

Cochrane review summary: specialist home-based nursing services for children with acute and chronic illnesses



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Review question

To evaluate the impact of specialist home-based nursing services for children with acute and chronic illnesses.

Relevance to primary care and nursing

The Department of Health's review on Community Children's Nursing Services highlights the need for a comprehensive out of hospital service involving nursing and primary care as well as multi-agency services to meet the complex needs of children with acute and chronic conditions (Department of Health, 2011). This systematic review has summarised all the available evidence for specialist home-based nursing services for children with acute and chronic illnesses (Parab *et al.*, 2013).

Type of review

This is a summary of a Cochrane review containing seven randomised controlled trials (RCTs). Data are presented in a narrative summary as meta-analysis was inappropriate.

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Characteristics of the evidence

The review included a total of 840 children (ranged from 29 to 399 in included studies) aged three months to 17 years, who had acute and/or chronic/long-term illnesses (no definition provided in the review and 'illnesses' and 'conditions' used interchangeably throughout the review). Interventions needed to have specialist paediatric nursing outreach services delivered in the home, compared with conventional health care. Studies describing a planned illness educational support by nurses independent of clinical review and management of children with acute and/or chronic conditions were excluded.

Outcomes needed to have at least one objective measure, for example, hospital admission data and/or a standardised measure such as a behaviour checklist, used for both intervention and control groups. The review did not pre-specify outcomes as primary or secondary which varied considerably.

Outcomes included:

- Physical and mental health of participants
- Utilisation of health care: emergency departments (ED), hospital admissions, length of stay in hospital
- Satisfaction: parent, child, referrer
- Adverse health outcomes
- Quality of life of children and their carers
- Cost of treatment for the family and to the service providers.

Outcomes were measured using hospital data for service use, health outcome rating scales, quality of life questionnaires and satisfaction surveys. Follow-up times varied from three months to 24 months. Four studies were conducted in Canada. Three were from the United Kingdom, the United States and Australia, respectively.

The interventions were diverse and complex and involved multidisciplinary teams. Whilst specialist home-based nursing outreach services were provided in each study, the seven included studies differed with respect to intensity (number of visits), duration (hours of service) and the availability and qualifications of nurses. Interventions were delivered to participants with diverse conditions which were grouped as follows:

Children with acute paediatric illnesses

Two studies delivered home-based nursing care to children with acute paediatric illnesses. One described clinical nursing care as an alternative to hospital admission, for children with breathing difficulty, diarrhoea and vomiting or fever. It involved between one and four home visits per day. The other compared continued home oxygen therapy after initial hospitalisation and parental education with traditional inpatient hospital care for children with acute bronchiolitis.

Children with a range of chronic conditions

Two studies targeted children with chronic conditions. One evaluated home care through traditional clinics, inpatient units or a home care office. It involved an initial assessment, a home visit and a monthly contact thereafter for at least six months, followed by six monthly reassessment. Another study examined a community-based stress point intervention provided by nursing staff two weeks before a planned hospital admission which continued until two weeks post discharge.

Children with newly diagnosed insulin-dependent diabetes mellitus (IDDM)

One study evaluated home-based care provided by nursing staff over an extended period to newly diagnosed diabetic children, as an alternative to inpatient care. After initial twice daily home visits, changing to less frequent visits or phone calls over two weeks, the nursing staff were available for telephone contacts up to 24 months.

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Children with chronic haematological illnesses

Two studies targeted children with haematological conditions. One provided access to a 24-h nursing service for treating acute bleeds in children with haemophilia as soon as they occurred at home or at school. It did not report on the number of days or visits for individual children. The other examined a home-based service for children with acute lymphoblastic leukaemia (ALL) compared with hospital-based care. Chemotherapy delivered by the hospital pharmacy to children's homes was given by a trained nurse from a community health service agency. Parents had the option to contact a hospital oncology nurse if required.

