Bilaga till rapport

Bemötande och stöd när barn föds döda, rapport 354 (2022)

Bilaga 6 Inkluderade kvantitativa studier

Appendix 6 Included quantitative articles

Author	**Aho et al.**
Year	2011
Country	Finland
Ref #	[1]
Study design	RCT
Setting	All Finnish University hospitals (Tampere, Helsinki, Kuopio, Oulu, and Turku) in all units of these hospitals where a child could die (intensive care unit, maternity ward, and emergency room) from June 2006 to April 2009.
Recruitment	Depending on the hospital where the child died, fathers were randomly assigned either to the intervention program (Tampere and Helsinki) or the control group that received routine hospital care (Kuopio, Oulu, and Turku) immediately after the death of their child.
Population	Grieving fathers whose child had died at the age of 3 years and younger (including perinatal deaths). Mean age (SD): I: 35.5 (NA), C: 33 (NA) Gestational week, n: 20 to 36 weeks: I: 26, C: 9 37 to 41 weeks: I: 12, C: 7 Age of deceased child, n: 1hr to 1 day: I: 6, C: 8 2 to 7 days: I: 7, C: 6 8 days to 3 years: I: 7, C: 11 Time since loss: NA, intervention was started shortly after the death. Singleton/twin pregnancies: NA
Inclusion criteria	Grieving fathers whose child had died at the age of 3 years and younger (including perinatal deaths at 22 weeks gestation or fetuses over 500 g). An additional criterion was that the fathers had sufficient Finnish language skills
	Exclusion: NA
Follow up	6 months after leaving hospital
Intervention	Bereavement follow-up and support - information letters on the mourning process and coping strategies, and poems and stories about the loss of a child - peer contact with fathers

	- health care personnels' contact with fathers.
Participants (n)	62
Drop-outs (n)	NA
Comparison	No intervention/care as usual
Participants (n)	41
Drop-outs (n)	NA
Primary outcomes	**Psychological wellbeing (fathers)** Hogan Grief Reactions Checklist (61-item self-report instrument); median(range), p-value for group difference with Mann–Whitney test: - Despair (13 items; min=1; max=5; higher = worse): I: 1.62 (1.00–4.08) C: 1.69 (1.00–3.92) p=0.475 - Panic Behavior (14 items; min=1; max=5; higher = worse): I: 1.43 (1.00–2.93) C: 1.57 (1.00–3.21) p=0.198 - Personal Growth (11 items; min=1; max=5; higher = better): I: 2.75 (1.50–4.58) C: 2.33 (1.33–4.17) p=0.026 - Blame and Anger (7 items; min=1; max=5; higher= worse): I: 1.43 (1.00–3.43) C: 1.43 (1.00–3.86) p=0.060 - Detachment (8 items; min= 1; max= 5; higher= worse): I: 1.38 (1.00–3.42) C: 1.38 (1.00–3.63) p=0.458 - Disorganization (8 items; min= 1; max= 5; higher= worse): I: 1.57 (1.00–4.19) C: 1.57 (1.00–4.29) p=0.647 **Quality of life** NA
Other outcomes	
Comments	
Risk of bias	High risk of bias

	(Domain 1. Randomization process: high; Domain 2. Deviations from intended interventions: some concerns; Domain 3. Missing outcome data: high; Domain 4. Measurement of the outcome: some concerns; Domain 5. Selection of the reported result: some concerns)
Author **Year** **Country** **Ref #**	**Forrest et al.** 1982 UK [2]
Study design	RCT
Setting	Maternity Hospital in Oxford
Recruitment	Unselected mothers of babies over 28 weeks' gestation were recruited over an 18-month period. Immediately after the death or stillbirth of their baby, the mothers were randomly allocated either to intervention or to control group.
Population	50 in total; 25 mothers of stillborn infants and 25 of babies who had died in the newborn period. Mean age (SD): Mothers=27 (range 18–40); fathers=30 (range 21–49).
	Gestational week: NA Time since loss: NA Singleton/twin pregnancies: 48/2
Inclusion criteria	Mothers of babies or fetuses of 28 weeks' gestation or more.
	Exclusion: NA
Follow up	6 months after the death 14 months after the death (not reported here due to incomplete reporting of data in the article)
Intervention	Planned support: - they were all encouraged to see, hold, and name their dead baby - a photograph of the baby was taken and kept - the mother was given the choice, of returning to her own ward or to the isolation floor - discharge was not hurried, allowing time for contact with the medical staff, social worker, community midwife, and general practitioner. - bereavement counselling was offered to both parents between 24 and 48 hours after the baby's death. - the follow-up arrangements were planned to ensure that parents received obstetric counselling from their obstetrician, genetic counselling if necessary, and an opportunity to discuss the postmortem results with a pediatrician.
Participants (n)	16 (at 6 months follow-up);
Drop-outs (n)	NA; (In total over both groups: 15 mothers dropped out; 6 husbands attended interviews and 26 husbands in filled in the ratings)
Comparison	Routine hospital care: A wide variety of care, which depended on several factors, including the attitude of individual staff members and the parents' own reactions to their loss. The minimum care (which applied in few

