Complications in hepato-pancreateo-biliary surgery

*Multidisciplinary and interdisciplinary approach*

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CHAPTER 9

The active involvement of family caregivers in hospital care: a systematic review.

Submitted

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**Introduction**

Family involvement in hospital care has received increased attention in recent years. In paediatric wards, the involvement of family members is almost standard; however, for hospitalised adults, care is slowly shifting to a more family-centred approach.\(^1\) Almost 25% of hospitals across the United States do not actively stimulate family participation,\(^2\) and this also seems to be generalisable to European countries. Family-centred care is more than the presence of family during hospitalisation, it also includes family participation in all aspects of care deliver.\(^3\) This approach supports the establishment of a mutual partnership and collaboration among healthcare professionals (HCPs), patients and their family caregivers (also known as informal caregivers) in a way that promotes patient satisfaction and self-determination.\(^4\)

The period of hospitalisation can be the optimum moment to actively involve informal caregivers in care, and prepare them for the transition from in-hospital professional care to informal care at home.\(^5\)\(^6\) Providing informal caregivers with new skills and knowledge related to their loved ones’ fundamental care needs\(^7\) (e.g. mobilisation, oral hygiene, orientation in time and place and eating) may also directly influence the number of potentially preventable complications, such as pneumonia, urinary tract infections and delirium.\(^8\)\(^-\)\(^11\)

Evidence suggests that the involvement of informal caregivers positively affects patient outcomes and quality of life (QoL), however, most of these studies are focusing on passive involvement, such as written information, verbal information and presence during medical rounds or nursing handovers.\(^12\) Despite the potential benefits of involving informal caregivers during the hospitalisation of adult patients, the effects remain unclear. Therefore this systematic review aims to investigate the effectiveness of this active involvement on readmissions, complications, mortality, length of stay, psychological health, activities of daily living and the satisfaction of patients, HCPs and informal caregivers.
Materials and Methods

We conducted this systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for the conduct of meta-analyses of intervention studies.\(^\text{13}\)

**Eligibility criteria**

Although randomised clinical trials (RCTs) are considered to be the methodologically preferable design for investigating treatment effects, there are some practical obstacles to evaluating the involvement of informal caregivers in a hospital setting using this design (e.g. due to strong patient preferences). Therefore we included a broader range of study designs, including (cluster) RCTs, controlled clinical trials, controlled before–after studies (CBA) and interrupted time series (ITS).\(^\text{14}\) All studies investigated the effectiveness of an in-hospital intervention, which included an active role for an informal caregiver in at least one fundamental care activity (i.e. assisting with eating, dressing, washing, mobilisation and oral hygiene), to improve the outcomes of adult patients (\(^\geq\)18 years) who were admitted to general medical wards.

We defined informal caregivers as “any person who, without being a professional or belonging to a social support network, usually lives with the patient and, in some way, is directly implicated in the patient’s care or is directly affected by the patient’s health problem”.\(^\text{15}\) Publications focussing only on caregiver burden or the unmet needs of caregivers were excluded.

In addition, the eligible studies must have reported on one of the predefined outcomes, namely readmissions (in numbers), complications sensitive to fundamental care activities (e.g. pneumonia, urinary tract infections and delirium),\(^\text{8,11}\) mortality, length of stay, activities of daily living (ADL, measured using the Barthel or Nothing Extended ADL Scale), QoL (using any validated QoL questionnaire), psychological distress (e.g. anxiety and depression) or the satisfaction of patients, HCPs and informal caregivers.

**Information sources and search strategy**

We performed a systematic search of the scientific literature in the leading biomedical bibliographic databases (Ovid Medline, Ovid Embase, EBSCO CINAHL and the Cochrane Library) with the help of a clinical librarian (FvEJ). We included studies conducted up to 25 July 2017 and did not impose any language restrictions. Appendix 1 contains details of the full electronic searches. In addition, we also screened the reference lists from the included studies to identify any other relevant articles, and we searched the www.clinicaltrials.gov website for ongoing or unpublished trials.
Study selection
Two reviews authors (AE and AS) independently selected potentially relevant articles based on titles and abstracts of the articles identified by the search using a free web and mobile app (http://rayyan.qcri.org). Full-text versions of articles were obtained if they match the eligibility criteria or if further scrutiny was needed regarding eligibility. Disagreement about study eligibility was resolved through consensus discussion or resolved by the last author (ENvD).