Summary of key evidence

Due to diverse interventions, outcomes and participants, the review presented a written summary of individual studies without data synthesis. Five RCTs employed parallel study designs and two were cross-over design. Whilst the review assessed risk of bias (graded as low, high, unclear) it was not possible to report an overall study quality and its impact on the outcomes. However, in only two studies, performance and detection bias (blinding of participants, providers and outcome assessment) was graded as 'low risk'. The remaining studies were graded as 'high risk' on these domains, suggesting that evidence from low quality studies needs to be interpreted with caution. The evidence is presented according to outcomes. The number of participants and *P*-values for significant results are shown in parentheses.

Physical health of participants (including harmful effects)

Five studies reported outcomes on physical health in children with various chronic conditions. One trial ($n = 219$) found no significant difference in general health between paediatric home care and standard care at one year follow-up. Another study of ALL ($n = 29$), reported no significant long-term difference between the hospital and home treatment groups on quality of life measures (Paediatric Oncology Quality of Life Scale) with respect to restrictions in physical functioning and the ability to maintain a normal physical routine. Three studies reported significant differences between the two groups. Of these, one ($n = 50$) reported a significant

improvement of stress point intervention in parental ability to cope with illness in a chronically ill child three months post-intervention ($P < 0.001$). Another study ($n = 63$) of newly diagnosed IDDM showed that at 24 months, the home care group had lower mean HbA1c levels (biological measure of diabetic control) than the control group (6.1% versus 6.8%; $P < 0.02$). There was no difference between the two groups for adverse diabetes-related clinical events. One study ($n = 40$) of children with haemophilia reported significantly more bleeding episodes, mostly mild to moderate, in the home care programme at two years. Severe bleeds were significantly more likely to occur in the hospital programme. Reported procrastination time (time between bleed occurring and reporting for treatment) decreased in the intervention group (mean 17 h versus 29 h; P -value and significance not reported).

Mental health of participants

Three studies reported on psychological health in various chronic conditions. One study ($n = 219$) showed that for children five years and over, there was a significant improvement in psychological adjustment at six months post-intervention ($P < 0.05$), which decreased by 12 months. Improved mental health symptoms were reported in mothers in the home care group compared with the control group ($P = 0.07$). Another study of stress point intervention ($n = 50$) showed no significant differences between the two groups for child behaviour. However, at three months, parents in the intervention group were significantly less anxious than those in the control group, with a significantly less discrepancy between desired and actual family functioning. One study of ALL ($n = 29$) reported no significant differences in behavioural problems and social competence (using child behaviour checklist) between the two groups at any of the follow-up times.

Utilisation of health care

ED use: No studies provided data for this outcome.

Hospital admissions

Two studies reported on hospital admissions in children with acute paediatric illness.

One ($n = 399$) reported no significant differences between home care and hospital care readmissions

over 90 days [$n = 21$ (10%) versus $n = 15$ (7.9%); $P = 0.49$]. The other study ($n = 44$) reported no group differences in hospital readmission rates for children with acute bronchiolitis within seven days of discharge.

Length of stay in hospital

Four studies reported on length of service provision which included bed days, inpatient stay and use of hospital-based services. Two reported findings in children with acute conditions. Of these, one study ($n = 399$) reported a significantly longer stay in the usual hospital care group compared with the home care group (mean bed stay 2.37 versus 1.37 days; $P < 0.0001$). The other study ($n = 44$) reported that children in the 'hospital in the home' treatment group spent significantly less time in a hospital bed compared to the hospital group (55.2 versus 96.9 h; $P = 0.001$).