	cases) consisted of no opportunity to see the baby; automatic placement in a single room on the isolation floor; discharge home within 24 hours; and no hospital follow-up.
Participants (n)	19
Drop-outs (n)	NA; (In total over both groups: 15 mothers dropped out; 6 husbands attended interviews and 26 husbands in filled in the ratings.)
Primary Outcomes	**Psychological wellbeing (mothers)** - General health questionnaire: nr above cut-off point for psychiatric disorder I: (n=16)=2 ; 2/16=13%* C: (n=19)=10 ; 10/19=53%* Test of difference: p<0.01 (Fisher's exact test) Risk ratio (95% CI)*=0.24 (0.06 to 0.93) Risk difference (95% CI)*= –0.40 (–0.68 to –0.12) - Leeds scales: nr above cut-off point for pronounced symptoms of depression and anxiety I: (n=16)=5; 5/16=31%* C: (n=19)=12; 12/19=63%* Test of difference: p=0.06 Risk ratio (95% CI)*=0.59 (0.26 to 1.38) Risk difference (95% CI)*= –0.21 (–0.53 to 0.11) **Psychological wellbeing (fathers)** - General health questionnaire: nr above cut-off point for psychiatric disorder I: (n=12)= 2; 2/12=17%* C: (n=14)= 2; 2/14=14%* Test of difference: p=NA; non-significant Risk ratio (95% CI)*=1.17 (0.19 to 7.07) Risk difference (95% CI)*=0.02 (–0.26 to 0.30) - Leeds scales: nr above cut-off point for pronounced symptoms of depression and anxiety I: (n=12)=2; 2/12=17%* C: (n=14)=2; 2/14=14%* Test of difference: p= NA; non-significant Risk ratio (95% CI)*=1.17 (0.19 to 7.07) Risk difference (95% CI)*=0.02 (–0.26 to 0.30) **Quality of life** NA
Other outcomes	
Comments	
Risk of bias	High risk of bias

	(Domain 1. Randomization process: some concerns; Domain 2. Deviations from intended interventions: some concerns; Domain 3. Missing outcome data: high; Domain 4. Measurement of the outcome: some concerns; Domain 5. Selection of the reported result: some concerns)
Author **Year** **Country** **Ref #**	**Lake et al.** 1987 USA [3]
Study design	RCT
Setting	Evaluation of an intervention for families experiencing perinatal death initiated at a large tertiary perinatal center serving a predominantly indigent population in west central Florida.
Recruitment	78 women experiencing perinatal death were enrolled in the study plan between June 1982 and June 1984.
Population	78 women experiencing perinatal death Mean age: I: 25.39; C: 23.93 Gestational week: NA Time since loss: NA
	Singleton/twin pregnancies: NA
Inclusion criteria	perinatal death was defined as the delivery of a fetus ≥ 20 weeks' gestation or weighing at least 500 gm that was either stillborn or died within 2 hours of birth. Exclusion: NA
Follow up	6 months after delivery
Intervention **Participants (n)** **Drop-outs (n)**	Perinatal grief support team e.g.: - grief support (comfort, make loss real, encourage communication and emotion expression) - share autopsy report - assess emotional progress and social support - discuss local support groups 18 NA; in total 78–34=44 (65%) drop-out
Comparison **Participants (n)** **Drop-outs (n)**	No intervention from the grief support team. 16 NA; in total 78–34=44 (65%) drop-out
Primary outcomes	**Psychological wellbeing (mothers)** Grief experience inventory (63-items on four-point Likert scale; min = NA; max = NA; higher= NA): Mean (SD) I: (n=18)=240.17 (NA) C: (n=16)=259.60 (NA) Test of difference: statistically non-significant **Quality of life** NA