Data collection
Two authors (AE, AS) independently extracted data from the included studies using a structured format. Disagreements were resolved through discussions between the review authors or by the last author (ENvD). The study characteristics recorded included the study design, year of publication, country, number of participants, age, sex distribution, setting, patient population, details about the nature and extent of involvement of the informal caregiver and predefined outcomes.

Quality assessment
Two authors (AE, AS) independently assessed the methodological quality of the studies using the suggested risk of bias criteria from The Effective Practice and Organization of Care Group. he last author (ENvD) arbitrated any discrepancies.

Summary measures
We calculated summary estimates of the treatment effect [with 95% confidence intervals (CIs)] for every comparison. The mean difference (MD) was presented for continuous outcomes, while the risk ratio (RR) was presented for dichotomous outcomes.

Dealing with missing data
We emailed the authors of the original papers to request additional data and one email reminder was sent. One reply was received from Forster et al., and we used the additional data given in the results section of this review.

Assessment of heterogeneity
We assessed clinical heterogeneity between studies by analysing the similarity of the interventions, outcomes, designs, participant characteristics and settings. If the studies were clinically homogeneous, we assessed statistical heterogeneity by eyeballing and assessing the value of the I² statistic. If the I² statistic was £30%, we used a fixed-effect model; if the I² was 31%–60%, we used a random-effects model and if the I² was >60%, we deemed pooling inappropriate due to the high statistical heterogeneity.
The active involvement of family caregivers in hospital care: a systematic review.

Results

We screened 2205 potentially relevant titles and abstracts, of which five met the eligibility criteria. Four studies had secondary publications, except the study by Li, et al. Figure 1 shows the study inclusion process. Four studies were RCTs, and one study was a CBA. The CBA was originally described as an ITS by the authors; however, they only used one time point before and one time point after the intervention to measure the effects. One of the RCTs was as a pilot study. Two out the studies published the complete protocol of the study separately.

The main reason we excluded studies was that the intervention involved the passive involvement of informal caregivers instead of active involvement (Figure 1). Furthermore, we excluded a feasibility study due to the logistical issues for a large trial. The larger trial is included in this review. We also found a Korean article that may have been eligible for inclusion; however, we were not able to translate this article.

Characteristics of the studies

Table 1 and 2 summarise the characteristics of the included studies. The studies were performed in four different countries (India, the United Kingdom, Finland and the USA) and published between 1996 and 2017. The most frequent study population involved informal caregivers for stroke patients, and the remaining studies focused on older hospitalised.

All interventions comprised multiple interacting components (e.g. education of informal caregivers and HCPs combined with mutual agreements, hands-on skills training and house visits after hospital discharge). Sample sizes ranged between 67 and 1250 patients. Most studies focused on the psychosocial distress and QoL of patients and informal caregivers. No study reported the satisfaction of HCPs.

Delivery of the intervention as intended

Lindley et al. reported that the intervention was delivered as planned with a mean training time of 3 hours in hospital (SD = 1.6) and an additional 3.1 hours (SD = 1.7) at home. Forster et al. reported an average intervention compliance of 44% (196 of 450 subjects). Both studies also performed a process evaluation alongside the trial; however, these results are beyond the scope of this review. The remaining studies did not provide information regarding the quality of the intervention delivery.

