mothers in the intervention group reported significantly less stress and less depression and anxiety at 2 months after birth. Anxiety: 28.72 (27.31-30.12) vs 30.83 (29.23-32.42)p<0.05 Depression: 5.56 (4.66-6.45) vs 7.21 (6.20-8.23)p<0.02 PSS: 3.29 (3.09-3.49) vs 3.58 (3.35-3.80), p<0.05 Parental Knowledge: 32(31.63-33.01)vs 30.50 (29.73-31.27)p<0.001 There were no significant differences found for Fathers anxiety or depressive symptoms. Infant length of stay at the NICU and at the hospital was significantly lower in the intervention group (3.8 days less in NICU, 3.9 days less in hospital p<0.05	1++
Browne 2005 USA	RCT	Family based intervention (Gp1: demonstration of pre-term baby behavioural cues; Gp2:viewed educational video and books about pre-term babies	Nursing Child Assessment Scale (NCAFS) and Knowledge of Preterm Infant Behavior Scale (KPIB)	Gp1: 28 Gp2: 31	25	Intervention group reported significantly greater sensitive interactions with pre-term babies, and significantly greater knowledge of pre-term babies than controls at 1 month after discharge (NCAFS 45.65, 6.20vs. 47.43, 7.36 vs. 48.88, 7.41, p<0.05; mean KPIB 23.32, SD 5.88 in group 1 vs. 25.90, 5.30, in group 2 vs. 19.58, 5.01 in group 3, p<0.001)	1+
Ferber 2004 Israel	RCT	Baby massage: I= to receive 15 massages 3 times per day for 5 days. Gp1: mothers conduct massage Gp2: Researchers conduct massage	Coding Interactive Behaviour Assessment for newborn	Gp 1: 18 Gp 2: 18	19	Significant results report that at 3 months, mothers of massaged infants were less intrusive, and interactions were more reciprocal. Gp1: Dyadic reciprocity (DR) – 2.42+0.87	1+

		Gp 3 controls				Maternal Intrusiveness(MI)-1.97+0.91 Gp2: DR – 2.46+0.99 MI – 1.68+0.63 Gp3: DR – 1.66+0.68 MI – 2.54+1.01 DR: F=4.69,p<0.01 MI: F=4.05,p<0.02 No significant difference in maternal sensitivity was reported.	
Als 2003 USA	RCT	NIDCAP (Neonatal individualised Developmental Care and Assessment Programme	PSI (Parental Stress Index)	38	38	Mothers in the intervention group reported significantly more favourable scores than the control group. Hospital 1: I= 35.7 (sd 21.3) C=44.9 (sd34.2) Hospital 2: I=55.8 (sd28.8) C=65.2 (sd27.5) Hospital 3: I=49.0 (sd28.6) C=55.9 (sd22.5) Group score ® = .41, p<.001 Summary: MANOVA: F=2.41, df=5.66, p<0.05	1++
Gray, 2000, USA	RCT	Babylink individual website information (CareLink)	The Picker Institute's Neonatal Intensive Care Unit Family Satisfaction survey			61% (31/51 parents completed the questionnaire) BabyLink families reported significantly higher scores in all other dimensions except in coordination of care. Within the dimension of overall quality, BabyLink families were 85% less likely to report problems with the duration of their child's hospitalization (6.7% vs 43.8%; p<04). Of those reporting problems most noted that their NICU stay was shorter than they felt necessary. Interestingly, even though the same visitation policies applied to both groups, BabyLink families were also less likely to report problems when asked if the unit's visitation policy met the needs of their other family members (13.3% vs 50%; p<02). BabyLink families also showed a trend toward fewer problems related to receiving practical support from the NICU (33.3% vs 68.7%; p<08). CareLink significantly improves family	1+

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						satisfaction with inpatient VLBW care	
Hall 2002 Canada	RCT	Weighing infant before and after feeds to assess maternal confidence in breast feeding	Parental sense of competence scale Maternal confidence questionnaire Influence of specific referents scale	30	30	No significant differences in maternal confidence or competence between weighed or not-weighed infants	1-
Huckaby 1999 USA	RCT	Photograph of baby given to mother to take with them while baby on neonatal unit	Bonding Observation Checklist (BOCL) Physical Examination Observation Checklist (PEOCL)	20	20	Mothers with picture had significantly better scores on bonding measure than those without picture (p<0.001 for BOCL and p<0.01 on PEOCL)	1+
Tessier 1998 Columbia	RCT	Effects of Kangaroo care	Mothers perception of premature babies questionnaire	246	246	Kangaroo care significantly increased mother's sense of competence in mothering their baby (F(1481) 10.36, P .001), and was significantly increased maternal sensitivity to their baby at the neonatal unit. (F(1481) 3.71, P .05). This improved perception of their baby effect is related to a subjective "bonding effect" that may be understood readily by the empowering nature of the KMC intervention. The study also reported a negative effect on the feelings of received support from health professionals of mothers practicing KMC (F 5.03, P .03). Kangaroo care significantly reduced length of stay especially in lighter babies. Two-way analysis of variance stratifying by birth weight showed that the savings in hospital stays were clearly related to weight at birth: an interaction effect (F(3480) 4.06, P .01) shows that the maximum saving in the KMC group was observed in infants weighing 1501 g (4.5 to 6.7 days), whereas in infants weighing 1500g, the length of hospital stay was virtually identical in both groups	1+
Meyer 1994 USA	RCT	Family based intervention (Psychological intervention for family, teaching care and	Parental Stressor scale	34	34	Intervention group reported significantly less stress (PSS) and reported significantly less depression (BDS) at	1+

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		behavioural cues of baby, home discharge plan)	(PSS) Maternal self esteem Inventory, Beck Depression Scale (BDS), Family Environment Scale			discharge. BDI: Int: 11% vs. 44%, p<0.05; 39% vs 31% NS. PSS: Int:2.4 ± 1.0; 2.0 ±0.8 vs Con 2.4 ± 0.9; 2.6 ± 0.8 p<0.05 No other significant results were reported.	
Spiker 1993 USA	RCT	Home Support (Infant Health and Development Program (IHDP) – Home visits from discharge up to 36 months	Quality of assistance in parenting pre-term baby Supportive presence for parents of pre-term infants	271	412	Intervention group reported significantly better quality of assistance ratings than control group (I: 3.6 [1.5], vs 3.3[1.5], p<0.05), but no significant difference on supportive presence was reported. Most outcomes in this study were baby outcomes.	1-
Cobiella 1990 USA	RCT	Two stress reduction programmes: a) Video-tape training in active problem – focussed coping strategies b) Video-tape in emotion-focussed strategies to manage anxiety	State-Trait Anxiety Inventory (STAI), Depression Adjective Checklist (DACL)	Gp. A – 10 Gp. B - 10	10	On post-treatment follow-up both the problem-focused and emotion-focused treatment groups were significantly less anxious than the controls and lower levels of depression were observed for the emotion-focused group STAI: PF-t(11)=2 71 p<0.01 EF-t2 56 p<0.02 DACL: PF – NS EF-t(12)=2 36, p<0.03	1-
Parker-Loewen 1987 Canada	RCT	8 X 40 minute interaction coaching to encourage sensitive responding by mothers	Satisfaction with Parenting Scale Knowledge of Infant Development Scale Life experiences survey Interaction rating scale	35	35	No significant difference between treatment and control group on interaction or knowledge of infant development or satisfaction with parenting	1-
Barrera 1986 Canada	RCT	Teaching developmental care	HOME Parent-infant interactions	40	40	At 4 mths and 16 mths, mothers in the Parent-Infant intervention group and full term control group were significantly better maternal responsiveness and mother-infant interaction compared to the pre-term baby control	1-

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						group. Manova: Maternal rseponsiveness I-7.32, FTC – 7.44, C- 6.41, f=6.78, p<0.001 Maternal involvement: I=7.23, FTC-7.16, C-6.26, f=2.70, p<0.05	
Nurcombe 1984 USA	RCT	Behavioural Assessment Scale: Mother-Infant Transaction Programme (MITP)	Hereford Parent Attitude Survey Seashore Self Confidence Rating Paired Comparison Questionn-aire	37	36	Intervention group scored better on maternal adaptation (role satisfaction, attitudes to child-rearing, self confidence) than low birth weight controls (F(3, 87), p<0.030. Univariate analysis: Maternal satisfaction F (2,89), 4.55, p<0.013 Maternal attitude (2,89), 4.05, p<0.021 Maternal self confidence F (1,89), 7.44, p<0.008 Full term controls scored better than combined low birth weight group (F [3,87], 3.27, p=0.025).	1+

2b. Quasi- experimental and cohort studies.

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant results	Quality (SIGN)
Byers 2006 USA	Cohort	Family-centred care/developmental supportive care	Questionnaire developed for study to measure parents perceptions and satisfaction. Study mainly reports baby outcomes	57	57	No differences in parent perception or satisfaction with the neonatal unit	2-
Jotzo 2005 Germany	Cohort	Psychological intervention to reduce stress at neonatal unit (One off psychological intervention to help parents cope with stress)	Questionnaire: Impact of events scale (IES) Trauma experiences measure	25	25	Mothers in intervention group had significantly lower traumatic impact from preterm birth (lower overall symptoms: traumatic impact I 25.2 (SD 13.9), C 37.5 (SD 19.2), mean difference 12.28 (2.74-21.82, p=0.013; lower avoidance I 7.7 (SD 5.3), C 12.4 (SD 8.4), mean difference 4.65 (0.67-8.69), p=0.023 and hyperarousal, I 5.9 (SD 4.7), C9.5 (SD 5.7), mean difference – 3.56 (0.61 – 6.51), p=0.019; lower intrusion symptoms but not significant). Control group: 76% of mothers showed clinically significant psychological trauma at discharge	2+

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						vs. 36% (p<0.01) in intervention group.	
Penticuff 2005 USA	Cohort	Discussion around Infant progress chart	Comprehension of infant medical condition and satisfaction with collaboration with health professionals while baby at neonatal unit	77	77	Intervention group had fewer unrealistic concerns (ANOVA): (4.32 (0.86) vs 8.56 (0.57), p<0.018; less uncertainty about the infant medical condition 1.92 (0.30) vs 3.52 (0.54), p< 0.003; had less decision conflict 45.88 (2.33) vs 59.10 (2.32), p<0.001; more satisfaction with medical decisions process 120.20 (4.07), 104.95 (4.33), p<0.012; more satisfaction with decision input 33.44 (1.30) vs 30.05 (1.21), p<0.058. No significant difference was reported in satisfaction of care for the infant by HC staff, and in satisfaction with decision made.	2++
Byers 2003 USA	Cohort	Co-bedding multiples in same incubator	NIDCAP infant behaviour State-Trait Anxiety Inventory Maternal Attachment Inventory Parental satisfaction tool	16	21	No significant results reported	2-
Preyde 2003 Canada	Cohort	Parent to Parent Peer Support	Parental Stressor scale (x) Sate-Trait Anxiety Scale (Spielberger)	32	28	Intervention group better scores on all measures at 4 or 16 weeks (groups were equivalent at baseline), e.g. mean PSS score 1.54 (1.3-1.7) in intervention group at 4 weeks vs. 2.93 (2.7-3.1) in controls, p<0.001 At 4 weeks mean PSS score was significantly less in the intervention group – 1.54 (1.3-1.7) vs 2.93 (2.7-3.1), p<0.001. At 16 weeks mean anxiety score, mean depression score, and perceived support were significantly less in the intervention group: anxiety - 31.4 (27.2-35.4) vs 38.6 (34.6-42.7), p<0.05; depression - 2.20 (0.89-3.60) vs 4.88 (3.51-6.17), p<0.01; perceived support – 6.49 (6.02-6.82) vs 5.48 (5.09-5.94), p<0.01. There were no different in trait anxiety between the groups at any time period.	2++
Feldman 2002 Israel	Cohort	Effects of Kangaroo care	Mother-Infant interaction scale Maternal depression Mothers perceptions HOME	73	73	At 37 weeks gestational age: After kangaroo care, interactions more positive, mothers showed more positive affect, touch, adaptation to infant cues, infants more alertness and less gaze aversion, mothers less depressed & viewed infants as less abnormal. Less maternal depression [KC mean 6.68 (5.55) vs control 9.05 (4.27), F=5.68, p<0.05]. At 3 months corrected age: mothers and fathers of kangaroo care infants more sensitive and provided better home environment. KC Mothers provided a better home environment Manova at 3 months – HOME: Wilks F (df=7,123), 2.99, p<0.01. KC fathers provided a better home	2+

						environment – HOME: Wilks F (df=7,110), 2.45, p<0.05. At 6 months corrected age: kangaroo care mothers more sensitive (maternal sensitivity: KC mean 4.20 (0.64) vs control mean 3.86 (0.76, univariate 5.36, p<0.05) & infants scored higher on Bayley Mental Development Index (96.39 vs. 91.81, p<0.01) and Psychomotor Development Index (85.47 vs. 80.53, p<0.05)	
Kurz 2002 Austria	Cohort	Home support (Phone call and counselling of parents after returning home) for parents of babies with monitors	Questionnaire about monitor use, stress reported by monitor use, and satisfaction	90	70	Home monitoring considered reassuring for 60% of families. After intensive counselling introduced, parents liked the instruction better (74% vs. 44% very satisfied; 24% vs. 51% satisfied; 2% vs. 5% not satisfied, p<0.005)), were less stressed by the monitor (42% vs. 63% stressed by false alarms, p<0.05) and reacted less aggressively to monitor alarms (8% vs. 24% reacted by vigorously shaking or lifting baby, p<0.05); used monitor mainly during sleeping periods; used monitor for less time (6.1 months vs. 7.6 months, p<0.05). Counselling did not reduce anxiety.	2+
Ortenstrand 2001 Sweden	Cohort	Early discharge with domiciliary nursing care Domiciliary nurse made an individual care and discharge plan together with the parents. During these planning sessions, parent's knowledge of how to care for their pre-term infant were checked and supplemented. The nurse was available for home visit/ telephone consultation from Monday to Friday, and at weekends parents could contact the neonatal ward	STAI	40	35	No differences in mothers' Trait anxiety at 1st or 2nd assessment. State (situational) anxiety lower for EDG mothers at 1st assessment (EDG 30.9 [SD 6.2] vs. CG 36.6 [8.4], p<0.01. Fathers showed a significant difference in trait anxiety at both 1st and 2nd study time period (30.1 (5.8) vs 33.5 (7.7), p<0.05, but only a significant difference in state anxiety at the 1st assessment (29.5 [5.4] vs32.8 [9.1], p<0.08. At 1 yr, no difference in recollection of anxiety in caring for the infant or in experiences of mental imbalance related to the birth of the infant	2+
Finello 1998 USA	Cohort	Home Support Gp1: Home healthcare and home visitng Gp2: Home healthcare only Gp3: Home visiting only	1 week after discharge: HOME CES-D FACES II 6 mths after: HOME 12 months: CES-D, FACESII HOME	81 in total	Not reported	Interventions improved the home environment (at 1 month, mean HOME 27.2, SD 6.0 for group 1 vs. 24.2, 2.7 for group 2 vs. 30.0, 6.2 for group 3 vs. 22.7, 3.3 for group 4, p<0.001; at 6 months, 33.7, 5.9 vs. 30.2, 4.3 vs. 34.4, 4.3 vs. 28.9, 5.0, p=0.003; at 12 months, 35.2, 5.2 vs. 31.2, 3.8 vs. 35.6, 5.3 vs. 30.5, 5.0, p=0.005). No difference between groups on FACES II at 1 or 12 months, or on maternal parenting satisfaction. The latter was more strongly associated with reports of support from husband (p<0.001), friend support (p<0.001) and family support (p<0.001). Mean depression score at 1 month 18.5 (SD 11.59, range 0-48 on a total scale range of 0-60; 16 considered cut-off for clinical depression (no differences between groups). Mean CES-D at 12 months 19.76, SD 10.21, range 2-42, still indicating clinically significant levels of depression. No other significant results were reported.	2+
Brown 1994 USA	Quasi experimental	Booklet, videotape and practical session. for parents of broncho-pulmonary dysplasia discharged from tertiary care centre.	Pre-test Post-test study Pre-test of	18 primary caregivers of 10 infants		Post-test scores (immediate mean = 17.33 [SD 3.91]; delayed 17.17 [4.41]) significantly higher than pretest scores (14.38 [3.72], p<0.01)	2+