Other outcomes	
Comments **Risk of bias**	High risk of bias (Domain 1. Randomization process: some concerns; Domain 2. Deviations from intended interventions: some concerns; Domain 3. Missing outcome data: high; Domain 4. Measurement of the outcome: some concerns; Domain 5. Selection of the reported result: some concerns)
Author **Year** **Country** **Ref #**	**Murray et al.** 2000 Australia [4]
Study design	CT
Setting	Three major maternity hospitals in the Brisbane metropolitan area in Queensland, Australia
Recruitment	All eligible families were contacted by phone or letter and were invited to participate. Of the 261 parents who were eligible to participate in the study, 172 (66%) agreed to do so
Population	Parents who had experienced a stillbirth (greater than 20 weeks gestation), neonatal death or a sudden infant death syndrome (SIDS) death. Mean age (SD), years=29.86 (5.34) Gestational week (SD)=33.37 (6.65) Time since loss: baseline measured at 4 to 6 weeks post loss Singleton/twin pregnancies: NA Participants were divided into 2 groups depending on assessed risk of developing mourning difficulties: - Low risk: fathers (30 intervention, 21 control) & mothers (23 intervention, 24 control) - High risk: fathers (7 intervention, 7 control) & mothers (24 intervention, 8 control)
Inclusion criteria	Parents who had experienced a stillbirth (greater than 20 weeks gestation), neonatal death or a sudden infant death syndrome (SIDS) death Exclusion: NA
Follow up	- 6 months post loss - 15 months post loss
Intervention	Contact with a trained grief worker and resource materials appropriate to their needs - information and support that would assist them to accept the reality of the loss - affirm their baby's existence - support the expression of emotional pain - encourage mourning
Participants (n)	84
Drop-outs (n)	NA; In total: 84% (n=144) of those who agreed to participate completed all three interviews.
Comparison	routine community care
Participants (n)	60
Drop-outs (n)	NA; In total: 84% (n=144) of those who agreed to participate completed all three interviews.

Primary outcomes	**Psychological wellbeing (Fathers)** Delusions-Symptoms-States Inventory (DSSI/sAD); rated the frequency of symptoms during the last month from 0, not at all to 3, almost all the time; mean (SD): - Depression (7 items; min=0, max=21; higher= worse) at baseline (4 to 6 weeks): I: Low Risk (n=30)=1.6 (1.4); High Risk (n=7)=6.7 (4.7); Combined*(n=37)=2.6 (3.1) C: Low Risk (n=21)=2.1 (2.7); High Risk (n=7)=6.7 (5.1); Combined*(n=28)=3.0 (3.7) Mean difference (I vs C in combined groups)*: –0.41 (95% CI –1.95 to 1.14) - Depression (7 items; min=0, max= 21; higher= worse) at 6 months: I: Low Risk (n=30)=0.6 (0.9); High Risk (n=7)=2.1 (1.5); Combined*(n=37)=0.9 (1.2) C: Low Risk (n=21)=1.0 (1.5); High Risk (n=7)=7.1 (5.2); Combined*(n=28)=2.5 (3.9) Mean difference (I vs C in combined groups)*: –1.64 (95% CI –3.12 to –0.16) SMD (I vs C in combined groups)*: –0.61 (95% CI –1.11 to –0.10) - Depression (7 items; min0, max= 21; higher= worse) at 15 months: I: Low Risk (n=30)=0.4 (0.5); High Risk (n=7)=0.6 (1.8); Combined*(n=37)=0.44 (0.86) C: Low Risk (n=21)=0.8 (1.8); High Risk (n=7)=4.6 (3.7); Combined*(n=28)=1.75 (2.87) Mean difference (I vs C in combined groups)*: –1.31 (95% CI –2.41 to –0.21) SMD (I vs C in combined groups)*: –0.65 (95% CI –1.16 to –0.15) - Anxiety (7 items; min=0, max= 21; higher= worse) at baseline (4 to 6 weeks): I: LowRisk (n=30)=1.9 (1.4); High Risk (n=7)=7.6 (5.1); Combined*(n=37)=3.0 (3.3) C: LowRisk (n=21)=1.6 (1.8); High Risk (n=7)=6.4 (3.6); Combined*(n=28)=2.8 (3.1) Mean difference (I vs C in combined groups)*: 0.18 (95% CI –1.40 to 1.75) - Anxiety (7 items; min=0, max=21; higher = worse) at 6 months: I: LowRisk (n=30)=1.5 (1.7); High Risk (n=7)=3.7 (4.5); Combined*(n=37)=1.9 (2.5) C: LowRisk (n=21)=1.2 (1.7); High Risk (n=7)=5.6 (4.8); Combined*(n=28)=2.3 (3.3) Mean difference (I vs C in combined groups)*: –0.38 (95% CI –1.86 to 1.09) - Anxiety (7 items; min=0, max=21; higher = worse) at 15 months: I: LowRisk (n=30)=1.0 (1.0); High Risk (n=7)=1.6 (1.5); Combined*(n=37)=1.1 (2.1) C: LowRisk (n=21)=1.3 (2.0); High Risk (n=7)=6.1 (4.7); Combined*(n=28)=2.5 (3.5) Mean difference (I vs C in combined groups)*: –1.39 (95% CI –2.74 to –0.04) SMD (I vs C in combined groups)*: –0.56 (95% CI –1.06 to –0.06) **Psychological wellbeing (Mothers)** Delusions-Symptoms-States Inventory (DSSI/sAD); rated the frequency with of 14 symptoms during the last month from 0,not at all to 3, almost all the time; mean (SD): - Depression (7 items; min=0, max=21; higher = worse) at baseline (4 to 6 weeks): I: LowRisk (n=23)=3.0 (2.8); High Risk (n=24)=9.2 (3.2); Combined*(n=47)=6.2 (4.3) C: LowRisk (n=24)=4.4 (2.8); High Risk (n=8)=7.1 (3.2); Combined*(n=32)=5.1 (3.1)