Risk of bias within the studies

The studies varied in methodological quality (Table 3). The nature of the intervention made blinding impossible for patients, informal caregivers and HCPs. Almost all studies used objective and subjective outcome parameters. It is unlikely that the objective outcomes (i.e. the length of stay, readmissions and complications) were influenced by
the lack of blinding of the outcome assessors. Regarding the subjective outcomes (i.e. satisfaction, QoL and stress), blinding was not possible and therefore the outcomes were open to overestimation in favour of the intervention. Three RCTs adequately reported the incomplete outcome data, and three RCTs showed a low risk of selective reporting. One study was considered to be of low quality. The remaining studies were considered to be acceptable. Forster et al. provided us with additional information stating that the randomisation sequence was carried out using a computerised system.

**Figure 1**: prisma flow diagram of study inclusion
Effects of the intervention
We were unable to carry out a quantitative assessment of heterogeneity due to the low number of studies included. Furthermore, the studies varied in terms of their interventions, comparator treatments and outcome parameters. The difference in time intervals in which the outcomes were assessed made the heterogeneity substantial and a meta-analysis inappropriate. Therefore we presented the results descriptively per reported outcome. Supplementary Appendix 2 provides full details of the data.

Readmissions, length of hospital stay, mortality and complications
The number of readmissions and complications were reported in three studies. Li et al. defined readmission rates as readmissions to hospital, nursing home replacement and emergency room visits and found a significant difference using an alpha level of 0.10 instead of the traditional 0.05 (P = 0.08); however, we were not able to perform separate analyses per setting. Complication rates (i.e. pneumonia, falls and delirium) did not significantly differ in any of these three studies.

Three studies reported on the length of stay, however, only Kalra et al. found a shorter mean length of stay in the intervention group after 12 months (MD = −12.4 days; 95% CI = −19.5 to −5.6).

Mortality rates were compared in three studies, however, no study reported a significant difference in the outcomes in favour of active involvement of informal caregivers compared to the control intervention (Supplementary Appendix 2, Tables A1 and A2).

Activities of daily living
Three studies measured the differences in ADL scores between the intervention group and the control group. Two studies reported that there were no baseline differences in ADL scores before the start of the intervention. ADL scores were measured using the Barthel score (n = 3) or the Nothing Extended ADL score (n = 2). Only Kalra et al. found a significant decrease in the Barthel score (defined as the number of patients with a score > 18 points) a after 3 months in the intervention group (RR = 1.47; 95% CI = 1.13–1.91). They reported a nonsignificant result after 12 months (P = 0.074); however, after recalculating the given data, we found a significant difference at this time point (RR = 1.24; 95% CI = 1.03–1.50). The remaining two high-quality studies reported no significant difference in ADL scores at the different time points (Supplementary Appendix 2, Table A3).

Patient’s psychological distress
Four studies reported the patient’s physiological distress and three of these studies used the validated Hospital Anxiety and Depression Scale (HADS). Kalra et al.
Table 1 – Characteristics of the included studies