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		Education on physical characteristics of infants on continuous low-flow oxygen & their care. Psychosocial development of infant, parental needs, oxygen equipment, CPR in NICU	knowledge immediately before and post-test immediately after programme; post-test repeated 6 weeks after discharge				
Lindsay 1993 USA	Cohort	Parent to Parent Peer support for parents with critically ill pre-term babies.	Parent report	NR	NR	Numerical data not reported in paper Reported benefit to parents: emotional support + Information support	2-
Rauh 1990 USA	Cohort	Vermont Mother-Infant Transaction Programme (teach parents to appreciate infants unique characteristics. teach behavioural cues, teach parents to respond to infant, enhance mothers enjoyment of baby).	Maternal Role Satisfaction questionnaire Self-Confidence rating Parent Attitude scale	40	41	At 6 months: significantly better intervention effects for maternal role satisfaction, self-confidence and perception of infant temperament in intervention group; no difference on maternal attitudes to child-rearing. Data not given in paper.	2-
Leonard 1989 USA	Cohort	Educational support programme for infants on home monitors (Infant Apnea Evaluation Programmes (IAEP)L Gp1 – with home monitoring Gp2- no home monitoring Gp3 – healthy term babies	Symptom checklist-90, schedule of recent events, satisfaction - all in interview 2 wks after going home	Gp1-40	Gp 2- 30 Gp3 - 32	Psychological symptoms highest in parents of non-monitored premature infants (M - 0.2845 [0 – 0.82] vs , NM – 0.4507 [0-1.3], p=0.037); particularly fathers of non-monitored infants scoring high on depression (0.6846)). Support highest in monitored infants (p=0.005) NS on family satisfaction .	2+
Resnick 1988 USA	Cohort	Educational developmental Intervention Programme at home – teach parents to use: parent's voice tape, massage, passive range of motion, exercises) and twice-monthly interventions at home by child development specialists through 12 months adjusted age (e.g. language and social skills enrichment exercises, cognitive development, motor exercises, parenting activities)	Greenspan-Lieberman Observations System (GLOS) to analyse infant-caregiver interactions at 6 and 12 months	21	20	Parent child positive verbal scores significantly higher in treatment than control groups (2.91 vs. 2.08), p=0.02. Intervention group dyads had fewer negative verbal interactions (0.07 vs. 0.17, p=0.03). The developmental intervention benefited the quality of the parent-infant interaction at home, as well as benefiting the infant development.	2-
Ross 1984 USA	Cohort	Teaching developmental care at home to lower socio-economic parents	HOME Maternal Attitudes Scale Maternal developmental Expectationsand child rearing attitudes survey Baby outcomes (not	44	40	Intervention group reported significantly higher HOME scores (total score 38.4 vs. 34.9, p<0.001). No other significant differences reported	2+

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			reported here)				
Piecuch 1983 USA	Cohort	videophone	No. of calls made to neonatal unit while baby at unit	17	17	Mean number of telephone calls to NICU used as proxy for interest in newborns. Mothers with access to videophone made more calls: (1.0 vs. 0.2, p< 0.05) when mothers hospitalised; (0.9 vs. 0.3, p<0.05) when mother discharged. Mothers appreciated videophone; relieved at being able to see infants; infant's condition not as bad as they had imagined; many talked to infant even though only viewing an image; wanted to see close-ups of hands and feet as well as face.	2 -

2c. Non-controlled studies (e.g. case series, cross-sectional, qualitative)

Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
Jones et al, 2007, Australia	Qualitative	To report mothers' and fathers' perceptions of effective and ineffective communication by nurses in the neonatal intensive care unit (NICU) environment	NICU 20 mothers and 13 fathers	Semi-structured interviews	None	The most frequently mentioned strategies for effective communication were discourse management and emotional expression, highlighting the importance for parents of communication that is both nurturing and shares the exchange of information as equal partners. Parents valued communication that was two-way and involved informal chatting as well as more formal discussions. Parents wanted provision of information in a reassuring and respectful way. The study highlights that not only do parents simply want lots of information they also want consistent information.	Strategies mentioned for effective communication were about shared management of the interaction and appropriate support and reassurance by nurses. Mothers emphasised more being encouraged as equal partners in the care of their infant.	3
Buarque, 2006	Qualitative	To investigate the influence of support groups on the family of risk newborn infants and	Neonatal unit 13 mothers, six fathers, two grandmothers and 16 healthcare workers	Semi-structured interviews	None	The analysis revealed that the support group to the family of risk newborns provided parents and family members with information, emotional support and strengthening so that they could come to terms with the birth of their child and his/her admission to the neonatal unit, in addition to enabling parents to take care	The support group to the family of risk newborns uses an approach that is based on family-centered care. These principles allow restoring parental competence, helping healthcare workers to respect values and feelings of family members, and establishing a collaborative work between parents and healthcare workers in	3

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		on neonatal unit workers.				of the newborn infant. There was interpersonal growth in the interaction between parents, family members, and healthcare workers.	the neonatal unit.	
Hurst et al, 2006	Qualitative	To identify parents' utilization and evaluation of a support program based in a newborn intensive care unit (NICU)	NICU 477 parents utilised support service, 48 completed survey	Program records and a survey developed by the author documented parental use and evaluation of services. Data analysis consisted of descriptive statistics and qualitative content analysis	Support programme that offered a combination of formats for support services: group support, one-to-one support, and telephone support	78% utilized 1 support service format exclusively. Eighteen percent utilized 2 support formats concurrently. A subsample of 48 parents completed an evaluation survey. Group support offered more opportunities for families to problem-solve communication issues with nursery personnel and provide information that assisted parents' involvement in their babies' care. Utilising more than one support format provided greater support for parents.	Parent support programs that utilize only one type of format may not be optimal for providing the range of support needed by many NICU families. Parent support programs offer an important mechanism to assess provider approaches to facilitate family-centered care.	3
Kowalski 2006,	Cross-sectional	To determine what information is wanted, who provides information and what expectations parents have regarding obtaining information.	Neonatal unit	A 19-item questionnaire was given to the parents of infants 32 weeks or younger prior to discharge from the NICU.	None	Out of the 101 parents who consented, almost all of the parents (96%) felt that 'the medical team gave them the information they needed about their baby' and that the 'neonatologist did a good job of communicating' with them (91%). However, the nurse was chosen as 'the person who spent the most time explaining the baby's condition', 'the best source of information,' and the person who told them 'about important changes in their baby's condition'	Although the neonatologist's role in parent education is satisfactory, the parents identified the nurses as the primary source of information.	3
Wielenga 2006, Netherlands	Qualitative	Evaluation of NIDCAP	NICU	NICU-Parent Satisfaction Form and the Nurse Parent Support Tool	NIDCAP	Parents were significantly more satisfied with care given according to NIDCAP principles than they were with the traditional care for their premature born babies.		3
Bennett 2005 UK	Qualitative	Evaluation of Rooming in (care by parent)	NICU	Interview	Rooming in (care by parent)	Most found it an extremely positive experience (scared but realised the opportunity to know each other more, feel a bit more in charge; promoting breastfeeding, increased bonding & confidence to take baby home).	Most mothers reported 'rooming in' to be a useful, informative time	3

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Broedsgaard 2005 Denmark		To present the parents' experiences of an educational programme	NICU 37 families with premature infants (<34 weeks)	Descriptive study Semi-structured interviews and focus groups	Educational programme (topic group discussions) for parents during hospitalisation; health visitor coordinator on NICU; visit and orientation about NICU for family's health visitor; multidisciplinary discharge conference; booklets for parents and health care providers; parents' evenings once a month after discharge	Families valued support and guidance from coordinator; having named contact nurse throughout child's stay; continuity of care; felt secure when they went home; NICU personnel and own health visitor collaborated well. They received extra visits from health visitor (most 4-6 extra but some >7 extra) in the first year and this was in accordance with their needs. Frustrated that mothers were on postnatal ward with mothers of full-term infants but they were separated from their infants (NICU on another floor). Felt that their needs not met in maternity unit. Felt assisted and reassured in NICU; the parents needed special care to tackle their situation and needed lots of information (repeated several times, plus written materials to reinforce). Discharge was time of anxiety; shock; needed to adjust; return home helped by meeting health visitor on NICU; 3-4 days rooming-in on NICU helped preparing to return home.	Intervention increased support, contributed to confidence in caring for infant and infant well-being after discharge.	3
Freer, 2005, Scotland	Case study	To report on Babylink (an individual website approach to sharing information with parents)	NICU	Descriptive reports from parents	Babylink individual website information	Parents reported the benefits of having access to information on their baby on a daily basis. BabyLink has been beneficial to families in communicating complex information and humanising the experience of neonatal intensive care.	An efficient means of keeping parents informed about the care and progress of their babies being cared for in the hospital's neonatal unit	3
Hawthorne 2005 UK	Cross-sectional	To evaluate Neonatal Behavioural Assessment Scale (NBAS) to support parent-infant relationship.	Neonatal unit 22 parents of premature infants	22 Questionnaire developed for study	Behavioural assessment scale	Parents reported: NBAS helped parents adjust to baby's behaviours, increased parents confidence in caring for their baby, satisfied their information needs about their baby.	NBAS can improve parents knowledge and improve their confidence in caring for their infant.	3
Remedios	Qualitative	To evaluate	Neonatal unit	Semi-structured interviews	Baby message	Parents reported feeling 'closer' to their	For the parents of a premature baby, baby	3

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2005, USA		the effect of baby massage on the parents of premature infants				infants, and reported improved confidence in caring for their infant. Parents felt the baby massage was beneficial to the infant and themselves.	massage can help improve the sense of closeness to their infant and improve their confidence in caring for their infant.	
Prentice 2004 Australia	Qualitative	To evaluate a develop-mental care	NICU – parents inter-viewed at home 9 parents in developmental care group compared with 8 historical controls before introduction of this programme into NICU	Retro-spective: Interviews: recall of mother's health and family functioning, particularly after discharge from NICU, review of family photos and memorabilia	Developmental care: forming partnerships with parents, Care by Parent programme	Developmental care group parents felt encouraged to be partners in infant's care (nervous of being hands-on but staff insisted which helped; fathers especially more than before); pre-DC parents were more onlookers than partners; inconsistency in amount of involvement they were allowed (depended on staff on duty); DC parents described comfort in reading infant cues and more confidence in responding; encouraged to dress baby (normalising experience). Sense of control & freedom when using Care by Parent area; felt more as though it was their baby. Pre-DC parents took time to develop confidence once at home; DC parents confident straight away. Partners also more confident, more congruent, both knew baby's personality, felt they knew baby really well. Both group maintained vigilance; DC group less anxious, more problem-solving, more self-reliant, whereas pre-DC parents found it difficult when there was no-one to tell them what to do. DC practices continued at home.	Developmental care seemed to help mitigate stress and provide new ways of coping to parents; encouraging an dinvolving the parents in care & decision-making led to greater self-reliance after discharge.	3
Jonsson 2003 Sweden	Qualitative	To report on an early discharge & home care programme	NICU 23 parents (17 women + 6 men) of babies on home care programme	Interviews	Home care programme – home visits at parent request (1 day-1 week apart); counselling & supervision	Becoming a family: do not feel like a family in NICU; shared infant with staff; feeling gradually disappeared when they went home. Being at home: nervous; less conflict between being with infant in hospital and being with other children at home Being reunited as a family; not having to share baby with others Feeling security: important for parents to have access to information and advice:	Parents wanted to come home earlier to feel like a family, but wanted security of access to staff knowledge & support	3

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						checked with checklist with the neonatal nurses; had questions when they got home Needed accessibility, usually by telephone, with home care team Needed support from health care professionals and relatives		
Lawhorn 2002 USA	Case series	To report on a facilitating parent assessment of infant behaviour and supportive responses	NICU Convenience sample of 10 infants (≤1500g, ≤32 weeks, appropriate for gestational age, no congenital abnormality) + 18 parents	Videotaped parent-infant interactions	An individualised nursing intervention based on assumptions of parent and infant competence; discussion of videotaped interactions to discuss infant cues and promote supportive responses	The intervention enhanced the parents' ability to appraise the infant's behaviour and respond in a supportive manner (data not presented). Parents found it helpful in getting to know their infant and being more empowered in the infant's care.	NICU staff should support parents in gaining greater understanding of infant and sensitive interactions; parents need to be active collaborators in infant care	3
Fenwick, 2001, Australia	Qualitative	To Gain a greater understandin g of the woman's experience of mothering in the nursery and how nurses' social interaction and verbal exchanges impacted on this experience	Special care nursery 28 women The average age of the women was 28 years (range 19±41) 15 gave birth at 30 weeks or less.	Semi-structured interviews	None	Nurses engaging in such 'chatting' resulted in the development of relationships that were reciprocal and interdependent rather than undesirable or difficult to achieve. Mothers described this as personal, and forming friendships. While women commented that all the facilitative behaviours were important, nurses who `chatted' in this way were singled out particularly as those that truly made a difference to their nursery experience.  It was these nurses that all the women in the study identified as the people who `most' facilitated their efforts to learn and take up their role as mothers, feel in control of the situation and, ultimately, assisted them in developing a connected relationship with their infants.	The results of this study relate to the importance of the shared `social' interactions between mother and nurse and the role these played in developing `personal' and `equal' relationships. This allowed the nurse to enter the woman's world and to facilitate their access to psychosocial information that assisted them in validating the woman's experiences, and helped them to plan individualized care that met the needs of the infant, mother and family	3

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Pearson 2001 USA	Qualitative	To evaluate a programme to promote positive parenting in NICU (Parent's Circle)	NICU (level III and special care (level II) nurseries 104 parents (59 mothers + 45 fathers) who attended Parent's Circle, + 44 NICU or special care nurses	Interviews	Parent's Circle: 90-minute information session + support to parents as they cope with early birth – allows parents to tell their story; curriculum based on parents' needs, includes development, how parents can help baby, how baby responds to stimuli, learning to read subtle cues from infant& respond appropriately, getting parents involved in infant care plan, sharing resources	Parents learned that they: could still parent even when baby is in hospital; could receive support from people going through similar experiences. They helped normalise the experience, helped parents to interact with their baby. Book list and classes were available after discharge. Staff reported that attending the Parent's Circle instils confidence in parents, helps them read baby's signals, normalises, introduces concepts such as kangaroo care that parents then want to try.	Attending Parent's Circle helped families gain perspective, feel supported, learn key developmental concepts, locate hospital and community resources, and optimise interaction with infant	3
Gannon 2000 USA	Case series	To evaluate 'Caring one day at a time' book	NICU 5 pilot families	Survey	'Caring one day at a time' book – three-ring binder book to organise information about child's medical, developmental and financial records from birth until adolescence and beyond	Allows parents to keep all information together, speeding up process when they have to see a new doctor for example & giving parents more confidence; allows parent to see child's progress (giving hope); allows new professionals to see history/ current status/ current medication etc written down	This family-centred approach with early involvement of families in child's care; enhances communication between families and professionals	3
White 2000 USA	Case series	To evaluate feeding support by occupation-nal therapists (OTs)	NICU 9 parents of premature infants receiving OT services for	Interview questionnaire	OTs involved in parent education in NICU (e.g. oral-facial stimulation, positioning, oral	Parents reported receiving education about oral-facial stimulation and oral support techniques (9/9 reported), positioning, typical feeding development (8/9 reported); hands-on training and demonstration reported most frequently.	Parents perceived OTs were providing effective education & support in infant feeding techniques	3

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			feeding issues		support techniques, typical feeding development) using demonstration, discussion, hands-on training, handouts, videos etc.	Overall, parents felt 'confident' or 'very confident' in their ability to understand topics. 5/9 indicated they thought they would not need additional help after discharge; 3/9 felt they would; 1 unsure.		
Langley 1999 UK	Cross-sectional study	To evaluate a home support - Community Neonatal Service	Home	Questionnaire developed for this study	Home support programme	Families reported feeling supported, and appreciated continuity of care after discharge. This benefit was reported more in vulnerable parents (isolated mothers, mothers with babies who had sleeping, crying or feeding problems).	Community Neonatal Service provided important support to families where mothers are vulnerable, or where infant has difficulties.	3
Bracht 1998b Canada	Cross-sectional	To report parent perceptions of NICU follow-up clinic	NICU 16 families attending clinic	Satisfaction survey – methods not described	Integrated Neonatal Follow-Up Program: comprehensive, long-term developmental assessments, diagnosis & referral for children at high risk of developmental delay	All families reported that they were very satisfied with services provided by multidisciplinary team; they valued information & support re high risk infant; but needed more information re growth & development, nutrition needs, medical concerns (e.g. asthma).	Continuity of care provided by clinic staff nurses provided: support, education, written information; maintenance of rapport developed during hospitalisation; and liaison with community resources	3
Costello 1998 Canada		To assess mothers' perceptions of Care by Parent programme	NICU and Level II nursery 6 mothers of preterm infants	Interviews the day after Care by Parent overnight stay in hospital, and when baby home at least 4 days	Care by Parent programme – mother stays with baby in room near NICU – assumes all care but help at hand if needed.	Mothers found Care by Parent reassuring to confirm their own and the baby's readiness for discharge; builds confidence in mother's parenting abilities; feeling more comfortable about bringing baby home; feeling confident in taking responsibility, making the right decisions; feeling more secure that mother would wake when baby cried & be able to respond; reassured that baby medically ready to go home (e.g. not having apnoea spells). Helped mothers	Care by Parent gave mothers opportunity to assume full responsibility for baby's care knowing that staff available if necessary. It helped mothers learn caregiving and confirm readiness for discharge.	3