	Mean difference (I vs C in combined groups)*: 1.09 (95% CI –0.54 to 2.73) - Depression (7 items; min=0, max=21; higher = worse) at 6 months: I: LowRisk (n=23)=1.1 (1.7); High Risk (n=24)=3.0 (2.1); Combined*(n=47)=2.1 (2.1) C: LowRisk (n=24)=1.6 (1.4); High Risk (n=8)=7.1 (2.0); Combined*(n=32)=5.1 (3.1) Mean difference (I vs C in combined groups)*: –3.00 (95% CI –4.24 to –1.77) SMD (I vs C in combined groups)*: –1.16 (95% CI –1.65 to –0.68) - Depression (7 items; min=0, max=21; higher = worse) at 15 months: I: LowRisk (n=23)=1.2 (1.5); High Risk (n=24)=2.0 (1.5); Combined*(n=47)=1.6 (1.5) C: LowRisk (n=24)=0.9 (1.1); High Risk (n=8)=4.9 (3.3); Combined*(n=32)=1.9 (2.5) Mean difference (I vs C in combined groups)*: –0.29 (95% CI –1.28 to 0.69) - Anxiety (7 items; min=0, max=21; higher = worse) at baseline (4 to 6 weeks): I: Low Risk (n=23)=5.0 (3.4); High Risk (n=24)=9.2 (3.0); Combined*(n=47)=7.1 (3.8) C: Low Risk (n=24)=5.3 (3.3); High Risk (n=8)=7.0 (2.3); Combined*(n=32)=5.7 (3.1) Mean difference (I vs C in combined groups)*: 1.42 (95% CI –0.12 to 2.96) - Anxiety (7 items; min=0, max=21; higher = worse) at 6 months: I: Low Risk (n=23)=2.9 (2.7); High Risk (n=24)=6.1 (2.8); Combined*(n=47)=4.5 (3.1) C: Low Risk (n=24)=2.5 (2.5); High Risk (n=8)=6.1 (2.1); Combined*(n=32)=3.4 (2.9) Mean difference (I vs C in combined groups)*: 1.13 (95% CI –0.21 to 2.47) - Anxiety (7 items; min=0, max=21; higher = worse) at 15 months: I: Low Risk (n=23)=2.1 (1.7); High Risk (n=24)=4.9 (4.2); Combined*(n=47)=3.5 (3.5) C: Low Risk (n=24)=1.8 (1.7); High Risk (n=8)=6.0 (2.7); Combined*(n=32)=2.9 (2.7) Mean difference (I vs C in combined groups)*: 0.68 (95% CI –0.68 to 2.04) **Quality of life (mothers/fathers/siblings)** NA
Other outcomes	
Comments	
Risk of bias	High risk of bias (Domain 1. Confounding: high ; Domain 2. Deviations from intended interventions: low; Domain 3. Missing outcome data: some concerns; Domain 4. Measurement of the outcome: some concerns; Domain 5. Selection of the reported result: some concerns)
Author **Year** **Country** **Ref #**	**Raitio et al.** 2015 Finland [5]
Study design	RCT
Setting	All Finnish University hospitals (Tampere, Helsinki, Kuopio, Oulu, and Turku) in all units of these hospitals where a child could die.