<table>
<thead>
<tr>
<th>First author (year)</th>
<th>Country</th>
<th>Study design</th>
<th>Setting</th>
<th>Inclusion criteria</th>
<th>Participants at baseline (n)</th>
<th>Participants at follow-up (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alim et al. (2016)</td>
<td>India</td>
<td>14-center RCT</td>
<td>In-hospital (low resource setting), and continues at home</td>
<td>Disabled adult patients with an acute stroke with a life expectation of 6 months or longer, and a suitable informal caregiver who is up for training and care delivery</td>
<td>Intervention: 623 (68% M)</td>
<td>Intervention: 607 (97%) at 6 months</td>
</tr>
<tr>
<td>Lindley et al. (2017)</td>
<td></td>
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<td>Control: 627 (66% M)</td>
<td>Control: 605 (96%) at 6 months</td>
</tr>
<tr>
<td>Forster et al. (2012)</td>
<td>United Kingdom (four different regions)</td>
<td>36-center cluster RCT (36 units)</td>
<td>In-hospital (stroke rehabilitation units)</td>
<td><em>Clusters:</em> Stroke units should met at least 4 out of five criteria used to define a stroke unit suggested by the Royal College of Physicians of London for the National Sentinel Stroke Audit 2006. Additional criteria: having a substantial number of stroke patients; able to deliver the LSCTC intervention; and the majority of patients should be discharged to a permanent place of residence. <em>Patients:</em> disabled and medically stable adult patients with a confirmed diagnose of new stroke and a suitable informal caregiver who is up for training and care delivery</td>
<td>Intervention: 450 (57% M)</td>
<td>Intervention: 350 (78%) at 12 months</td>
</tr>
<tr>
<td>Forster et al. (2013)</td>
<td></td>
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<td></td>
<td>Control: 478 (55% M)</td>
<td>Control: 333 (70%) at 12 months</td>
</tr>
<tr>
<td>Kalra et al. (2004)</td>
<td>United Kingdom</td>
<td>Single-center RCT</td>
<td>Stroke rehabilitation unit</td>
<td>Adult stroke patients who were independent in daily living activities before stroke, are medically stable, and are expected to go home with residual disability. They should have a suitable informal caregiver who is up to deliver care after discharge.</td>
<td>Intervention: 151 (89% M)</td>
<td>Intervention: 134 (88%) at 12 months</td>
</tr>
<tr>
<td>Patel et al. (2004)</td>
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<td></td>
<td>Control: 149 (74% M)</td>
<td>Control: 134 (90%) at 12 months</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Design</td>
<td>Setting</td>
<td>Study Population</td>
<td>Outcome Measures</td>
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</table>
| Laitinen et al. (1996) | Finland | CBA          | University hospital (two acute medical wards; control ward is a cardiac unit) | Patients (>75 years) with a minimum hospital stay of 2 days and good orientation (MMSE over 21) and a suitable informal caregiver who is up for training and care delivery | Intervention:  
Pre-test: 41  
Post-test 1: 33  
Post-test 2: 43  
Control:  
Pre-test: 18  
Post-test: 24  
Follow-up duration three years (%) M not reported |
| Li (2003) et al.       | USA     | Single-center pilot RCT | University hospital               | Patients (>65 years) admitted to one of four units (not further specified), and a suitable unpaid informal caregiver. Patients were excluded if they were diagnosed with dementia, were admitted from a long-term care facility, were transferred from the ICU or stayed in the ICU more than two nights; or stayed in the hospital longer than 30 days. | Initial total group: 67  
Only data given on patients received intervention as intended:  
Intervention: 25 (40% M)  
Control: 24 (7% M)  
Total group: 49 (73%) at 2 months (%) unclear |

M, male; N, number; RCT, randomised clinical trial; CBA, controlled-before-after study; LSCTC, London Stroke Carers Training Course; MMSE, Mini-mental state examination; ICU, intensive care unit.
<table>
<thead>
<tr>
<th>First author (year)</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Outcomes</th>
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<tbody>
<tr>
<td>Alim et al. (2016)</td>
<td>ICs received additional structured rehabilitation training – including information provision, joint goal setting, carer training, and task-specific training</td>
<td>Specialized stroke HCPs gave the training and visit the patients and caregiver's home (up to six visits within two months after discharge)</td>
<td>Usual care, comprising access to rehabilitation, timeliness of discharge and follow-up without explicit provision of accelerated discharge or IC training</td>
</tr>
<tr>
<td>Lindley et al. (2017)</td>
<td>ICs received a structured competency-based training program, including a skill assessment (London Stroke Carer Training Course [LSCTC].)</td>
<td>The whole multidisciplinary ward team were trained to deliver the LSCTC intervention to ICs. They did one follow-up session after discharge (by phone or in person).</td>
<td>Usual care as recommend in national guidelines regarding stroke treatment</td>
</tr>
</tbody>
</table>
Kalra et al. (2004) ICs received instruction on common stroke related problems and hands-on skills training (e.g. transfers, and how to assist in activities of daily living. Training sessions lasted 30-45 minutes (3-5 sessions). HCPs visit the patients and caregiver’s home to adapt skills learnt to the home situation. Usual care, comprising information, involvement in goal setting, encouragement to attend nursing and therapy activities, advice on community services, benefits, and allowances.