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						learn about infant's pattern of behaviour & responses to infant's cues. Fail-safe opportunity; taking responsibility with a safety net. Opportunity to 'test reality' of parenting – feeling more as though the baby belonged to the mother not the nurses; facilitates transition to parenthood in reality; bridges gap between hospital and home.		
Elliott 1998 Canada	Qualitative	To evaluate a telephone follow up programme to support breast-feeding	Home 20 mothers	Structured interview	Telephone call with structured questions to complete form (e.g. feeding patterns, any problems, plan to address problems, any referrals needed)	All mothers reported finding telephone call helpful and increasing their confidence in continuing to breast feed.	Telephone support can help mothers breastfeed premature infants at home	3
Koh 1998 Australia	Cross-sectional	To evaluate tape-recording doctor-patient communication	NICU 80 parents of babies admitted to NICU	Questionnaire	Tape recording initial conversation between parents and neonatologist (covering baby's condition, management, likely progress and outcome) and subsequent important conversations and giving parents the tapes	Parent response rate=76% (75/99). Mothers listened to the tape on average 2.5 times, Fathers listened to the tape on average 1.8 times; tape usefulness rated as 9 (SD: 7-10) by parents. 85% (44/75) of parents who listened to the tapes again found it contained things they had forgotten – some mothers who had been sedated had forgotten the conversation had taken place. Relatives were also able to listen to tape & saved parents repeating what doctor had said. Parents found tapes comforting & supportive. No negative comments.	The tape recording of parent-doctor consultations was useful to parents, particularly in reminding them of information they had forgotten or not heard due to anxiety or sedation during the consultation.	3
Macnab 1998 Canada	Cross-sectional	Evaluation of Journal writing	Special care nursery (SCN) 73 parents	Survey 6 weeks after giving information booklet on journal writing	Giving information about journal writing	32% kept a journal; 73% found it reduced their stress; 68% used it as a means to address the most stressful elements of the experience (most stressful elements were the feelings engendered by having a baby in special care & interactions with staff; the same	Encouraging parents to keep a journal is a constructive way to deal with SCN-related stress.	3

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						percentage as those talking things through with a friend to reduce stress). Journals were used to document involvement in care (45%), record keeping (36%) and organising thoughts (27%). All those who kept a journal recommended it to others. Positive feelings were holding baby for the first time; meeting & speaking with other parents; openness and honesty of nursery staff; impression that infant was loved and cared for. Parents said the journal would be a record for the child for later; helped to record progress & show how well parents coped. Parents made suggestions that photos etc should be included in the journals.		
Griffin 1997 USA	Qualitative	To evaluate a tour of neonatal unit prior to birth if high risk pregnancy diagnosed	NICU 10 mothers 3 fathers	Interview	Tour of NICU	All parents recommended that parents diagnosed with a high-risk pregnancy be offered a prenatal tour of the NICU. The tour benefited parents and (a) decreased fears, (b) inspired hope for the infant's prognosis, (c) provided reassurance about the care in the NICU, and (d) prepared parents for their infant's hospitalization in the NICU		3
Swanson 1997 USA	Case series	Evaluation of neonatal integrated home care program	NICU/ home	Descriptive	Neonatal integrated Home Care Program – follow up care to high risk neonates at home, teaching re specific infant care needs (e.g. feeding)	Program made it possible to bring home baby, nurse provided help, support, instruction & encouragement (e.g. with nasogastric feeding tube)	Families supported to take high risk infants home sooner, ease transition from NICU to home & keep them home (i.e. reduce readmissions)	3
Costello 1996 Canada	Qualitative	To describe a parent information binder system of individual-ising info for	NICU	'Written and verbal feedback' on the binder – not formal assessment	Parent information binder Includes relevant individualised information for	Binder facilitates organisation of information over time and therefore parents were empowered to be active in acquiring information relevant to their particular infant; and had improved understanding and ability to participate in decision-making. Helps ensure	Facilitates collaboration between parents and health professionals, keeps parents informed, aids decision making.	3

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		parents on NICU			parents about their infants – e.g. admission, feeding, parent clinical, and discharge. Binder taken to weekly parent support group meetings where info can be added or questions asked.	consistent communication between health professionals and parents, and health professionals know what has already been shared with parents		
Jarrett 1996 USA	Case series	Evaluation of parent support programme	Neonatal unit	Reported discussion	Parents were trained to be parent partners – being taught factual information and to be active listeners. Trained parents matched with new parents by infant characteristics	Parents reported feeling less anxious and less worried about their infant. The program was meeting its goal of support and programme provided a special relationship where parents in the NICU could take their worries and concerns. This relationship was most often nurtured through exchanges on the telephone, but parents also met in the parent lounge that was set up as part of the parent support effort in the hospital. New parents unanimously reported that the most helpful thing about the program was the comfort in talking with someone who had experienced a similar situation.	The parent support programme has provided parents with trained partner parents reducing parents level of anxiety and improving their confidence with their infant.	3
Drake 1995 USA		To assess a method of prioritising information needs of parents for discharge	NICU Pilot study of 10 parents	Q-sort – ranking of topics in order of priority to parents for learning prior to discharge; feedback on how easy Q-sort was to complete	Card sort method of prioritising teaching/learning topics that parents need prior to discharge	Parents sorted 14 topics into most important, important, and least important piles and had opportunity to add in 3 other topics they wanted. Parents' highest priorities were infant CPR, illness and development, with feeding, giving medication & hygiene issues medium priority and use of car seat & getting help at home low priorities. Parents and nurses found it helpful to assess what parents needed to know – better than closed questions to parents like 'Do you know how to give the baby a bath?' which can be threatening	Parents are the best sources to assess their learning needs, and addressing topics parents feel are important helps teaching and learning, especially if nurse does not know family well.	
Legault	Cross-	Effects of	NICU	Satisfaction questionnaire	Kangaroo (skin to	Kangaroo method was preferred by	Kangaroo method encourages early contact	3

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1995 Canada	sectional	kangaroo (skin to skin) care	61 mother-infant dyads experiencing both traditional and kangaroo-type transfers from incubator	Maternal Satisfaction Question-naire	skin) care	73.8% of mothers, mainly because the infant was closer to them and they could touch them more easily.	with infant& induces feelings of wellbeing & fulfilment in parents	
Affonso 1993, USA	Qaultiative	Evaluation of Skin to skin care (SSC) for premature infants	NICU Mothers	Interview	Kangaroo care	SSC provided a way for mothers to know their infants, to develop strong positive feelings towards them, and to reconcile their feelings about having a premature birth, so that emotional healing could take place.	Kangaroo care improved mother-infant interactions.	3
Gale 1993 USA	Case series	Effects of kangaroo (skin to skin) care	NICU 25 intubated infants and their parents	Interviews	Kangaroo (skin to skin) care	Parents described kangaroo care as beneficial, giving stronger identity with and knowledge of infant; greater confidence in infant's need for them and their ability to need these needs; greater confidence in asking questions	Nurses can support parental attachment by supporting kangaroo holding	3
Meier 1993 USA	Cross-sectional	Breast feeding support	NICU 132 parents of premature infants	Survey	Breast feeding intervention record	Mothers more likely to be breast feeding than comparable populations	Breast feeding support encourages mothers in the NICU to breast feed and to continue to breast feed for longer.	3
Culp 1989 USA	Cohort	Demonstra-ting assessment of Premature Infant Behavior (APIB)	NICU 14 couples + premature infants (<32 weeks)	Alternate allocation to demonstra-tion of assessment (2 weeks before assessment of outcome) or not until afterwards STAI Neonatal Perception Inventorry	Demonstrating assessment of Premature Infant Behavior (APIB)	Intervention fathers reported lower anxiety than non-intervention fathers (p<0.05).Both mothers and fathers in intervention group had more realistic perception of newborns (p<0.04). Intervention mothers more aware of newborn's abilities to shut out disturbing stimulation on repeated exposure (p<0.02)	Intervention appeared to reduce paternal anxiety and fostered more realistic perceptions of the premature infant	3
Szajnberg 1987, USA	Qualitative (within cohort for infant outcomes)	Evaluation of Brazelton Newborn Behavioural Assessment Scale	Home	Structured interview	BNBAS	At 6 months, mothers in the intervention group remembered more details from the BNBAS than control mothers did of the standard physical examinations. Intervention mothers tried more exam items at home and found more of the		3

		(BNBAS)				items helpful. There was a trend for mothers to visit their infants more often after the intervention.		
Zeanah 1984 USA	Case reports	Psycho-therapy	NICU	Interview	Psychotherapy	Psychotherapy helped parents accept their feelings and conflicts as common to many NICU parents; Case conferences helped clarify misconceptions that had arisen because of the large number of people involved in baby's care. When unable to travel to unit, calls kept parents informed, enhanced participation; consistency maintained in information given, questions encouraged. Parents were encouraged to make tape of themselves singing & talking to baby, telling stories so that they could 'be with' her even when they were at home; encouraged to discuss using photo of infant. Became able to discuss disappointment about babies many problems and anxiety about long-term effects & involvement with babies increased.	Psychotherapy as crisis intervention, supportive and insight-orientated (awareness that conflicts interfere with optimal parent-infant relationship	3
Dammers 1982 UK	Case Series	To report parents' perceptions of support group	Neonatal unit	Reported discussion		Parents reported having increased knowledge and greater confidence in caring for their infant	Parents found the support group beneficial in increasing their knowledge and confidence	3
Isaacs 1980 USA	Case series	Evaluation of newborn Intensive Care Coordinator	Home 40 families of high-risk infants discharged from NICU	Questionnaire	Home visits for teaching, guidance and support	More than 2/3 parents felt concerned about infant discharge and had anxiety about caring for infant at home. All families strongly agreed that the coordinator made families feel completely comfortable, they had complete trust in her, she was available, she gave emotional support, felt they could discuss fear & worries with her, and helped them mother infant. Teaching gave support, confidence & necessary skills.	Coordinator met the needs of parents	3

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Ethics Approval:

Ethics approval was gained for the study through MREC, South East Ethics Research Unit (ref: 06/MRE 01/6)

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Guarantor: The University of Warwick, Coventry, CV7 4AL is the guarantor of this study

WHAT IS ALREADY KNOWN ON THIS TOPIC

It has long been recognised that family-centred care at the neonatal unit is beneficial no for the parents of premature infants, but for the infants themselves. While the importan family centred care is known, neonatal units are unsure which are the most effective far centred care interventions to support, communicate with, and provide information to the parents

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WHAT THIS STUDY ADDS

The evidence from the systematic review provides a summary pathway of family-centre care interventions to assist in providing support, information and communication with pa of premature infants throughout their stay at the neonatal unit and after discharge home

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3. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this paper? No

4. Have you acted as an expert witness on the subject of your study, review, editorial, or letter? No

5. Do you have any other competing financial interests? If so, please specify. No

Contributorship statement

JB conducted the systematic review, sat on the advisory group and steering group for the study, synthesized the evidence and wrote the drafts of the paper.

SS was the principal investigator of the study, obtaining funding for the study, sat on the advisory group and steering groups for the study, over saw all stages of the study, assisted in the identification and quality assessment of the evidence, and assisted in the writing of the first draft of the paper.

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MN was the fund holder, sat on the advisory group and steering group of the study and commented on the synthesis of the evidence and draft papers.

NJ was the patient representative on this study. She was integral in the development of this project, in the development of the proposal, sat on the advisory group and the steering group, and commented on the synthesis of the data and the drafts of the paper

LT was integral in the development of this project, in the development of the proposal, sat on the advisory group and the steering group, and commented on the synthesis of the data and the drafts of the paper

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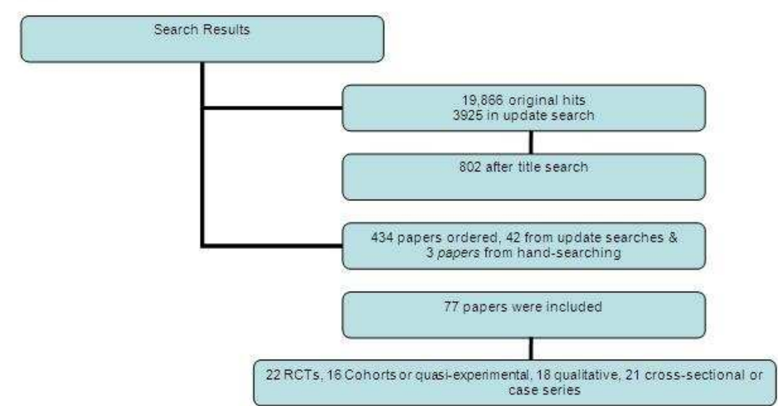

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Figure 2: Individualised developmental and behavioural care programmes

1) COPE[4] (Creating Opportunities for Parent Empowerment) provides an educational programme for parents at the neonatal unit on the appearance and behavioural characteristics of pre-term infants, how parents can participate in their infant's care, and how parents can make more positive interactions with their infant.

2) NIDCAP[11,12,13] (Neonatal Individualised Developmental Care and Assessment Programme) is an intervention that stimulates pre-term infants and improves the interaction between mothers and infants

3) MITP (Mother-Infant Transaction Programme)[14,15,16] helps to enable the parents to appreciate their infant's unique characteristics, temperament, and developmental potential, sensitising parents to their infant's cues so that they can respond appropriately.

4) NCATS (Nursing Child Assessment Teaching Scale) NCATS (Nursing Child Assessment Teaching Scale)[17] : Examines the mother-child relationship in conjunction with teaching mothers how to interact with the baby, teaching behavioural cues, how to play etc

NB: While the developmental care programmes are designed to improve the development of the baby, these interventions give parents psychological support and practical guidance on how to care for their infants.

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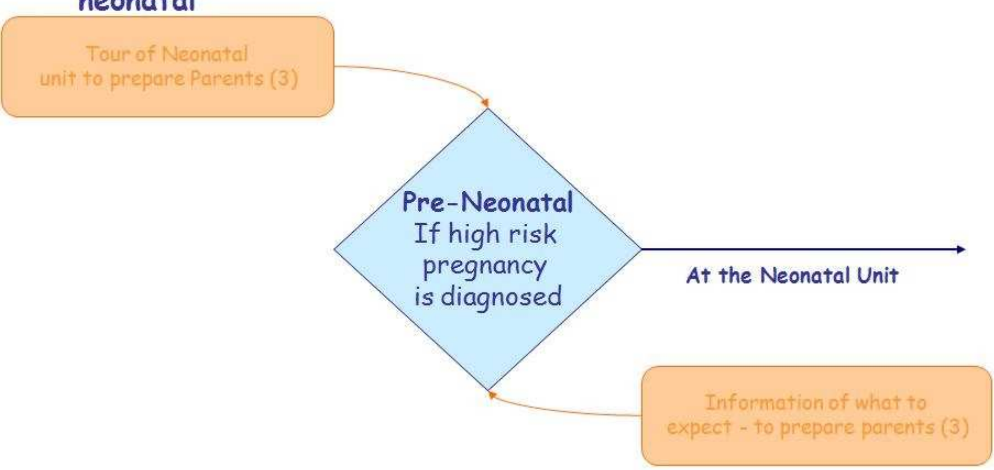

SIGN level of evidence used to grade evidence e.g. (3), or (1+) as described in SIGN table

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Figure 4

Scottish Intercollegiate Guideline Network (SIGN) Levels of Evidence

Level	Description
1++	High quality meta analysis, systematic reviews of RCTs, or RCTs with very low risk of bias
1+	Well conducted meta-analysis, systematic review of RCTs or RCTs with low risk of bias
1-	Meta analyses, systematic reviews of RCTs, or RCTs with high risk of bias
2++	High quality systematic reviews of case-control or cohort studies High quality case-control studies with a very low risk of confounding bias, or chance and a high probability that the relationship is causal
2+	Well conducted case control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal
2-	Case control or cohort studies with high risk of confounding, bias, or chance and a significant risk that the relationship is not causal
3	Non-analytical studies, e.g. case series, case reports, qualitative
4	Expert opinion

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PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2,3,4,5
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	www.poppy-project.org.uk
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A Few quantitative studies
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A Few quantitative

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			studies
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	7

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Few quantitative studies
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Discussed in limitations
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	18-31
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A Non-quantitative analysis performed
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	30-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	31

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Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Big Lottery

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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Page 2 of 2

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A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of pre-term infants

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Keywords:	NEONATOLOGY, Community child health < PAEDIATRICS, Social Health

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A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of pre-term infants

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Abstract

Background and Objective: The birth of a pre-term infant can be an overwhelming experience of guilt, fear, and helplessness for parents. Provision of interventions to support and engage parents in the care of their infant may improve outcomes for both the parents and the infant. The objective of this systematic review is to identify and map out effective interventions for communication with, supporting and providing information for parents of pre-term infants.

Design: Systematic searches were conducted in the electronic databases Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS. Hand-searching of reference lists and journals was conducted. Studies were included if they provided parent-reported outcomes of interventions relating to information, communication, and/or support for parents of pre-term infants prior to the birth, during care at the NICU, and after going home with their pre-term infant. Titles and abstracts were read for relevance and papers judged to meet inclusion criteria were included. Papers were data extracted, quality assessed and a narrative summary was conducted in line with the York Centre for Reviews and Dissemination guidelines.