Of the two studies of children with chronic conditions, one ($n = 63$) reported no difference between the two groups in the mean days spent in the intensive care unit at diagnosis for IDDM. However, mean hospital inpatient stay was lower with home-based care (2.2 ± 1.6 nights, 70 total) compared with hospital-based care (4.7 ± 1.6 nights, 147 total). Children receiving home care used fewer services while hospitalised due to shorter initial hospital stay. However, they used more diabetes nursing care during a 24-month period compared with standard care (58.9 h per child versus 17.3 hours; P -value and significance not reported), which suggests that home care required more intensive nursing support. The other study of children with haemophilia ($n = 40$) reported that the total number of treatment days in the home care group was greater than the hospital-based group (2030 versus 1644).

Parental, child and referrer satisfaction

Two studies evaluated satisfaction with interventions. One study collected parent-reported data for children with acute paediatric illnesses from a subset of the intervention group. Hospital at Home service was preferred by 36 of 40 (90%) parents and 7 of 11 (66%) children. Children receiving the 'Hospital at Home' service were perceived to recover more quickly in their own environment with less social disruption and financial burden for the family. The other study reported overall greater satisfaction from respondents, with medical care provided in the home

care group ($P < 0.05$) for children with a range of chronic conditions.

Quality of life of children and their carers

Four studies reported on quality of life in children with chronic conditions and their carers. In one study ($n = 50$) at three months post-intervention compared with usual care, the home care group had greater satisfaction in family functioning ($P < 0.001$); greater parental ability to cope ($P < 0.001$); greater family ability to cope ($P < 0.001$); a greater ability in personal and social care coping ($P < 0.01$); and a greater perception of helpfulness from health care providers and institutional sources ($P < 0.001$). Another study ($n = 40$) reported significantly better school attendance in the home care group, with an average of 2.5 school days missed compared with six days in the hospital care group for children with haemophilia (P -value not reported). One study did not show a significant effect for the impact of chronic illness on families between those receiving home care and those in the control group ($P = 0.14$). One study reported no evidence of an effect of the site where chemotherapy was given (ie, hospital or home) in relation to parental burden of care (using caregiving burden scale) at different stages during the study period. Interestingly, the age of the child was a significant predictor with an inverse effect on quality of life, caregiver burden and adverse events.

Costs

Four studies reported on costs. One study of acute paediatric illness ($n = 399$) reported costs for children in a separate paper. Parents believed that hospital care was more costly for them, with 20% of parents in the home care programme commenting on savings resulting from remaining at home and 30% of parents in the hospital care group commenting on the financial cost of the child staying in hospital.

One study ($n = 63$) showed that for children with newly diagnosed IDDM, there were social cost savings, suggesting savings across hospital, physicians, tax payers and families. The study also identified parental cost savings (difference between out-of-pocket expenses and the value of their time diverted to care for their child from other activities) of CAD188 (Canadian dollar) for each child on the home care programme ($P < 0.001$) and an increased cost to the hospital of

CAD 87 per child on the home care programme ($P < 0.001$). One study of haemophilia ($n = 40$) reported total costs for providing both the home care and the hospital programme but did not report separate costs for the intervention and control groups. There were no significant differences in costs for the family (societal perspective) associated with home chemotherapy and standard care.

Implications for practice

There is insufficient evidence from the seven RCTs to support the effectiveness of specialist home-based nursing services for children with acute and chronic illnesses in reducing hospital admissions and ED use. The cost effectiveness of these services needs to be established. However, the evidence suggests that home care programmes may provide greater parent satisfaction, improve quality of life and reduce the length of stay in hospitals.

Implications for research

There was considerable heterogeneity in participants, disease conditions, programmes and outcomes as well as measurement tools employed in the studies. Clinically relevant outcomes need to be defined particularly for health care utilisation, physical and mental health and satisfaction measures for which standardised measurement methods need to be developed. High quality RCTs examining programmes for children from birth to 18 years with adequate sample sizes are required. Economic evaluations need to consider both direct costs to health care providers and indirect costs to the child and their family, as well as to society (eg, time off work, loss of earnings and childcare expenses). Good quality service level data with details about effects on health economy are required.

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Conflicts of Interest

None.

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