Patel et al. (2004) ICs received activation programs including booklets, leaflets, videos and games. HCPs built a quality assurance program and they introduced primary nursing to improve interaction with patients and ICs. They also created a quest room was arranged where patients and relatives were able to meet in peace. Usual care, not further specified.

Laitinen et al. (1996) ICs received activation programs including booklets, leaflets, videos and games. USUsal care, not further specified.

Li et al. (2003) ICs received audiotaped and written information about common patient behaviours and strategies to get involved in care, and signed a mutual agreement with caregivers. Nurses signed a mutual agreement with ICs to assist caregivers in implementing the program. ICs received two audiotapes with information about hospital services and policies.

ICs = informal caregivers; HCP = health care professionals
## Table 3. Quality assessment

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<tr>
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<td>Lindley et al. (2017)</td>
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<td>Forster et al. (2013)</td>
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<td>Kalra et al. (2004)</td>
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<td>Patel et al. (2004)</td>
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<td>n/a</td>
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<tr>
<td>Li et al. (2003)</td>
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<td>n/a</td>
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## Quality assessment CBA

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Baseline measurement</th>
<th>Characteristics for studies using second site as control</th>
<th>Blinded assessment of primary outcome(s)</th>
<th>Protection against contamination</th>
<th>Reliable primary outcome measurements</th>
<th>Follow-up of professionals</th>
<th>Follow-up of patients</th>
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<tbody>
<tr>
<td>Laitinen et al. (1996)</td>
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ADL, activities of daily living; HCP, health care professional; IC, informal caregiver; QoL, quality of life; CBA, controlled-before-after study; RCT, randomised clinical trial
found a significant decrease in anxiety and depression scores after 3 and 12 months in the intervention group. Li et al.\textsuperscript{20} used the Patient Depression Scale and reported a significant decrease in depression scores at approximately 2 weeks after discharge and 2 months later ($P = 0.01$ and $0.04$, respectively); however, after recalculating the data, we did not find a significant difference at 2 weeks after discharge (MD = −0.23; 95% CI = −0.53–0.07).

Lindley et al.\textsuperscript{21} and Forster et al.\textsuperscript{18} did not find significant differences in the anxiety and depression scores (Supplementary Appendix 2, Table A4).

**Informal caregiver's psychological distress**

Four studies reported on informal caregiver's psychological distress, and three of these studies used the validated HADS and the Caregiver Burden Scale.\textsuperscript{18,21,23} One study used the validated Beck Depression Inventory and found no significant difference following the intervention.\textsuperscript{20} These results are in line with two other studies that did not find a significant difference in anxiety and depression scores between the intervention and control group.\textsuperscript{18,21} However, Kalra et al.\textsuperscript{23} reported significant favorable scores after 12 months for active informal caregiver involvement (P-value = <0.01).

Regarding the caregiver burden, only Kalra et al.\textsuperscript{23} reported less caregiver burden in the intervention group ($P = 0.01$), while the other studies did not find any significant differences (Supplementary Appendix 2, Table A5).\textsuperscript{18,21}

**Quality of life**

Three studies measured patient QoL,\textsuperscript{18,21,23} and two of these studies also investigated the influence of the intervention on the informal caregiver’s QoL.\textsuperscript{18,23} Lindley et al.\textsuperscript{21} and Forster et al.\textsuperscript{18} did not find a significant difference in patient or informal caregiver's QoL between the intervention and control group. However, Kalra et al.\textsuperscript{23} reported better QoL scores for patients and informal caregivers ($P< 0.01$ and 0.0001, respectively) (Supplementary Appendix 2, Table A6).