Studies reviewed: 72 papers identified, 19 papers were randomised controlled trials, 16 were cohort or quasi-experimental studies, 37 were non-intervention studies.

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Results: Interventions for supporting, communicating with, and providing information to parents that have had a premature infant are reported. Parents report feeling supported through individualised developmental and behavioural care programmes, through being taught behavioural assessment scales, and through breast feeding, kangaroo care and baby massage programmes. Parents also felt supported through organised support groups and through provision of an environment where parents can meet and support each other. Parental stress may be reduced through individual developmental care programmes, through psychotherapy, through interventions that teach emotional coping skills and active problem solving, and journal writing.

Evidence reports the importance of preparing parents for the neonatal unit through the neonatal tour, and the importance of good communication throughout the infant admission phase and after discharge home. Providing individual web-based information about the infant, recording doctor-patient consultations, and provision of an information binder may also improve communication with parents.

The importance of thorough discharge planning throughout the infant's admission phase and the importance of home support programmes are also reported.

Conclusion: The paper reports evidence of interventions that help support, communicate with and inform parents who have had a premature infant throughout the admission phase of the infant, discharge, and returning home. The level of evidence reported is mixed, and this should be taken into account when developing policy. A summary of interventions from the available evidence is reported.

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Article focus:

A systematic mapping review to identify and synthesize evidence of effective interventions for communicating with, supporting and providing information for parents of pre-term infants.

Key messages:

- The review highlights the importance of encouraging and involving parents in the care of their pre-term infant at the neonatal unit to enhance their ability to cope with and improve their confidence in caring for the infant, which may also lead to improved infant outcomes and reduced length of stay at the neonatal unit.

- Interventions for supporting parents included: 1) involving parents in individualised developmental and behavioural care programmes (e.g. COPE, NIDCAP, MITP) and behavioural assessment programmes; 2) breastfeeding, kangaroo care and infant massage programmes; 3) support forums for parents; 4) interventions to alleviate parental stress; 5) preparation of parents for various stages, for example seeing their infant for the first time, preparing to go home; 6) home support programmes.

- Involving parents in the exchange of information with and between health professionals is important, with various modes of providing this information reported, for example ward rounds with doctors, discussion around infant notes, websites, and hard copy information.

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Strengths and limitations of study:

Strengths

This is the first review to synthesize the evidence of interventions to support parents of pre-term infants through improved provision of information, improved communications between parents and health professionals and alleviation of stress at all stages of a parents journey through the neonatal unit. It highlights relatively inexpensive interventions that can be integrated into their pathway through the neonatal unit and going home, enhancing parental coping, and potentially improving infant outcomes and reducing the infants length of stay at the neonatal unit.

Limitations

The quality of the evidence that this review reports is variable, and includes all types of study designs. It has been difficult to evaluate one piece of evidence over another because of the nature of the evidence. For example, whether RCTs are an appropriate method of evaluating the parents' experiences of interventions over and above, say, a qualitative study is debatable. While the RCT studies are more objective, they often fail to provide a more indepth empirical reality of parents' experiences of having a premature infant. A well conducted RCT may not provide a true reflection of improved self-esteem or empowerment, for example. Whereas a qualitative study, provides an understanding of the experiences. Furthermore, evaluation of such complex interventions is challenging because of the various interconnecting parts of the pathway reported in figure 2.

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It is therefore very difficult to evaluate the results to say that one study method is better than another. For this reason we have been inclusive in our selection of studies, resulting in a large number of studies selected for the review. Being inclusive of studies benefits the evidence base by bringing together 'experience' studies in a systematic way gaining a greater breadth of perspectives and a deeper understanding of issues from the point of view of those targeted by the interventions. However, if studies were fatally flawed they were excluded from the review.

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Introduction

While medical advances mean that very premature neonates have an increasingly better chance of survival, the impact of this experience on the child and their parents cannot be underestimated. The birth of a pre-term infant can be an intensely stressful, confusing and difficult time for parents and families[1]. Parents can have feelings of fear about their infant's condition or doubt in their ability to care for the child. Parents may also experience anger or grief, or they may blame themselves and experience intense guilt. Once mothers have returned home, hospital visits to see their baby can be difficult if coping with other siblings and travelling long distances to the neonatal unit[2]. It is therefore not surprising that mothers of pre-term babies experience significantly higher levels of post-natal depression than mothers of healthy full-term infants[3]. Fathers, who are often the main source of comfort and support for their wives, report feeling powerless to help, and often feel isolated from their infant as the health professionals focus on the infant and mother[4].

Furthermore, while going home with their infant can be a time of joy and relief for these parents, bringing home a fragile infant and caring for them on your own for the first time can be a worrying time, causing additional stress for the parents.

Reducing parent stress and introducing interventions to improve parents confidence and ability to care for their premature infant at the neonatal unit and after

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returning home can improve outcomes for parents and their child, reduce the length of stay at the neonatal unit[5,6] and reduce the re-admittance to hospital[7].

The Parents of Premature Babies (POPPY) study aims to develop a better understanding of the experiences of a range of parents with pre-term babies, particularly with regards to the communication, information and support they received on the NICU, ensuring that the perspectives of parents are at the heart of the study[8]. This paper reports the results of the first phase of the POPPY study, which takes the form of a systematic mapping review to identify effective interventions for communicating with, supporting and providing information for parents of pre-term babies.

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Methods

Systematic searches were undertaken for the period of January 1980 to October 2006 in the following databases: Medline, Embase, PsychINFO, the Cochrane library, CINHAL, MIDIRS, HMIC, and HELMIS (see table 1 for search strategy). A combination of text terms and MeSH terms were used to maximise the volume of literature retrieved. Grey literature was sought from specialists in the field, and the following journals were hand-searched from 1990 onwards for all relevant English language articles: Neonatal Network Journal, Journal of Neonatal Nursing and Journal of Obstetric, Gynecologic, and Neonatal Nursing. Update searches were undertaken in October 2009.

Studies were included if they met the inclusion criteria:

- Outcomes reported by parents who have had a premature infant (i.e. ≤36 weeks gestation).
- Provided parent-reported outcomes (i.e. outcomes were reported by the parent themselves, not reported by health professionals or others) of interventions relating to information provision at the neonatal unit and after discharge.
- Provided parent-reported outcomes of interventions relating to communication with health professionals at the neonatal unit and after discharge.
- Provided parent-reported outcomes of interventions relating to provision of support at the neonatal unit and after discharge.

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- Design of study was: RCTs, Quasi experimental, cohort, case-control, cross-sectional, case series, case reports, or qualitative
- Studies were relevant to that of developed countries
- Passed quality assessment
- Published between January 1980 to October 2009
- English language

Studies were excluded in the met the exclusion criteria

- Reported parent-reported outcomes of parents who had a sick full-term infant at the neonatal unit.
- Outcomes were not reported by parents (e.g. evaluation of parent intervention by health professionals)
- Editorials or opinions
- Study was fatally flawed
- Not English Language
- Published before Jan 1980

It was felt that the systematic review should be inclusive of all study designs as it is often not feasible or appropriate to conduct randomised control trials (RCTs) or other intervention studies on the outcomes for parents that were measured. It was deemed therefore that, despite the potential bias inherent in descriptive studies, the results of these studies nonetheless gave an important insight into parent-related interventions and should be included in this review.

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The data extraction form and quality assessment for inclusion criteria were based on the guideline from the NHS Centre for Reviews and Dissemination (NHS CRD)[(9)] Initially, two reviewers extracted data (JB, SS) independently for 20% of papers and disagreements were resolved by discussion with a third reviewer. There was a high level of agreement between reviewers, so the remaining data was extracted by one reviewer and checked by a second. Any disagreements were resolved by discussion with a third reviewer. The quantitative studies covered a wide range of interventions and different methods of assessment so it was not possible to carry out a meta-analysis. A non-quantitative synthesis was conducted based on the extracted data. In the summary figure (Figure 2), the included evidence was assessed using the Scottish Intercollegiate Guidelines Assessment (SIGN)[(10)].

Search Results

Figure 1: The results from the literature search.

Seventy two papers were included (four were deemed relevant in two of the sections). Papers were excluded for a number of reasons including the fact that no parent outcome was identified, the study was irrelevant to neonatal services offered in developed countries such as the UK (3), or the study was deemed to be fatally flawed (11)

Tables 2a to 2j report the data extraction by sections described below in the results section. Figure 2 below provides a summary of evidence for interventions at the neonatal unit and after discharge.

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Figure 2: Summary of evidence for interventions at the neonatal unit and after discharge

Results

Interventions for supporting parents included: 1) individualised developmental and behavioural care programmes[4,11,12,13,14,15,16,17] (e.g. COPE, NIDCAP, MITP – see below); 2) behavioural assessment scales; 3) breastfeeding, kangaroo care and infant massage programmes; 4) support forums for parents; 5) the alleviation of parental stress; 6) preparing parents for seeing their infant for the first time; 7) communication and information sharing; 8) discharge planning; and 9) home support programmes.

1) Supporting parents through individualised developmental and behavioural care programmes

Figure 3: Individualised developmental and behavioural care programmes

Fourteen studies reported individualised developmental and behavioural care programmes, of which nine were RCTs. The RCT evidence (1++ & 1+) suggested that the involvement of parents in an individualised developmental and behavioural care programme significantly reduced the maternal stress created by the NICU environment and the demands of their infant [4,11,14,16,18,19]. This intervention also significantly improved the parental understanding of their infant and their interactions with their infant[4].

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Recent RCT evidence suggested that the introduction of the NIDCAP intervention had not significantly changed levels of parental stress, confidence or nursing support. However, the outcomes were measured only 1-2 weeks after the baby was born (Van der Pal 2007, 1+)[(12)]. The introduction of the NCATS programme in the NICU made no significant difference to parental stress levels and maternal-infant interactions when assessed at discharge and at three months after discharge (Glazebrook et al. 2007, 1+)[(20)]. One RCT found that coaching parents on how to interact with their pre-term infant made no difference to knowledge of care, sensitivity to the infant or satisfaction in parenting compared with the control group(Parker-Loewen 1987, 1-)[(21)]. However, this may have been confounded by the amount of contact that the control mothers had with the researchers, as these mothers reported that they enjoyed having someone show an interest in them.

Evidence from a cohort reported that the Vermont Mother-Infant Transaction Programme (MITP) significantly improved maternal satisfaction, maternal self-confidence, and mothers' perception of their infant's temperament at six months[(15)]. One cohort study reported that individualised developmental care programmes appeared to make no difference to parents' perceptions of the neonatal unit or satisfaction with care, despite significantly lowering stress cues in the pre-term infants[(22)].

Evidence from qualitative studies provides an insight into the benefits of individualised developmental and behavioural care programmes at the neonatal unit, such as empowering parents to take care of their infants, teaching parents

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behavioural cues of their infants, problem-solving, and learning how to interact with their infants, resulting in a greater satisfaction with the care provided[13,23,24]. Furthermore, parents reported a reduction in stress after such programmes and said that they felt more confident in caring for their infants, which promoted parental self-reliance when returning home[24].

2) Supporting parents through use of Behavioural Assessment Scales

No RCT evidence was reported on this intervention. Three cross-sectional studies provided insights into how to teach parents assess and interpret the behaviour of their pre-term through using the Brazelton Behavioual Assessment scales. The studies reported this intervention may improve mother-infant bonding, reduce maternal anxiety, and help mothers foster a more realistic perception of their pre-term infants[25,26,27].

3) Supporting parents through breast feeding, kangaroo care and infant massage

Four studies reported on parent outcomes of interventions around breast-feeding, of which one was a RCT, six studies reported on parent outcomes of interventions around kangaroo care (skin to skin contact with baby out of the incubator), of which 2 were RCTs, and two studies reported parent outcomes around baby massage. An RCT (1-) reported no significant difference in the mother's confidence and competence in carrying out breast feeding by weighing the infant before and after feeds[28].

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Three cross-sectional studies and one case series study reported on breast feeding interventions. The studies reported that parents receiving breastfeeding support at the neonatal unit were more likely to continue breastfeeding up to a month after discharge than comparable groups. Breast-feeding education and support at the neonatal unit in the form of counselling, information (handouts and videos), practical help and group breast-feeding clinics improved the confidence of mothers in breast-feeding. An individualised discharge plan for breast feeding mothers with follow-up telephone calls or home visits appeared to maintain mothers' confidence in breastfeeding, and provide reassurance[29,30,31]

Six studies reported parent outcomes of using kangaroo care with their pre-term infants, of which two were RCTs. The RCT evidence (1+) suggests that use of kangaroo care significantly reduces maternal anxiety around her infant, gives the mother a significantly greater sense of competence with their infant, and a significantly greater sensitivity towards her infant[32)]. Furthermore, RCT evidence (1+) suggests that music during kangaroo care resulted in significantly lower maternal anxiety [33].

One cohort study, which assessed outcomes of mothers using kangaroo care at 37 weeks, at 3 months, and at 6 months, reported significantly better levels of mother-infant interaction, more touch, better adaptation to infant cues, and better perception of their infant at all time periods. Mothers also reported significantly less post-natal depression compared to the controls at 37 weeks[34].

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One cross-sectional study reported that the majority of mothers preferred the kangaroo method, mainly because their baby was closer to them. Touch was important to mothers, as it induced feelings of well-being and fulfilment in parents[35].

In the qualitative studies, parents described how kangaroo care helped them to get to know their infant, increased their confidence, and made them feel that their infant needed them[36]; parents reported that their mood was improved, that they perceived their infant differently and felt a stronger sense of identifying with their infant[37].

Two studies reported on parent outcomes of baby massage on pre-term infants, of which one was an RCT. RCT evidence (1+) reported that at three months, mothers of massaged infants felt significantly less intrusive towards caring for their baby, interactions were more reciprocal, and treated infants were more socially involved compared to controls[38]. One cross-sectional study also reported improved maternal-infant interactions[39].

4) Support forums for parents

No RCT evidence was reported for these interventions. Nine studies reported the benefits of participating in support groups set up within the NICU, either run by staff at the neonatal unit or by parents who have experienced having a pre-term infant themselves. Evidence from cohort studies reported that parent-led peer support groups at the NICU led to mothers in the intervention group having

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significantly less stress at four weeks and 16 weeks after support was initiated at the neonatal unit[40,41]. Mothers of critically ill pre-term infants had significantly better maternal mood states, maternal-infant relationships, and home environments in the intervention group compared to the control group[42]

Evidence from a qualitative study gave insights into how a health professional led support group assisted parents to gain perspective, feel supported, and learn practical information about how to interact with their baby[43]. Qualitative evidence also reports that parent-to-parent support groups provided parents with information, emotional support, and strength[44]. Cross-sectional studies and case series studies reported on how health professional led support groups also helped to relieve anxiety, gave an opportunity to communicate with staff, and gain confidence in their parenting skills[45,46,47]. Another case series study reported how a support programme run by parents gave parents space to express their worries and concerns and provided comfort in talking to 'experienced' parents[48].

5) Alleviating parent stress

Seven studies report interventions that attempt to alleviate the adverse psycho-social consequences of having a pre-term infant, of which four were RCTs. RCT evidence (1+ - 1++) is reported in the individualised developmental behavioural programme section for the stress reduction benefits of COPE, NIDCAP, and MITP[4,11,14,16]. Other RCT evidence (1-) reports that the use of videotape in

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strategies that focus on coping with emotions and active problem solving significantly reduced maternal stress [49].

Evidence from a cohort study reported that the use of one-off psychological interventions to teach relaxation and coping mechanisms to normalise their experience, as well as emotional and practical support significantly reduced the traumatic impact for parents compared to controls[50]. Two case series studies gave insights into the use of journal writing for documenting feelings, thoughts, milestones and involvement in care; the use of psychotherapy to offer support and insight at a time of crisis was also found to reduce stress[51,52].

6) Preparing parents for seeing their infant the neonatal unit for the first time

Two studies reported evidence for different ways of preparing parents for seeing their pre-term infant for the first time, of which one was an RCT[53,54]. The RCT evidence (1+) reported that giving parents a photograph of their pre-term infant provides a positive effect by improving bonding with their infant[53].

The qualitative study gave an insight into how a tour of the neonatal unit prior to having a pre-term infant (when a pregnancy at high risk of premature labour was diagnosed) may decrease parent's fears, inspire hope in their infant's prognosis, and give parents reassurance about the care offered at the NICU[54]. However, some parents found the appearance of the babies and the technology overwhelming, and some expressed concerns that the tour was not supported by staff on the neonatal unit.

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7) Interventions for communication and information sharing

Eight studies assessed interventions to improve the issues of communication at the neonatal unit, of which one was a RCT[55]. The RCT evidence (1+) reported that taping parent-doctor consultations improved the recall of parents of the consultation[55]. The trial found that mothers who received audiotapes of their consultation recalled significantly more information about the diagnosis, treatment, and outcome of their children than women in the control group at ten days and at four months.