Recruitment	Depending on the hospital where the child died, fathers were randomly assigned either to the intervention program (Tampere and Helsinki) or the control group that received routine hospital care (Kuopio, Oulu, and Turku) immediately after the death of their child.
Population	Grieving mothers whose child had died at the age of 3 years and younger (including perinatal deaths at 22 weeks of gestation or fetuses over 500 g). Mean age (range): I: 33.2 (23 to 43), C: 32.2 (19 to 47) Gestational week (if stillbirth), n (%): 20–36 weeks: I: 43 (70%), C: 16 (70%) 37–41 weeks: I: 18 (30%), C: 7 (30%) Age of deceased child, n (%): 1 hour to 1 day: I: 7 (29%), C: 5 (17%) 2 to 7 days: I: 10 (42%), C: 8 (26%) 8 days to 3 years: I: 7 (29%), C: 17(57%) Time since loss: NA, intervention was started shortly after the death. Singleton/twin pregnancies: NA
Inclusion criteria	Grieving mothers whose child had died at the age of 3 years and younger (including perinatal deaths at 22 weeks gestation or fetuses over 500 g). An additional criterion was that the mothers had sufficient Finnish language skills. Exclusion: NA
Follow up	6 months after leaving hospital
Intervention	Bereavement follow-up and support - information letters on the mourning process and coping strategies, and poems and stories about the loss of a child - peer-support contact - health care personnel contact
Participants (n)	86
Drop-outs (n)	NA
Comparison	No intervention/care as usual
Participants (n)	53
Drop-outs (n)	NA
Primary outcomes	**Psychological wellbeing (mothers)** Hogan Grief Reactions Checklist (61-item self-report instrument); median(range), p-value for group difference with Mann–Whitney test: - Despair (13 items; min=1; max=5; higher = worse): I: 2.00 (1.6–2.5) C: 2.00 (1.7–2.9) p=0.938 - Panic Behavior (14 items; min=1; max=5; higher = worse): I: 2.07 (1.6–2.6) C: 2.00 (1.5–2.5)

	p=0.520 - Personal Growth (11 items; min=1; max=5; higher = better): I: 2.75 (2.3–3.2) C: 2.75 (2.3–3.3) p=0.797 - Blame and Anger (7 items; min=1; max=5; higher = worse): I: 1.86 (1.4–2.4) C: 1.86 (1.3–2.4) p=0.413 - Detachment (8 items; min=1; max=5; higher = worse): I: 1.94 (1.4–2.9) C: 1.88 (1.4–2.8) p=0.743 - Disorganization (8 items; min=1; max=5; higher = worse): I: 2.29 (1.6–2.9) C: 2.14 (1.4–2.7) p=0.491 **Quality of life** NA
Other outcomes	
Comments	
Risk of bias	High risk of bias (Domain 1. Randomization process: high; Domain 2. Deviations from intended interventions: some concerns; Domain 3. Missing outcome data: high; Domain 4. Measurement of the outcome: some concerns; Domain 5. Selection of the reported result: some concerns)

* calculated by SBU (if no formula is presented, calculations were done in Review Manager).

C = Control group; **CI** = Confidence Interval; **CT** = Controlled trial (no randomization); **I** = Intervention group; **n** = Number of participants; **NA** = Not appicable; **p** = p-value; **RCT** = Randomized controlled trial; **SD** = Standard deviation

References

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5. Raitio K, Kaunonen M, Aho AL. Evaluating a bereavement follow-up intervention for grieving mothers after the death of a child. Scand J Caring Sci. 2015;29(3):510-20. Available from: https://doi.org/10.1111/scs.12183.