**Satisfaction of patients, HCPs and informal caregivers**

Laitinen et al.\textsuperscript{25} reported the overall satisfaction of care experienced by patients on a five-point scale. They reported that patients in the intervention group were more satisfied with the care given, although there was no significant difference. Kalra et al. reported that a significantly higher proportion of informal caregivers were satisfied with the care given (45% vs. 58%; $P = 0.001$) and the instructions for looking after the patient (75% vs. 36%; $P = 0.001$).\textsuperscript{23} No study reported the satisfaction of HCPs.
Discussion

Despite the widespread endorsement of family-centred care, only a few studies have reported the effectiveness of the active involvement of informal caregivers during hospitalisation. The small number of studies included in this review suggest that there is no clear benefit of the active involvement of informal caregivers on the number of readmissions, complication rates and length of stay. The studies also described inconsistent evidence regarding psychosocial distress and QoL outcomes of patients and informal caregivers, and no study reported the satisfaction of HCPs.

The absence of a benefit of active informal caregiver involvement may be explained by the content of the programmes; for example, the largest study stated that patients received less therapy time compared to conventional western rehabilitation. Furthermore, all the studies investigated complex interventions and focused on active informal caregiver involvement with multiple components. These components were delivered in various modes, at different levels and by different HCPs, therefore the implementation of such a complex intervention is challenging. One study reported that the compliance rate of the intervention was only 60%. The underlying reasons for the low compliance rate were that the in-hospital training of informal caregivers started later than planned and that the staff training on delivering the intervention did not reach all HCPs.

Furthermore, three of the five studies included patients who suffered a stroke, and therefore differ from acute medical or surgical patients. Two previously published reviews also reported that there was limited evidence on effective interventions to promote family involvement in care on adult acute wards; however, these studies mainly focused on different methods to facilitate active involvement of informal caregivers itself instead of the effects on patient outcomes.

In addition to the challenge of actively promoting informal caregivers in care, the attitudes, competencies and perceptions of HCPs regarding patient- and family-centred care is another feature, even as the strict legal provisions regarding patient rights of autonomy and confidentiality. Involving informal caregivers in care requires HCPs to be able to share important information about a patient's healthcare status.

Limitations of the study

There were some limitations to this systematic review. Firstly, the lack of consistent terminology, poor reporting of the characteristics of the complex intervention and lack of a clear definition of ‘active involvement’ means that we may have missed some potentially relevant studies. This is also one of the methodological issues encountered when conducting systematic reviews to evaluate complex interventions. Secondly, we mainly focused on ultimate outcomes that represented the overall goals of active involvement.
of informal caregivers during hospitalisation (i.e. primary and secondary outcomes such as readmissions and QoL). We did not report all the results of process evaluations (e.g. assessment of the theoretical basis per study) or the underlying mechanism responsible for its effect on ultimate outcomes. However, we provided a short description if the intervention was delivered as intended, which was necessary to draw conclusions about the outcome of the intervention. A systematic review of process evaluations may be of additional value to provide more insight into the ways in which interventions lead to behaviour change and how they are moderated by different facilitators and barriers. Finally, although we did not use a language restriction in our search, we were unable to assess a potentially relevant article as it was written in Korean and no author was able to translate it. Therefore, we may have introduced a selection bias.

Implications for practice
Despite the unclear effects found in this review, it is still advisable to consider active informal caregiver participation in adult in-hospital care. This approach fits the perspective of patient- and family-centred care and should include 24/7 visiting hours, rooming-in possibilities and the encouraged presence and participation of family in all aspects of care delivery. The involvement of informal caregivers during hospital admission is already widely accepted by HCPs in paediatric care and in the treatment of adult patients with severe cognitive impairment or dementia. The involvement of informal caregivers for other hospitalised patients is often assumed as optional and unnecessary; however, these patients would also benefit from the involvement of informal caregivers as hospitalization, surgical procedures, and hospital discharge are often experienced as stressful events.