Evidence from a cohort study reported that discussions between health professionals and parents around their infant's progress chart resulted in the intervention group having significantly fewer unrealistic concerns, less uncertainty about the medical condition of the infant, less conflict and a greater satisfaction with regards to shared decision-making[56]. Another cohort study reported that parents had significantly greater contact with the NICU during the infant's admission and reported a sense of relief at seeing their infant when they had access to the neonatal unit via a videophone[57].

Qualitative evidence investigated the perception of parents regarding the methods of effective and ineffective communication at the NICU. Parents perceived that the most effective communication with nurses was through discourse management (nurses asking questions and encouraging parents to ask questions), caring and reassuring communication, and communication as equal partners in the care of the infant. Ineffective communication was perceived as when the information given was inconsistent, staff did not check if parents understood the

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information, and if questions were not allowed[58]. Furthermore, qualitative evidence reported that 'chat' or 'social talk' between nurses and parents had a positive influence on mothers' confidence, their sense of control, and their feeling of connection with their baby[59].

Cross-sectional studies provided an insight into the methods of improving communication between parents of pre-term infants and health professionals. The use of a web-based programme (BabyLink) to provide individualised information to parents helped communicate complex issue, and parents reported that it helped to humanise the experience of the neonatal unit[60]. Furthermore, a study reported that the use of BabyLink improved the overall satisfaction of the family with care at the neonatal unit and actually reduced the length of stay at the neonatal unit[6]. Parents reported that they found the tape-recorded consultations with doctors helpful to process the information, as well as being comforting and supportive[61].

Five studies reported evidence on the information needs of parents, none of which provided RCT level evidence. One pre-test/post-test study concluded that information and training for specific practical care of their infant on oxygen therapy could significantly improve the relevant knowledge of parents, and reduced their distress when entering the transition period of returning home[62].

Three qualitative studies described an information binder that provided relevant information about medical and practical issues relating to the NICU. Parents could add information to the folder. The information binder empowered parents to take an active interest in acquiring relevant information about their infant

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and improved parents understanding and ability to participate in decision-making. Furthermore, the information binder increased parent's confidence in caring for their infant, and gave them hope of progress for their infant[63, 64]. Prioritising information through a "card sort" (cards which state information topics for parents who have had a pre-term infant) was reported by a qualitative study as being a less intimidating way for parents to access important and timely information [65]. This study reported that parents' highest priorities were infant cardiopulmonary resuscitation (CPR), infant illness and development; information with a moderate priority were feeding, giving medication, and hygiene; and information topics that were given the lowest priority included getting help at home and the use of car seats. One cross-sectional study reported that the neonatal nurses were the best source of information at the NICU[66].

8) Discharge planning

Six studies reported on discharge programmes, of which one reported RCT level evidence[67]. RCT evidence (1-) suggests that a parent-infant discharge programme within a therapeutic problem-solving model significantly improved parent interactions with their infants, and parents were significantly more engaged with their infants after returning home compared with the parents who did not go through a discharge programme[67].

One cohort study assessed an early discharge programme with an individualised care and discharge plan, followed by domiciliary nursing care, and reported significantly less anxiety in mothers in the intervention group at

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discharge[68]. No significant differences in the experiences of parents with regards to their infant's emotional well-being and breast feeding issues were reported. The levels of anxiety did not appear to be different between groups of parents who did not receive a formal discharge programme at one year after discharge from the neonatal unit[68].

The qualitative studies gave insights into how discharge planning provided support for parents. One study conducted a discharge programme that comprised of an educational programme during the period of hospitalisation for parents with pre-term infants, a visit and orientation about the neonatal unit by the family's health visitor, a multidisciplinary and cross-sector discharge conference, and the publication of relevant booklets for parents and health care providers[69]. The parents found that most of the intervention initiatives contributed to a feeling of overall increased support and met their needs, including improving their confidence in caring for their pre-term infant and ensuring the well-being of their child following discharge. Families valued the support and guidance they received from the co-ordinating health visitor, and valued having a named contact nurse throughout their stay at the neonatal unit and at home, which demonstrated the importance of continuity of care. All participants in this study felt secure when they returned home.

One qualitative study assessed the perceptions of parents of pre-term infants regarding an early discharge and home-care programme[70]. The study concluded that parents of children who were discharged early may feel more positive about coming home as early as possible from the hospital, as this may help parents to feel like a 'normal' family and not to have to share their infant with the nurses and other

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health professionals on the neonatal unit. However, parents in this study appreciated the 24 hour accessibility of the staff on the neonatal unit for support and knowledge.

Two further qualitative studies reports a Care by Parent discharge programme and describes how the mother can stay in the same room or in a room close to her pre-term infant, assuming all of the aspects of care but with help at hand if needed [71,72]. Mothers reported that it gave them the opportunity to test reality and bridge the gap between hospital and home, so gaining confidence in taking their infant home, and it helped mothers to feel like a proper family, and promoted their "ownership" of the infant.

9) Home support programmes

Ten studies reported the outcomes of parents who participated in home intervention programmes, of which two were RCTs. RCT evidence (1-) reported that home support programmes, where parents are visited and given emotional and practical support regularly for the first year and for up to three years afterwards, lead to significantly reduced parental stress levels, a greater positive effect on maternal behaviour and greater interactions with their pre-term infant. However, the intervention was not significantly associated with improved maternal coping[73]. RCT evidence also reports that regular home support programmes that last for up to a year made mothers significantly more responsive to their infant and meant that they were able to provide more appropriate and varied stimulations for the infant[67].

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Evidence from a cohort study where parents were visited regularly and taught care-taking skills, games and exercises reported a significantly better home environment for the family. However, there was no difference found between the intervention group and the control group with regards to maternal coping[74]. Evidence from a cohort study also assessed the support and psychological impact of an Infants Apnea Evaluation Programme (IAEP) for infants on home monitors and reported that monitoring itself significantly reduced anxiety. The structured support programme was found to be supportive by parents[75]. A similar cohort study introduced a home counselling programme for parents who used home monitoring. Parents were significantly less stressed by the presence of the monitor and by false alarms, and reacted less aggressively to monitor alarms. Parents in the structured support programme used the monitor less, and mainly during sleeping periods[76]. One cohort conducted an educational developmental programme at home twice monthly using a parent's voice tape, baby massage, and a passive range of motion and exercise. The programme resulted in a significant improvement in parent-infant interaction at six months and 12 months after discharge, as well as benefiting the infant[77].

Evidence from a cohort study reported that a home healthcare programme and home visiting programme significantly improved the home environment of the intervention groups compared to the control groups at one month and 12 months[5]. However, there were no significant differences between groups with regard to family experiences and parental satisfaction.

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Evidence from one cross-sectional study and two case series studies give insights into the effect of home support programmes. Specific to the UK, the community neonatal service (CNS) was valued positively in providing support and continuity of care for parents who needed a high level of support (e.g. experiencing depression and bonding struggles with their infant, infant sleeping issues and feeding problems) [(78)]. One study assessed the impact of an intensive care co-ordinator who provided home visits for providing teaching, guidance and support to parents[(79)]. The study reported that the intensive care co-ordinator made families feel comfortable, offering emotional and practical support, and taught parents the necessary skills for parenting the pre-term infant. Another similar study assessed a neonatal integrated home care programme where neonatal nurses taught specific infant care needs and provided emotional support to parents. Parents reported that the programme helped them to bring their pre-term infants home earlier, provided nurse help, support, instruction and encouragement [(80)].

Discussion

The aim of this systematic review focused on identifying interventions that were effective in supporting, informing and communicating with parents who have had a pre-term infant. This study has identified a range of interventions that can produce beneficial outcomes for parents in relation to communication, information and support.

RCT evidence reports that developmental and behavioural care programmes such as COPE and MITP significantly reduce stress and depression in mothers of premature infants, significantly increase mothers'

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knowledge of her infant's condition and care (COPE) and significantly improved mothers attitude and confidence in caring for their infant (MITP). COPE and MITP performed better than other such programmes because they were developed to improve both mother and infant outcomes, whereas other developmental programmes focussed more on infant outcomes. Such interactive learning programmes appear to be more successful at reducing mother's stress and improving mother's knowledge than stand alone coaching sessions for parents.

Other RCT evidence reported that skin to skin care and baby massage significantly improved the mother-infant interaction and increased the mother's sense of competence in handling their infant. These are inexpensive interventions that can be introduced relatively easily to most NICUs. Perhaps more controversial RCT evidence reports that recording parent's consultations with their doctors significantly improved the parent's recall of diagnosis, treatment and outcomes of their infant. However, in our growing litigious society, doctors may be reluctant to do this.

Cohort evidence reports the benefits of several interventions including discussions around the infant progress chart, parent support groups at the neonatal unit and home support programmes once the infant has been discharged. The non-intervention studies further added to the review by bring a wider breadth of information around the beneficial experiences of developmental care programmes, educational interventions, preparation for

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visiting the neonatal unit, and interventions to reduce parent's stress, that might not have been reported within an RCT design.

Important messages have come through this research, which healthcare professionals and neonatal units should consider. Some neonatal units may have already utilised some of these interventions, but we would urge them to use the results of this systematic review to re-evaluate current practice around parents of premature infants and consider whether unit and professional practice requires adaptation or change. Changing practice can be difficult and a number of key elements are required, including evidence, an understanding of the context of care and a way of facilitating this evidence into practice[(81)]. We also acknowledge that part of the context is a complex range of workforce issues that limits what neonatal units can achieve, despite their best efforts. The focus on developing patient-centred care within the NHS in the UK also applies to neonatal units and should include parent-focused care as an extension of this concept[(82)].

Many of the interventions that have been identified in this study could be described as being building blocks for a family-centred model of care in the UK setting, which embraces the mother and father or significant others in the medical care of their infant. Such interventions act through establishing key actions and interventions that emphasise the importance of communicating with, supporting and informing the family. Furthermore, our review demonstrated that such family-centred interventions resulted in shorter stays at the neonatal units, less re-hospitalisation of pre-term infants and better long-term outcome with regards to morbidity in this group of infants[(4)]. This contributes to a strong argument that highlights the potential for

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family-centred care to be made more cost-effective, more acceptable to parents, and in some cases offer important clinical benefits.

The scope of this review was very broad, and the searches were therefore developed to be inclusive. This resulted in the search being sensitive, but not specific. Furthermore, this systematic review includes intervention studies and non-intervention studies. It is implicit that the non-interventional studies will bring bias to the evidence base. We have therefore stratified the summary of results into RCTs and non RCTs, with the non-RCTs being stratified further within observational designs by study design (ie., cohort, case-control, cross-sectional, etc). It was important to include the non-interventional studies as much of the literature around parents' views and experiences does not lend itself to the RCT design. Being inclusive of studies benefits the evidence base by bringing together 'experience' studies in a systematic way gaining a greater breadth of perspectives and a deeper understanding of issues from the point of view of those targeted by the interventions.

The Scottish intercollegiate group network (SIGN) grading system used in this review is intended to place greater weight on the quality of evidence, and to emphasise that the body of evidence should be considered as a whole, and not rely on a single study. It is also intended to allow more weight to be given to recommendations supported by the good quality observational studies where RCTs are not available for practical or ethical reasons, as shown in figure 4.

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The majority of studies included in this review are from the USA, which may affect the generalisation of interventions in neonatal units today and the ability of such studies to be applied in a UK practice setting would need to be considered. While this review identified a range of interventions that can help parents, certain groups were under-represented in the study samples, including amongst others minority ethnic groups, individuals from lower social classes and young parents. Further good quality research within a UK setting, and research on under-represented groups of parents at the neonatal units is needed.

Despite the limitations of the evidence-base, this systematic review highlights interventions for providing improved support, information and communication to parents of a pre-term infant. These interventions are summarised in Figure 2.

Figure 4: Scottish Intercollegiate Guideline Network (SIGN) Levels of Evidence

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Ethics Approval:

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Guarantor: The University of Warwick, Coventry, CV7 4AL is the guarantor of this study

WHAT IS ALREADY KNOWN ON THIS TOPIC

It has long been recognised that family-centred care at the neonatal unit is beneficial not just for the parents of premature infants, but for the infants themselves. While the importance of family centred care is known, neonatal units are unsure which are the most effective family-centred care interventions to support, communicate with, and provide information to these parents

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WHAT THIS STUDY ADDS

The evidence from the systematic review provides a summary pathway of family-centred care interventions to assist in providing support, information and communication with parents of premature infants throughout their stay at the neonatal unit and after discharge home.

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Contributors statement

JB made substantial contributions to the design, acquisition of data and analysis and interpretation of the data, and wrote the first draft of the paper. JB wrote the first amendments to the draft paper and the first draft of responses to the reviewers

SS was the principal investigator of the POPPY study, obtaining funding for the study, made substantial contributions to the conception and design of the study, assisting in the selection of papers and the quality assessment of papers, assisted with the interpretation of the data, assisted in the writing of the first draft of the paper, and approved the version for publication

MN was the fund holder, made substantial contributions to the conception and design of the study, assisted in the interpretation of the data, revised drafts of the paper, and approved the version for publication

NJ was the patient representative on this study, made substantial contributions to the conception and design of the study, assisted in the interpretation of the data, revised drafts of the paper, and approved the version for publication

LT was a representative of the National Childbirth Trust and a patient representative. She made substantial contributions to the conception and design of the study, assisted in the interpretation of the data, revised drafts of the paper, and approved the version for publication.

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Table 2: Data extraction tables

2a) Supporting parents through individualised developmental and behavioural care programmes

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Van der Pal 2007 Netherlands	RCT	NIDCAP	PSI Parents of Mother and Baby Scale Nurse Parent Support Tool	94	84	No significant differences were reported in Parental Stress Index, Confidence of parents, or perceived nursing support at 1 to 2 weeks after birth	1+
Glazebrook et al 2007 UK	RCT	Nursing Child Assessment Teaching Scale (NCATS) at neonatal unit, with optional follow-up	Parental Stress Index (PSI) Home Observation for Measurement of the Environment (HOME)	99	111	No significant differences reported at discharge or at 3 months after discharge.	1+
Kaaresen 2006	RCT	Mother-Infant Transaction Program The intervention consisted of 8 sessions shortly before discharge and 4 home visits by specially trained nurses focusing on the infant's unique characteristics, temperament, and developmental potential and the interaction between the infant and the parents.	PSI	71	69 preterm 75 term	Early-intervention program reduces parenting stress in both mothers and fathers during the first year after a preterm birth to a level comparable to their term peers Mothers 6 mths - total stress: 16.9 (5.2 to 28.5) .005 Mothers 12mths – total stress: 13.7 (1.6 to 25.9) .03 Fathers 12 moths – total stress: 14.8 (2.1 to 27.6) .02	1+
Byers 2006 USA	Cohort	Family-centred care/developmental supportive care	Questionnaire developed for study to measure parents perceptions and satisfaction.	57	57	No differences in parent perception or satisfaction with the neonatal unit	2-

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			Study mainly reports baby outcomes				
Browne 2005 USA	RCT	Family based intervention (Gp1: demonstration of pre-term baby behavioural cues; Gp2:viewed educational video and books about pre-term babies	Nursing Child Assessment Scale (NCAFS) and Knowledge of Preterm Infant Behavior Scale (KPIB)	Gp1: 28 Gp2: 31	25	Intervention group reported significantly greater sensitive interactions with pre-term babies, and significantly greater knowledge of pre-term babies than controls at 1 month after discharge (NCAFS 45.65, 6.20vs. 47.43, 7.36 vs. 48.88, 7.41, p<0.05; mean KPIB 23.32, SD 5.88 in group 1 vs. 25.90, 5.30, in group 2 vs. 19.58, 5.01 in group 3, p<0.001)	1+
Als 2003 USA	RCT	NIDCAP (Neonatal individualised Developmental Care and Assessment Programme	PSI (Parental Stress Index)	38	38	Mothers in the intervention group reported significantly more favourable scores than the control group. Hospital 1: I= 35.7 (sd 21.3) C=44.9 (sd34.2) Hospital 2: I=55.8 (sd28.8) C=65.2 (sd27.5) Hospital 3: I=49.0 (sd28.6) C=55.9 (sd22.5) Group score ® = .41, p<.001 Summary: MANOVA: F=2.41, df=5.66, p<0.05	1++
Meyer 1994 USA	RCT	Family based intervention (Psychological intervention for family, teaching care and behavioural cues of baby, home discharge plan)	Parental Stressor scale (PSS) Maternal self esteem Inventory, Beck Depression Scale (BDS), Family Environment Scale	34	34	Intervention group reported significantly less stress (PSS) and reported significantly less depression (BDS) at discharge. BDI: Int: 11% vs. 44%, p<0.05; 39% vs 31% NS. PSS: Int:2.4 ± 1.0; 2.0 ± 0.8 vs Con 2.4 ± 0.9; 2.6 ± 0.8 p<0.05 No other significant results were reported.	1+
Rauh 1990 USA	Cohort	Vermont Mother-Infant Transaction Programme (teach parents to appreciate infants unique characteristics. teach behavioural cues, teach parents to respond to infant, enhance mothers enjoyment of baby).	Maternal Role Satisfaction questionnaire Self-Confidence rating	40	41	At 6 months: significantly better intervention effects for maternal role satisfaction, self-confidence and perception of infant temperament in intervention group; no difference on maternal attitudes to child-rearing. Data not given in paper.	2-