Implications for further research
Further evaluations through well-designed studies are needed to corroborate the clinically relevant effects of the active involvement of informal caregivers during hospitalisation. RCTs should always be considered, but may cause contamination, for example, as HCPs should be trained to stimulate active family involvement on medical wards, they will use their newly acquired knowledge, skills and attitude to train patients and their families in the control group. Furthermore, patient and informal caregiver preferences have to be taken into account, as they need to make efforts to take this active role in care. Therefore other study designs, such as cluster RCTs, stepped wedge designs, and preferences trials, should also be considered. Furthermore, the mechanism of action (including the modes) should be explicitly described to understand how the intervention can lead to changes in outcomes.
Conclusions
As the care of hospitalised adults is shifting to a more family-centric approach, investigating the effects of an active role of informal caregivers in adult in-hospital care is necessary; however, the small number of studies available and the heterogeneity between studies hampers firm conclusions.
References


17. Cochrane Effective Practice and Organisation of Care (EPOC). Suggested risk of bias criteria for EPOC reviews. EPOC Resources for review authors, 2017. Available at: http://epoc.cochrane.org/resources/epoc-resources-review-authors


The active involvement of family caregivers in hospital care: a systematic review.


### Appendix 1. Full details of search strategy

**MEDLINE (Ovid)**

<table>
<thead>
<tr>
<th>#</th>
<th>Searches</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Caregivers/ or ((family or families or relative* or informal*) adj6 (caregiv* or care-giv* or carer or carers)).ti,ab,kw. or family centered care.ti,ab,kw.</td>
</tr>
<tr>
<td>2</td>
<td>Inpatients/ or (hospital* adj6 patient*).ti,ab,kw. or (hospital* adj3 ward*).ti,ab,kw. or (inpatient* or in-patient*).ti,ab,kw.</td>
</tr>
<tr>
<td></td>
<td>Patient Readmission/ or &quot;Activities of Daily Living&quot;/ or exp disease progression/ or Infection/ or exp Intraoperative Complications/ or exp Postoperative Complications/ or exp Wound Infection/ or exp</td>
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<tr>
<td>3</td>
<td>Delirium/ or exp Morbidity/ or “Length of Stay”/ or exp Patient Satisfaction/ or (readmiss* or re-admiss* or re-hospital* or re-hospital* or activities of daily living or daily activit* or daily living activit* or daily life activit* or activity programme* or satisf*).ti,ab,kw.</td>
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<tr>
<td>4</td>
<td>1 and 2 and 3</td>
</tr>
<tr>
<td>5</td>
<td>((exp Child/ or exp Pediatrics/ or (child* or p?ediatric*).ti,ab,kw.) not exp Adult/) or Hospitals, Pediatric/ or (child* or p?ediatric*).ti.</td>
</tr>
<tr>
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**EMBASE (Ovid)**

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</tr>
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<td>hospital patient/ or aged hospital patient/ or (hospital* adj6 patient*).ti,ab,kw. or (hospital* adj3 ward*).ti,ab,kw. or (inpatient* or in-patient*).ti,ab,kw.</td>
</tr>
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<td>hospital readmission/ or daily life activity/ or complication/ or disease exacerbati0on/ or infection/ or infection complication/ or exp infectious complication/ or peroperative complication/ or exp</td>
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<td>postoperative complication/ or wound complication/ or exp delirium/ or morbidity/ or “length of stay”/ or health care utilization/ or patient satisfaction/ or satisfaction/ or (readmiss* or re-admiss* or rehospital* or re-hospital* or activities of daily living or daily activit* or daily living activit* or daily life activit* or activity programme* or satisf*).ti,ab,kw.</td>
</tr>
<tr>
<td>4</td>
<td>1 and 2 and 3</td>
</tr>
<tr>
<td>5</td>
<td>((child/ or exp pediatrics/ or (child* or p?ediatric*).ti,ab,kw.) not (adult/ or aged/)) or pediatric hospital/ or (child* or p?ediatric*).ti.</td>
</tr>
<tr>
<td>6</td>
<td>4 not 5</td>
</tr>
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</table>
The active involvement of family caregivers in hospital care: a systematic review.