			Parent Attitude scale				
Parker-Loewen 1987 Canada	RCT	8 X 40 minute interaction coaching to encourage sensitive responding by mothers	Satisfaction with Parenting Scale Knowledge of Infant Development Scale Life experiences survey Interaction rating scale	35	35	No significant difference between treatment and control group on interaction or knowledge of infant development or satisfaction with parenting	1-
Nurcombe 1984 USA	RCT	Behavioural Assessment Scale: Mother-Infant Transaction Programme (MITP)	Hereford Parent Attitude Survey Seashore Self Confidence Rating Paired Comparison Questionn-aire	37	36	Intervention group scored better on maternal adaptation (role satisfaction, attitudes to child-rearing, self confidence) than low birth weight controls (F(3, 87), p<0.030. Univariate analysis: Maternal satisfaction F (2,89), 4.55, p<0.013 Maternal attitude (2,89), 4.05, p<0.021 Maternal self confidence F (1,89), 7.44, p<0.008 Full term controls scored better than combined low birth weight group (F [3,87], 3.27, p=0.025).	1+

Author (Year) Country	**Study design**	**Objective**	**Setting**	**Study design/ outcome measures**	**Intervention**	**Results**	**Authors Conclusions**	**Sign**
Wielenga 2006, Netherlands	Qualitative	Evaluation of NIDCAP	NICU	NICU-Parent Satisfaction Form and the Nurse Parent Support Tool	NIDCAP	Parents were significantly more satisfied with care given according to NIDCAP principles than they were with the traditional care for their premature born babies.		3
Lawhorn 2002 USA	Case series	To report on a facilitating parent assessment of infant behaviour	NICU Convenience sample of 10 infants (≤1500g, ≤32 weeks,	Videotaped parent-infant interactions	An individualised nursing intervention based on assumptions of parent and infant competence;	The intervention enhanced the parents' ability to appraise the infant's behaviour and respond in a supportive manner (data not presented). Parents found it helpful in getting to know their infant and being more empowered in the infant's care.	NICU staff should support parents in gaining greater understanding of infant and sensitive interactions; parents need to be active collaborators in infant care	3

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		and supportive responses	appropriate for gestational age, no congenital abnormality) + 18 parents		discussion of videotaped interactions to discuss infant cues and promote supportive responses			

2b) Supporting parents through use of Behavioural Assessment Scales

Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
Hawthorne 2005 UK	Cross-sectional	To evaluate Neonatal Behavioural Assessment Scale (NBAS) to support parent-infant relationship.	Neonatal unit 22 parents of premature infants	22 Questionnaire developed for study	Behavioural assessment scale	Parents reported: NBAS helped parents adjust to baby's behaviours, increased parents confidence in caring for their baby, satisfied their information needs about their baby.	NBAS can improve parents knowledge and improve their confidence in caring for their infant.	3
Culp 1989 USA	Cohort	Demonstra-ting assessment of Premature Infant Behavior (APIB)	NICU 14 couples + premature infants (<32 weeks)	Alternate allocation to demonstra-tion of assessment (2 weeks before assessment of outcome) or not until afterwards STAI Neonatal Perception Inventorry	Demonstrating assessment of Premature Infant Behavior (APIB)	Intervention fathers reported lower anxiety than non-intervention fathers ($p<0.05$).Both mothers and fathers in intervention group had more realistic perception of newborns ($p<0.04$). Intervention mothers more aware of newborn's abilities to shut out disturbing stimulation on repeated exposure ($p<0.02$)	Intervention appeared to reduce paternal anxiety and fostered more realistic perceptions of the premature infant	3
Szajnberg 1987, USA	Qualitative (within cohort for infant outcomes)	Evaluation of Brazelton Newborn Behavioural Assessment Scale (BNBAS)	Home	Structured interview	BNBAS	At 6 months, mothers in the intervention group remembered more details from the BNBAS than control mothers did of the standard physical examinations. Intervention mothers tried more exam items at home and found more of the items helpful. There was a trend for mothers to visit their infants more often after the intervention.		3

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2c) Supporting parents through breast feeding, kangaroo care and infant massage

Author (Year) Country	**Study design**	**Intervention**	**Outcome measure**	**No of cases**	**No. of controls**	**Statistically significant**	**Quality (SIGN)**
Lai 2006 Taiwan	RCT	Effects of kangaroo care combined with music	State-Trait Anxiety Inventory (STAI)	15	15	Music during KC also resulted in significantly lower maternal anxiety in the treatment group on day 3 of the interention (t (19.6) =−2.14, p<.05). Maternal state anxiety improved daily, indicating a cumulative dose effect (F(1.49,40.39)=5.81, p<.01). Anxiety levels in the control remained unchanged	1+
Ferber 2004 Israel	RCT	Baby massage: I= to receive 15 massages 3 times per day for 5 days. Gp1: mothers conduct massage Gp2: Researchers conduct massage Gp 3 controls	Coding Interactive Behaviour Assessment for newborn	Gp 1: 18 Gp 2: 18	19	Significant results report that at 3 months, mothers of massaged infants were less intrusive, and interactions were more reciprocal. Gp1: Dyadic reciprocity (DR) – 2.42+0.87 Maternal Intrusiveness(MI)-1.97+0.91 Gp2: DR – 2.46+0.99 MI – 1.68+0.63 Gp3: DR – 1.66+0.68 MI – 2.54+1.01 DR: F=4.69,p<0.01 MI: F=4.05,p<0.02 No significant difference in maternal sensitivity was reported.	1+
Feldman 2002 Israel	Cohort	Effects of Kangaroo care	Mother-Infant interaction scale Maternal depression Mothers perceptions HOME	73	73	At 37 weeks gestational age: After kangaroo care, interactions more positive, mothers showed more positive affect, touch, adaptation to infant cues, infants more alertness and less gaze aversion, mothers less depressed & viewed infants as less abnormal. Less maternal depression [KC mean 6.68 (5.55) vs control 9.05 (4.27), F=5.68, p<0.05]. At 3 months corrected age: mothers and fathers of kangaroo care infants more sensitive and provided better home environment.	2+

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						KC Mothers provided a better home environment Manova at 3 months – HOME: Wilks F (df=7,123), 2.99, p<0.01. KC fathers provided a better home environment – HOME: Wilks F (df=7,110), 2.45, p<0.05. At 6 months corrected age: kangaroo care mothers more sensitive (maternal sensitivity: KC mean 4.20 (0.64) vs control mean 3.86 (0.76, univariate 5.36, p<0.05) & infants scored higher on Bayley Mental Development Index (96.39 vs. 91.81, p<0.01) and Psychomotor Development Index (85.47 vs. 80.53, p<0.05)	
Hall 2002 Canada	RCT	Weighing infant before and after feeds to assess maternal confidence in breast feeding	Parental sense of competence scale Maternal confidence questionnaire Influence of specific referents scale	30	30	No significant differences in maternal confidence or competence between weighed or not-weighed infants	1-
Tessier 1998 Columbia	RCT	Effects of Kangaroo care	Mothers perception of premature babies questionnaire	246	246	Kangaroo care significantly increased mother's sense of competence in mothering their baby (F(1481) 10.36, P .001), and was significantly increased maternal sensitivity to their baby at the neonatal unit. (F(1481) 3.71, P .05). This improved perception of their baby effect is related to a subjective "bonding effect" that may be understood readily by the empowering nature of the KMC intervention. The study also reported a negative effect on the feelings of received support from health professionals of mothers practicing KMC (F 5.03, P .03). Kangaroo care significantly reduced length of stay especially in lighter babies. Two-way analysis of variance stratifying by birth weight showed that the savings in hospital stays were clearly related to weight at birth: an interaction effect (F(3480) 4.06, P .01) shows that the maximum saving in the KMC group was observed in infants weighing 1501 g (4.5 to 6.7 days), whereas in infants weighing 1500g, the length of hospital stay was virtually identical in both groups	1+

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Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
White 2000 USA	Case series	To evaluate feeding support by occupation-nal therapists (OTs)	NICU 9 parents of premature infants receiving OT services for feeding issues	Interview questionnaire	OTs involved in parent education in NICU (e.g. oral-facial stimulation, positioning, oral support techniques, typical feeding development) using demonstration, discussion, hands-on training, handouts, videos etc.	Parents reported receiving education about oral-facial stimulation and oral support techniques (9/9 reported), positioning, typical feeding development (8/9 reported); hands-on training and demonstration reported most frequently. Overall, parents felt ‘confident’ or ‘very confident’ in their ability to understand topics. 5/9 indicated they thought they would not need additional help after discharge; 3/9 felt they would; 1 unsure.	Parents perceived OTs were providing effective education & support in infant feeding techniques	3
Elliott 1998 Canada	Qualitative	To evaluate a telephone follow up programme to support breast-feeding	Home 20 mothers	Structured interview	Telephone call with structured questions to complete form (e.g. feeding patterns, any problems, plan to address problems, any referrals needed)	All mothers reported finding telephone call helpful and increasing their confidence in continuing to breast feed.	Telephone support can help mothers breastfeed premature infants at home	3
Legault 1995 Canada	Cross-sectional	Effects of kangaroo (skin to skin) care	NICU 61 mother-infant dyads experiencing both traditional and kangaroo-type transfers from incubator	Satisfaction questionnaire Maternal Satisfaction Question-naire	Kangaroo (skin to skin) care	Kangaroo method was preferred by 73.8% of mothers, mainly because the infant was closer to them and they could touch them more easily.	Kangaroo method encourages early contact with infant& induces feelings of wellbeing & fulfilment in parents	3

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Remedios 2005, USA	Qualitative	To evaluate the effect of baby massage on the parents of premature infants	Neonatal unit	Semi-structured interviews	Baby message	Parents reported feeling 'closer' to their infants, and reported improved confidence in caring for their infant. Parents felt the baby massage was beneficial to the infant and themselves.	For the parents of a premature baby, baby massage can help improve the sense of closeness to their infant and improve their confidence in caring for their infant.	3
Meier 1993 USA	Cross-sectional	Breast feeding support	NICU 132 parents of premature infants	Survey	Breast feeding intervention record	Mothers more likely to be breast feeding than comparable populations	Breast feeding support encourages mothers in the NICU to breast feed and to continue to breast feed for longer.	3
Affonso 1993, USA	Qaulitative	Evaluation of Skin to skin care (SSC) for premature infants	NICU Mothers	Interview	Kangaroo care	SSC provided a way for mothers to know their infants, to develop strong positive feelings towards them, and to reconcile their feelings about having a premature birth, so that emotional healing could take place.	Kangaroo care improved mother-infant interactions.	3
Gale 1993 USA	Case series	Effects of kangaroo (skin to skin) care	NICU 25 intubated infants and their parents	Interviews	Kangaroo (skin to skin) care	Parents described kangaroo care as beneficial, giving stronger identity with and knowledge of infant; greater confidence in infant's need for them and their ability to need these needs; greater confidence in asking questions	Nurses can support parental attachment by supporting kangaroo holding	3

2d) Support Forums for Parents:

Author (Year) Country	**Study design**	**Intervention**	**Outcome measure**	**No of cases**	**No. of controls**	**Statistically significant**	**Quality (SIGN)**
Preyde 2003 Canada	Cohort	Parent to Parent Peer Support	Parental Stressor scale (x) Sate-Trait Anxiety Scale (Spielberger)	32	28	Intervention group better scores on all measures at 4 or 16 weeks (groups were equivalent at baseline), e.g. mean PSS score 1.54 (1.3-1.7) in intervention group at 4 weeks vs. 2.93 (2.7-3.1) in controls, p<0.001 At 4 weeks mean PSS score was significantly less in the intervention group – 1.54 (1.3-1.7) vs 2.93 (2.7-3.1), p<0.001. At 16 weeks mean anxiety score, mean depression score, and perceived support were significantly less in the intervention group: anxiety - 31.4 (27.2-35.4) vs 38.6 (34.6-42.7), p<0.05; depression - 2.20 (0.89-3.60) vs 4.88 (3.51-	2++

						6.17), $p<0.01$; perceived support – 6.49 (6.02-6.82) vs 5.48 (5.09-5.94), $p<0.01$. There were no different in trait anxiety between the groups at any time period.	
Lindsay 1993 USA	Cohort	Parent to Parent Peer support for parents with critically ill pre-term babies.	Parent report	NR	NR	Numerical data not reported in paper Reported benefit to parents: emotional support + Information support	2-

Author (Year) Country	**Study design**	**Objective**	**Setting**	**Study design/ outcome measures**	**Intervention**	**Results**	**Authors Conclusions**	**Sign**
Buarque, 2006	Qualitative	To investigate the influence of support groups on the family of risk newborn infants and on neonatal unit workers.	Neonatal unit 13 mothers, six fathers, two grandmothers and 16 healthcare workers	Semi-structured interviews	None	The analysis revealed that the support group to the family of risk newborns provided parents and family members with information, emotional support and strengthening so that they could come to terms with the birth of their child and his/her admission to the neonatal unit, in addition to enabling parents to take care of the newborn infant. There was interpersonal growth in the interaction between parents, family members, and healthcare workers.	The support group to the family of risk newborns uses an approach that is based on family-centered care. These principles allow restoring parental competence, helping healthcare workers to respect values and feelings of family members, and establishing a collaborative work between parents and healthcare workers in the neonatal unit.	3
Hurst et al, 2006	Qualitative	To identify parents' utilization and evaluation of a support program based in a newborn intensive care unit (NICU)	NICU 477 parents utilised support service, 48 completed survey	Program records and a survey developed by the author documented parental use and evaluation of services. Data analysis consisted of descriptive statistics and qualitative content analysis	Support programme that offered a combination of formats for support services: group support, one-to-one support, and telephone support	78% utilized 1 support service format exclusively. Eighteen percent utilized 2 support formats concurrently. A subsample of 48 parents completed an evaluation survey. Group support offered more opportunities for families to problem-solve communication issues with nursery personnel and provide information that assisted parents' involvement in their babies' care. Utilising more than one support format provided greater support for parents.	Parent support programs that utilize only one type of format may not be optimal for providing the range of support needed by many NICU families. Parent support programs offer an important mechanism to assess provider approaches to facilitate family-centered care.	3
Pearson 2001 USA	Qualitative	To evaluate a programme to promote positive parenting in NICU	NICU (level III and special care (level II) nurseries 104 parents (59 mothers +	Interviews	Parent's Circle: 90-minute information session + support to parents as they cope with early	Parents learned that they: could still parent even when baby is in hospital; could receive support from people going through similar experiences. They helped normalise the experience, helped parents to interact with their baby. Book	Attending Parent's Circle helped families gain perspective, feel supported, learn key developmental concepts, locate hospital and community resources, and optimise interaction with infant	3

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		(Parent's Circle)	45 fathers) who attended Parent's Circle, + 44 NICU or special care nurses		birth – allows parents to tell their story; curriculum based on parents' needs, includes development, how parents can help baby, how baby responds to stimuli, learning to read subtle cues from infant& respond appropriately, getting parents involved in infant care plan, sharing resources	list and classes were available after discharge. Staff reported that attending the Parent's Circle instils confidence in parents, helps them read baby's signals, normalises, introduces concepts such as kangaroo care that parents then want to try.		
Bracht 1998b Canada	Cross-sectional	To report parent perceptions of NICU follow-up clinic	NICU 16 families attending clinic	Satisfaction survey – methods not described	Integrated Neonatal Follow-Up Program: comprehensive, long-term developmental assessments, diagnosis & referral for children at high risk of developmental delay	All families reported that they were very satisfied with services provided by multidisciplinary team; they valued information & support re high risk infant; but needed more information re growth & development, nutrition needs, medical concerns (e.g. asthma).	Continuity of care provided by clinic staff nurses provided: support, education, written information; maintenance of rapport developed during hospitalisation; and liaison with community resources	3
Jarrett 1996 USA	Case series	Evaluation of parent support programme	Neonatal unit	Reported discussion	Parents were trained to be parent partners – being taught factual information and to be active listeners. Trained parents matched with new parents by infant	Parents reported feeling less anxious and less worried about their infant. The program was meeting its goal of support and programme provided a special relationship where parents in the NICU could take their worries and concerns. This relationship was most often nurtured through exchanges on the telephone, but parents also met in the parent lounge that was set up as part of	The parent support programme has provided parents with trained partner parents reducing parents level of anxiety and improving their confidence with their infant.	3

					characteristics	the parent support effort in the hospital. New parents unanimously reported that the most helpful thing about the program was the comfort in talking with someone who had experienced a similar situation.		
Dammers 1982 UK	Case Series	To report parents' perceptions of support group	Neonatal unit	Reported discussion		Parents reported having increased knowledge and greater confidence in caring for their infant	Parents found the support group beneficial in increasing their knowledge and confidence	3

2e) Alleviate parental stress

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Kaaresen 2006	RCT	Mother-Infant Transaction Program The intervention consisted of 8 sessions shortly before discharge and 4 home visits by specially trained nurses focusing on the infant's unique characteristics, temperament, and developmental potential and the interaction between the infant and the parents.	PSI	71	69 preterm 75 term	Early-intervention program reduces parenting stress in both mothers and fathers during the first year after a preterm birth to a level comparable to their term peers Mothers 6 mths - total stress: 16.9 (5.2 to 28.5) .005 Mothers 12mths – total stress: 13.7 (1.6 to 25.9) .03 Fathers 12 moths – total stress: 14.8 (2.1 to 27.6) .02	1+
Jotzo 2005 Germany	Cohort	Psychological intervention to reduce stress at neonatal unit (One off psychological intervention to help parents cope with stress)	Questionnaire: Impact of events scale (IES) Trauma experiences measure	25	25	Mothers in intervention group had significantly lower traumatic impact from preterm birth (lower overall symptoms: traumatic impact I 25.2 (SD 13.9), C 37.5 (SD 19.2), mean difference 12.28 (2.74-21.82, p=0.013; lower avoidance I 7.7 (SD 5.3), C 12.4 (SD 8.4), mean difference 4.65 (0.67-8.69), p=0.023 and hyperarousal, I 5.9 (SD 4.7), C9.5 (SD 5.7), mean difference – 3.56 (0.61 – 6.51), p=0.019; lower intrusion symptoms but not significant). Control group: 76% of mothers showed clinically significant psychological trauma at discharge vs. 36% (p<0.01) in intervention group.	2+
Als 2003 USA	RCT	NIDCAP (Neonatal individualised Developmental Care and Assessment Programme	PSI (Parental Stress Index)	38	38	Mothers in the intervention group reported significantly more favourable scores than the control group. Hospital 1: I= 35.7 (sd 21.3)	1++

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						C=44.9 (sd34.2) Hospital 2: I=55.8 (sd28.8) C=65.2 (sd27.5) Hospital 3: I=49.0 (sd28.6) C=55.9 (sd22.5) Group score ® = .41, p<.001 Summary: MANOVA: F=2.41, df=5.66, p<0.05	
Cobiella 1990 USA	RCT	Two stress reduction programmes: a) Video-tape training in active problem – focussed coping strategies b) Video-tape in emotion-focussed strategies to manage anxiety	State-Trait Anxiety Inventory (STAI), Depression Adjective Checklist (DACL)	Gp. A – 10 Gp. B - 10	10	On post-treatment follow-up both the problem-focused and emotion-focused treatment groups were significantly less anxious than the controls and lower levels of depression were observed for the emotion-focused group STAI: PF-t(11)=2 71 p<0.01 EF-t2 56 p<0.02 DACL: PF – NS EF-t(12)=2 36, p<0.03	1-
Nurcombe 1984 USA	RCT	Behavioural Assessment Scale: Mother-Infant Transaction Programme (MITP)	Hereford Parent Attitude Survey Seashore Self Confidence Rating Paired Comparison Questionn-aire	37	36	Intervention group scored better on maternal adaptation (role satisfaction, attitudes to child-rearing, self confidence) than low birth weight controls (F(3, 87), p<0.030. Univariate analysis: Maternal satisfaction F (2,89), 4.55, p<0.013 Maternal attitude (2,89), 4.05, p<0.021 Maternal self confidence F (1,89), 7.44, p<0.008 Full term controls scored better than combined low birth weight group (F [3,87], 3.27, p=0.025).	1+

Author (Year) Country	**Study design**	**Objective**	**Setting**	**Study design/ outcome measures**	**Intervention**	**Results**	**Authors Conclusions**	**Sign**
Macnab 1998 Canada	Cross-sectional	Evaluation of Journal writing	Special care nursery (SCN) 73 parents	Survey 6 weeks after giving information booklet on journal writing	Giving information about journal writing	32% kept a journal; 73% found it reduced their stress; 68% used it as a means to address the most stressful elements of the experience (most stressful elements were the feelings engendered by having a baby in special care & interactions with staff; the same percentage as those talking things through with a friend to reduce stress). Journals were used to document	Encouraging parents to keep a journal is a constructive way to deal with SCN-related stress.	3

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						involvement in care (45%), record keeping (36%) and organising thoughts (27%). All those who kept a journal recommended it to others. Positive feelings were holding baby for the first time; meeting & speaking with other parents; openness and honesty of nursery staff; impression that infant was loved and cared for. Parents said the journal would be a record for the child for later; helped to record progress & show how well parents coped. Parents made suggestions that photos etc should be included in the journals.		
Zeanah 1984 USA	Case reports	Psycho-therapy	NICU	Interview	Psychotherapy	Psychotherapy helped parents accept their feelings and conflicts as common to many NICU parents; Case conferences helped clarify misconceptions that had arisen because of the large number of people involved in baby's care. When unable to travel to unit, calls kept parents informed, enhanced participation; consistency maintained in information given, questions encouraged. Parents were encouraged to make tape of themselves singing & talking to baby, telling stories so that they could 'be with' her even when they were at home; encouraged to discuss using photo of infant. Became able to discuss disappointment about babies many problems and anxiety about long-term effects & involvement with babies increased.	Psychotherapy as crisis intervention, supportive and insight-orientated (awareness that conflicts interfere with optimal parent-infant relationship	3

2f) Preparing parents for seeing their infant the neonatal unit for the first time

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Huckaby	RCT	Photograph of baby given to mother to take with	Bonding	20	20	Mothers with picture had significantly better scores on	1+

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1999 USA		them while baby on neonatal unit	Observation Checklist (BOCL) Physical Examination Observation Checklist (PEOCL)			bonding measure than those without picture (p<0.001 for BOCL and p<0.01 on PEOCL)	

Author (Year) Country	**Study design**	**Objective**	**Setting**	**Study design/ outcome measures**	**Intervention**	**Results**	**Authors Conclusions**	**Sign**
Griffin 1997 USA	Qualitative	To evaluate a tour of neonatal unit prior to birth if high risk pregnancy diagnosed	NICU 10 mothers 3 fathers	Interview	Tour of NICU	All parents recommended that parents diagnosed with a high-risk pregnancy be offered a prenatal tour of the NICU. The tour benefited parents and (a) decreased fears, (b) inspired hope for the infant's prognosis, (c) provided reassurance about the care in the NICU, and (d) prepared parents for their infant's hospitalization in the NICU		3

2g) Interventions to improve communication at the neonatal unit

Author (Year) Country	**Study design**	**Intervention**	**Outcome measure**	**No of cases**	**No. of controls**	**Statistically significant**	**Quality (SIGN)**
Koh 2007 Australia	RCT	Recording doctors consultation	Information recall 91% of mothers in the tape group listened to the tape (once by day 10, twice by four months, and three times by 12 months;	93	93	At 10 days and four months, mothers in the tape group recalled significantly more information about diagnosis, treatment and outcomes than control group. Recall at 10 days:1.35 (1.08 to 1.69) p<0.007, treatment 1.35 (1.00 to 1.84) and outcome 1.24 (1.05 to 1.47), p<0.009 than mothers in the control group. Recall at 4 months: diagnosis 1.27 (0.99 to 1.63) p<0.05, treatment 1.35 (1.00 to 1.84) p<0.045, and outcome 1.75 (1.27 to 2.4), p<0.004 No statistically significant differences were found between	1+

			range 1-10).			the groups in satisfaction with conversations (10 days), postnatal depression and anxiety scores (10 days, four and 12 months), and stress about parenting (12 months).	
Penticuff 2005 USA	Cohort	Discussion around Infant progress chart	Comprehension of infant medical condition and satisfaction with collaboration with health professionals while baby at neonatal unit	77	77	Intervention group had fewer unrealistic concerns (ANOVA): (4.32 (0.86) vs 8.56 (0.57), p<0.018; less uncertainty about the infant medical condition 1.92 (0.30) vs 3.52 (0.54), p< 0.003; had less decision conflict 45.88 (2.33) vs 59.10 (2.32), p<0.001; more satisfaction with medical decisions process 120.20 (4.07), 104.95 (4.33), p<0.012; more satisfaction with decision input 33.44 (1.30) vs 30.05 (1.21), p<0.058. No significant difference was reported in satisfaction of care for the infant by HC staff, and in satisfaction with decision made.	2++
Piecuch 1983 USA	Cohort	videophone	No. of calls made to neonatal unit while baby at unit	17	17	Mean number of telephone calls to NICU used as proxy for interest in newborns. Mothers with access to videophone made more calls: (1.0 vs. 0.2, p< 0.05) when mothers hospitalised; (0.9 vs. 0.3, p<0.05) when mother discharged. Mothers appreciated videophone; relieved at being able to see infants; infant's condition not as bad as they had imagined; many talked to infant even though only viewing an image; wanted to see close-ups of hands and feet as well as face.	2 -

Author (Year) Country	**Study design**	**Objective**	**Setting**	**Study design/ outcome measures**	**Intervention**	**Results**	**Authors Conclusions**	**Sign**
Jones et al, 2007, Australia	Qualitative	To report mothers' and fathers' perceptions of effective and ineffective communication by nurses in the neonatal intensive care unit	NICU 20 mothers and 13 fathers	Semi-structured interviews	None	The most frequently mentioned strategies for effective communication were discourse management and emotional expression, highlighting the importance for parents of communication that is both nurturing and shares the exchange of information as equal partners. Parents valued communication that was two-way and involved informal chatting as well as more formal discussions. Parents wanted provision of information in a reassuring and respectful way. The	Strategies mentioned for effective communication were about shared management of the interaction and appropriate support and reassurance by nurses. Mothers emphasised more being encouraged as equal partners in the care of their infant.	3

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		(NICU) environment				study highlights that not only do parents simply want lots of information they also want consistent information.		
Freer, 2005, Scotland	Case study	To report on Babylink (an individual website approach to sharing information with parents)	NICU	Descriptive reports from parents	Babylink individual website information	Parents reported the benefits of having access to information on their baby on a daily basis. BabyLink has been beneficial to families in communicating complex information and humanising the experience of neonatal intensive care.	An efficient means of keeping parents informed about the care and progress of their babies being cared for in the hospital's neonatal unit	3
Fenwick, 2001, Australia	Qualitative	To Gain a greater understanding of the woman's experience of mothering in the nursery and how nurses' social interaction and verbal exchanges impacted on this experience	Special care nursery 28 women The average age of the women was 28 years (range 19±41) 15 gave birth at 30 weeks or less.	Semi-structured interviews	None	Nurses engaging in such 'chatting' resulted in the development of relationships that were reciprocal and interdependent rather than undesirable or difficult to achieve. Mothers described this as personal, and forming friendships. While women commented that all the facilitative behaviours were important, nurses who `chatted' in this way were singled out particularly as those that truly made a difference to their nursery experience.  It was these nurses that all the women in the study identified as the people who `most' facilitated their efforts to learn and take up their role as mothers, feel in control of the situation and, ultimately, assisted them in developing a connected relationship with their infants.	The results of this study relate to the importance of the shared `social' interactions between mother and nurse and the role these played in developing `personal' and `equal' relationships. This allowed the nurse to enter the woman's world and to facilitate their access to psychosocial information that assisted them in validating the woman's experiences, and helped them to plan individualized care that met the needs of the infant, mother and family	3
Koh 1998 Australia	Cross-sectional	To evaluate tape-recording doctor-patient communication	NICU 80 parents of babies admitted to NICU	Questionnaire	Tape recording initial conversation between parents and neonatologist (covering baby's condition,	Parent response rate=76% (75/99). Mothers listened to the tape on average 2.5 times, Fathers listened to the tape on average 1.8 times; tape usefulness rated as 9 (SD: 7-10) by parents. 85% (44/75) of parents who listened to the tapes again found it contained things they had	The tape recording of parent-doctor consultations was useful to parents, particularly in reminding them of information they had forgotten or not heard due to anxiety or sedation during the consultation.	3

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					management, likely progress and outcome) and subsequent important conversations and giving parents the tapes	forgotten – some mothers who had been sedated had forgotten the conversation had taken place. Relatives were also able to listen to tape & saved parents repeating what doctor had said. Parents found tapes comforting & supportive. No negative comments.		

2h) Interventions to improve information needs of parents

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Brown 1994 USA	Quasi experimental	Booklet, videotape and practical session. for parents of broncho-pulmonary dysplasia discharged from tertiary care centre. Education on physical characteristics of infants on continuous low-flow oxygen & their care. Psychosocial development of infant, parental needs, oxygen equipment, CPR in NICU	Pre-test Post-test study Pre-test of knowledge immediately before and post-test immediately after programme; post-test repeated 6 weeks after discharge	18 primary caregivers of 10 infants		Post-test scores (immediate mean = 17.33 [SD 3.91]; delayed 17.17 [4.41]) significantly higher than pretest scores (14.38 [3.72], p<0.01)	2+

Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
Kowalski 2006,	Cross-sectional	To determine what information is wanted, who provides information and what expectations parents have regarding obtaining information.	Neonatal unit	A 19-item questionnaire was given to the parents of infants 32 weeks or younger prior to discharge from the NICU.	None	Out of the 101 parents who consented, almost all of the parents (96%) felt that 'the medical team gave them the information they needed about their baby' and that the 'neonatologist did a good job of communicating' with them (91%). However, the nurse was chosen as 'the person who spent the most time explaining the baby's condition', 'the best source of information,' and the person who told them 'about important changes in their baby's condition'	Although the neonatologist's role in parent education is satisfactory, the parents identified the nurses as the primary source of information.	3

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Gannon 2000 USA	Case series	To evaluate 'Caring one day at a time' book	NICU 5 pilot families	Survey	'Caring one day at a time' book – three-ring binder book to organise information about child's medical, developmental and financial records from birth until adolescence and beyond	Allows parents to keep all information together, speeding up process when they have to see a new doctor for example & giving parents more confidence; allows parent to see child's progress (giving hope); allows new professionals to see history/ current status/ current medication etc written down	This family-centred approach with early involvement of families in child's care; enhances communication between families and professionals	3
Costello 1998 Canada	Qualitative	To assess mothers' perceptions of Care by Parent programme	NICU and Level II nursery 6 mothers of preterm infants	Interviews the day after Care by Parent overnight stay in hospital, and when baby home at least 4 days	Care by Parent programme – mother stays with baby in room near NICU – assumes all care but help at hand if needed.	Mothers found Care by Parent reassuring to confirm their own and the baby's readiness for discharge; builds confidence in mother's parenting abilities; feeling more comfortable about bringing baby home; feeling confident in taking responsibility, making the right decisions; feeling more secure that mother would wake when baby cried & be able to respond; reassured that baby medically ready to go home (e.g. not having apnoea spells). Helped mothers learn about infant's pattern of behaviour & responses to infant's cues. Fail-safe opportunity; taking responsibility with a safety net. Opportunity to 'test reality' of parenting – feeling more as though the baby belonged to the mother not the nurses; facilitates transition to parenthood in reality; bridges gap between hospital and home.	Care by Parent gave mothers opportunity to assume full responsibility for baby's care knowing that staff available if necessary. It helped mothers learn caregiving and confirm readiness for discharge.	3
Drake 1995 USA		To assess a method of prioritising information needs of parents for discharge	NICU Pilot study of 10 parents	Q-sort – ranking of topics in order of priority to parents for learning prior to discharge; feedback on how easy Q-sort was to complete	Card sort method of prioritising teaching/learning topics that parents need prior to discharge	Parents sorted 14 topics into most important, important, and least important piles and had opportunity to add in 3 other topics they wanted. Parents' highest priorities were infant CPR, illness and development, with feeding, giving medication & hygiene issues medium priority and use of car seat & getting help at home low priorities.	Parents are the best sources to assess their learning needs, and addressing topics parents feel are important helps teaching and learning, especially if nurse does not know family well.	

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						Parents and nurses found it helpful to assess what parents needed to know – better than closed questions to parents like 'Do you know how to give the baby a bath?' which can be threatening		

2i) Discharge planning

Author (Year) Country	Study design	Intervention	Outcome measure	No of cases	No. of controls	Statistically significant	Quality (SIGN)
Ortenstrand 2001 Sweden	Cohort	Early discharge with domiciliary nursing care Domiciliary nurse made an individual care and discharge plan together with the parents. During these planning sessions, parent's knowledge of how to care for their pre-term infant were checked and supplemented. The nurse was available for home visit/ telephone consultation from Monday to Friday, and at weekends parents could contact the neonatal ward	STAI	40	35	No differences in mothers' Trait anxiety at 1st or 2nd assessment. State (situational) anxiety lower for EDG mothers at 1st assessment (EDG 30.9 [SD 6.2] vs. CG 36.6 [8.4], p<0.01. Fathers showed a significant difference in trait anxiety at both 1st and 2nd study time period (30.1 (5.8) vs 33.5 (7.7), p<0.05, but only a significant difference in state anxiety at the 1st assessment (29.5 [5.4] vs32.8 [9.1], p<0.08. At 1 yr, no difference in recollection of anxiety in caring for the infant or in experiences of mental imbalance related to the birth of the infant	2+
Barrera 1986 Canada	RCT	Teaching developmental care	HOME Parent-infant interactions	40	40	At 4 mths and 16 mths, mothers in the Parent-Infant intervention group and full term control group were significantly better maternal responsiveness and mother-infant interaction compared to the pre-term baby control group. Manova: Maternal rseponsiveness I-7.32, FTC – 7.44, C- 6.41, f=6.78, p<0.001 Maternal involvement: I=7.23, FTC-7.16, C-6.26, f=2.70, p<0.05	1-

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Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
Broedsgaard 2005 Denmark	Qualitative	To present the parents' experiences of an educational programme	NICU 37 families with premature infants (<34 weeks)	Descriptive study Semi-structured interviews and focus groups	Educational programme (topic group discussions) for parents during hospitalisation; health visitor coordinator on NICU; visit and orientation about NICU for family's health visitor; multidisciplinary discharge conference; booklets for parents and health care providers; parents' evenings once a month after discharge	Families valued support and guidance from coordinator; having named contact nurse throughout child's stay; continuity of care; felt secure when they went home; NICU personnel and own health visitor collaborated well. They received extra visits from health visitor (most 4-6 extra but some >7 extra) in the first year and this was in accordance with their needs. Frustrated that mothers were on postnatal ward with mothers of full-term infants but they were separated from their infants (NICU on another floor). Felt that their needs not met in maternity unit. Felt assisted and reassured in NICU; the parents needed special care to tackle their situation and needed lots of information (repeated several times, plus written materials to reinforce). Discharge was time of anxiety; shock; needed to adjust; return home helped by meeting health visitor on NICU; 3-4 days rooming-in on NICU helped preparing to return home.	Intervention increased support, contributed to confidence in caring for infant and infant well-being after discharge.	3
Bennett 2005 UK	Qualitative	Evaluation of Rooming in (care by parent)	NICU	Interview	Rooming in (care by parent)	Most found it an extremely positive experience (scared but realised the opportunity to know each other more, feel a bit more in charge; promoting breastfeeding, increased bonding & confidence to take baby home).	Most mothers reported 'rooming in' to be a useful, informative time	3
Jonsson 2003	Qualitative	To report on an early	NICU 23 parents (17	Interviews	Home care programme –	Becoming a family: do not feel like a family in NICU; shared infant with staff;	Parents wanted to come home earlier to feel like a family, but wanted security of access to	3

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Sweden		discharge & home care programme	women + 6 men) of babies on home care programme		home visits at parent request (1 day-1 week apart); counselling & supervision	feeling gradually disappeared when they went home. Being at home: nervous; less conflict between being with infant in hospital and being with other children at home Being reunited as a family; not having to share baby with others Feeling security: important for parents to have access to information and advice: checked with checklist with the neonatal nurses; had questions when they got home Needed accessibility, usually by telephone, with home care team Needed support from health care professionals and relatives	staff knowledge & support	
Costello 1998 Canada		To assess mothers' perceptions of Care by Parent programme	NICU and Level II nursery 6 mothers of preterm infants	Interviews the day after Care by Parent overnight stay in hospital, and when baby home at least 4 days	Care by Parent programme – mother stays with baby in room near NICU – assumes all care but help at hand if needed.	Mothers found Care by Parent reassuring to confirm their own and the baby's readiness for discharge; builds confidence in mother's parenting abilities; feeling more comfortable about bringing baby home; feeling confident in taking responsibility, making the right decisions; feeling more secure that mother would wake when baby cried & be able to respond; reassured that baby medically ready to go home (e.g. not having apnoea spells). Helped mothers learn about infant's pattern of behaviour & responses to infant's cues. Fail-safe opportunity; taking responsibility with a safety net. Opportunity to 'test reality' of parenting – feeling more as though the baby belonged to the mother not the nurses; facilitates transition to parenthood in reality; bridges gap between hospital and home.	Care by Parent gave mothers opportunity to assume full responsibility for baby's care knowing that staff available if necessary. It helped mothers learn caregiving and confirm readiness for discharge.	3

2j) Home Support Programmes

Author (Year)	**Study design**	**Intervention**	**Outcome measure**	**No of cases**	**No. of controls**	**Statistically significant**	**Quality (SIGN)**

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Country							
Kurz 2002 Austria	Cohort	Home support (Phone call and counselling of parents after returning home) for parents of babies with monitors	Questionnaire about monitor use, stress reported by monitor use, and satisfaction	90	70	Home monitoring considered reassuring for 60% of families. After intensive counselling introduced, parents liked the instruction better (74% vs. 44% very satisfied; 24% vs. 51% satisfied; 2% vs. 5% not satisfied, p<0.005)), were less stressed by the monitor (42% vs. 63% stressed by false alarms, p<0.05) and reacted less aggressively to monitor alarms (8% vs. 24% reacted by vigorously shaking or lifting baby, p<0.05); used monitor mainly during sleeping periods; used monitor for less time (6.1 months vs. 7.6 months, p<0.05). Counselling did not reduce anxiety.	2+
Spiker 1993 USA	RCT	Home Support (Infant Health and Development Program (IHDP) – Home visits from discharge up to 36 months	Quality of assistance in parenting pre-term baby Supportive presence for parents of pre-term infants	271	412	Intervention group reported significantly better quality of assistance ratings than control group (I: 3.6 [1.5], vs 3.3[1.5], p<0.05), but no significant difference on supportive presence was reported. Most outcomes in this study were baby outcomes.	1-
Leonard 1989 USA	Cohort	Educational support programme for infants on home monitors (Infant Apnea Evaluation Programmes (IAEP)L Gp1 – with home monitoring Gp2- no home monitoring Gp3 – healthy term babies	Symptom checklist-90, schedule of recent events, satisfaction - all in interview 2 wks after going home	Gp1-40	Gp 2- 30 Gp3 - 32	Psychological symptoms highest in parents of non-monitored premature infants (M - 0.2845 [0 – 0.82] vs , NM – 0.4507 [0-1.3], p=0.037); particularly fathers of non-monitored infants scoring high on depression (0.6846)). Support highest in monitored infants (p=0.005) NS on family satisfaction .	2+
Resnick 1988 USA	Cohort	Educational developmental Intervention Programme at home – teach parents to use: parent's voice tape, massage, passive range of motion, exercises) and twice-monthly interventions at home by child development specialists through 12 months adjusted age (e.g. language and social skills enrichment exercises, cognitive development, motor exercises, parenting activities)	Greenspan-Lieberman Observations System (GLOS) to analyse infant-caregiver interactions at 6 and 12 months	21	20	Parent child positive verbal scores significantly higher in treatment than control groups (2.91 vs. 2.08), p=0.02. Intervention group dyads had fewer negative verbal interactions (0.07 vs. 0.17, p=0.03). The developmental intervention benefited the quality of the parent-infant interaction at home, as well as benefiting the infant development.	2-
Ross 1984 USA	Cohort	Teaching developmental care at home to lower socio-economic parents	HOME Maternal Attitudes Scale	44	40	Intervention group reported significantly higher HOME scores (total score 38.4 vs. 34.9, p<0.001). No other significant differences reported	2+

			Maternal developmental Expectations and child rearing attitudes survey Baby outcomes (not reported here)				

Author (Year) Country	Study design	Objective	Setting	Study design/ outcome measures	Intervention	Results	Authors Conclusions	Sign
Langley 1999 UK	Cross-sectional study	To evaluate a home support - Community Neonatal Service	Home	Questionnaire developed for this study	Home support programme	Families reported feeling supported, and appreciated continuity of care after discharge. This benefit was reported more in vulnerable parents (isolated mothers, mothers with babies who had sleeping, crying or feeding problems).	Community Neonatal Service provided important support to families where mothers are vulnerable, or where infant has difficulties.	3
Swanson 1997 USA	Case series	Evaluation of neonatal integrated home care program	NICU/ home	Descriptive	Neonatal integrated Home Care Program – follow up care to high risk neonates at home, teaching re specific infant care needs (e.g. feeding)	Program made it possible to bring home baby, nurse provided help, support, instruction & encouragement (e.g. with nasogastric feeding tube)	Families supported to take high risk infants home sooner, ease transition from NICU to home & keep them home (i.e. reduce readmissions)	3
Isaacs 1980 USA	Case series	Evaluation of newborn Intensive Care Coordinator	Home 40 families of high-risk infants discharged from NICU	Questionnaire	Home visits for teaching, guidance and support	More than 2/3 parents felt concerned about infant discharge and had anxiety about caring for infant at home. All families strongly agreed that the coordinator made families feel completely comfortable, they had complete trust in her, she was available, she gave emotional support, felt they could discuss fear & worries with her, and helped them mother infant. Teaching gave support, confidence & necessary skills.	Coordinator met the needs of parents	3

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PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2,3,4,5
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	www.poppy-project.org.uk
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A Few quantitative studies
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A Few quantitative

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PRISMA 2009 Checklist

			studies
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	7

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Few quantitative studies
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	8
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Discussed in limitations
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	18-31
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A Non-quantitative analysis performed
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	30-32
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	31

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PRISMA 2009 Checklist

Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Big Lottery

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

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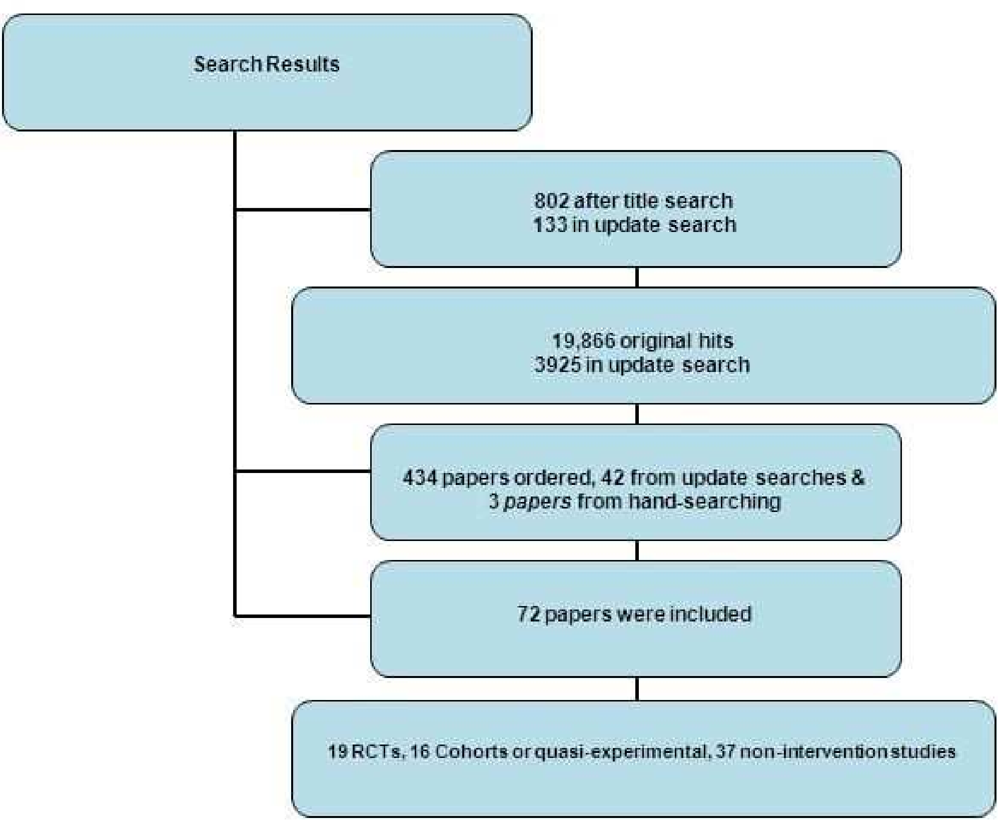

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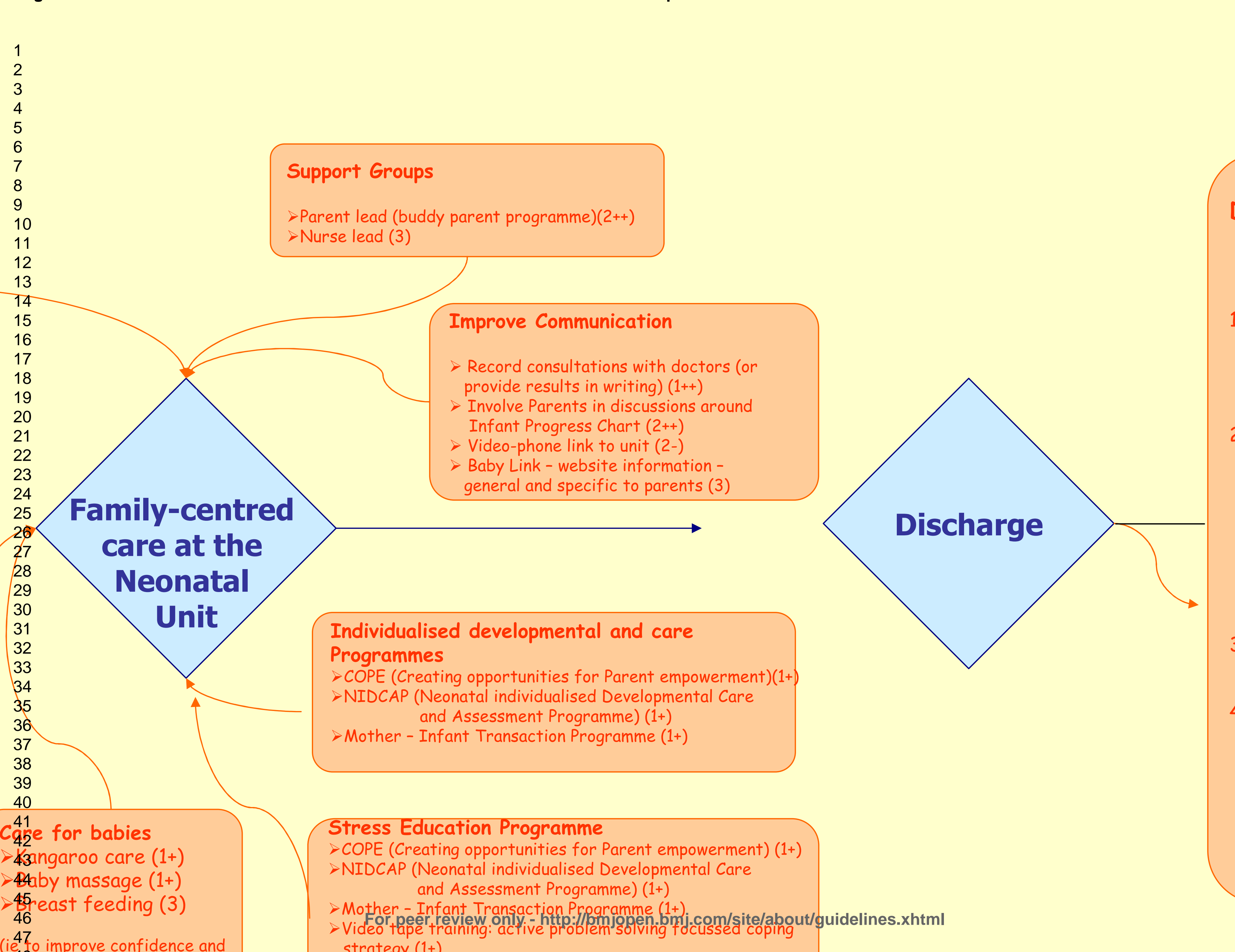

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Figure 3. Individualised developmental and behavioural care programmes

1) COPE(4) (Creating Opportunities for Parent Empowerment) provides an educational programme for parents at the neonatal unit on the appearance and behavioural characteristics of pre-term infants, how parents can participate in their infant's care, and how parents can make more positive interactions with their infant.

2) NIDCAP(11,12,13) (Neonatal Individualised Developmental Care and Assessment Programme) is an intervention that stimulates pre-term infants and improves the interaction between mothers and infants

3) MITP (Mother-Infant Transaction Programme) (14,15,16) helps to enable the parents to appreciate their infant's unique characteristics, temperament, and developmental potential, sensitising parents to their infant's cues so that they can respond appropriately.

4) NCATS (Nursing Child Assessment Teaching Scale) NCATS (Nursing Child Assessment Teaching Scale) (17) : Examines the mother-child relationship in conjunction with teaching mothers how to interact with the baby, teaching behavioural cues, how to play etc

NB: While the developmental care programmes are designed to improve the development of the baby, these interventions give parents psychological support and practical guidance on how to care for their infants

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Figure 4

Scottish Intercollegiate Guideline Network (SIGN) Levels of Evidence

1++	High quality meta analysis, systematic reviews of RCTs, or RCTs with very low risk of bias
1+	Well conducted meta-analysis, systematic review of RCTs or RCTs with low risk of bias
1-	Meta analyses, systematic reviews of RCTs, or RCTs with high risk of bias
2++	High quality systematic reviews of case-control or cohort studies High quality case-control studies with a very low risk of confounding bias, or chance and a high probability that the relationship is causal
2+	Well conducted case control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal
2-	Case control or cohort studies with high risk of confounding, bias, or chance and a significant risk that the relationship is not causal
3	Non-analytical studies, e.g. case series, case reports, qualitative
4	Expert opinion

55x59mm (300 x 300 DPI)