**COCHRANE library**

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<td>#1 or #2</td>
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<td>MeSH descriptor: [Inpatients] explode all trees</td>
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<td>#4 or #5</td>
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<td>#7</td>
<td>MeSH descriptor: [Patient Readmission] explode all trees</td>
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<td>#8</td>
<td>MeSH descriptor: [Disease Progression] explode all trees</td>
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<td>MeSH descriptor: [Infection] this term only</td>
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<td>#10</td>
<td>MeSH descriptor: [Intraoperative Complications] explode all trees</td>
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<td>MeSH descriptor: [Postoperative Complications] explode all trees</td>
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<td>MeSH descriptor: [Wound Infection] explode all trees</td>
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<td>MeSH descriptor: [Delirium] explode all trees</td>
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<td>#14</td>
<td>MeSH descriptor: [Morbidity] explode all trees</td>
</tr>
<tr>
<td>#15</td>
<td>MeSH descriptor: [Length of Stay] explode all trees</td>
</tr>
<tr>
<td>#16</td>
<td>MeSH descriptor: [Patient Satisfaction] explode all trees</td>
</tr>
<tr>
<td>#17</td>
<td>MeSH descriptor: [Activities of Daily Living] explode all trees</td>
</tr>
<tr>
<td>#18</td>
<td>readmiss* or re-admiss* or rehospital* or re-hospital* or activities of daily living or daily activit* or daily living activit* or activity programme* or satisf*:ti,ab,kw (Word variations have been searched)</td>
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<td>#7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18</td>
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<td>#20</td>
<td>#3 and #6 and #19</td>
</tr>
<tr>
<td>#21</td>
<td>MeSH descriptor: [Child] explode all trees</td>
</tr>
<tr>
<td>#22</td>
<td>MeSH descriptor: [Pediatrics] explode all trees</td>
</tr>
<tr>
<td>#23</td>
<td>child* or p?ediatric*:ti,ab,kw (Word variations have been searched)</td>
</tr>
<tr>
<td>#24</td>
<td>MeSH descriptor: [Adult] explode all trees</td>
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<td>#25</td>
<td>(#21 or #22 or #23 or #24) not #24</td>
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<td>#26</td>
<td>MeSH descriptor: [Hospitals, Pediatric] explode all trees</td>
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<tr>
<td>#27</td>
<td>child* or p?ediatric*:ti (Word variations have been searched)</td>
</tr>
<tr>
<td>#28</td>
<td>#25 or #26 or #27</td>
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## CINAHL (Ebsco)

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<td>2</td>
<td>(MH “Inpatients”) OR TI (hospital* N6 patient*) OR AB (hospital* N6 patient*) OR TI (hospital* N3 ward*) OR AB (hospital* N3 ward*) OR TI (inpatient* or in-patient*) OR AB (inpatient* or in-patient*)</td>
</tr>
<tr>
<td>3</td>
<td>(MH “Readmission”) OR (MH “Activities of Daily Living+”) OR (MH “Disease Progression”) OR (MH “Infection”) OR (MH “Intraoperative Complications+”) OR (MH “Postoperative Complications+”) OR (MH “Wound Infection+”) OR (MH “Delirium”) OR (MH “Morbidity+”) OR (MH “Length of Stay”) OR (MH “Patient Satisfaction”) OR TI (readmiss* or re-admiss* or rehospital* or re-hospital* or activities of daily living or daily activit* or daily living activit* or daily life activit* or activity programme* or satisf*) OR AB (readmiss* or re-admiss* or rehospital* or re-hospital* or activities of daily living or daily activit* or daily living activit* or daily life activit* or activity programme* or satisf*)</td>
</tr>
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</table>
| 4 | (MH “Child+” OR MH “Pediatrics+”) OR TI (child* or p?ediatric*) OR AB (child* or p?ediatric*) NOT (MH “Adult+”) OR (MH “Hospitals, Pediatric
## Appendix 2. Full details of the data of the included studies

### Table A1 – Readmissions and length of hospital stay

<table>
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<tr>
<th>Study</th>
<th>Follow-up</th>
<th>Intervention</th>
<th>Length of hospital stay</th>
<th>Comparison</th>
<th>Length of hospital stay</th>
<th>Readmissions Relative Risk [95% CI]</th>
<th>Length of hospital stay</th>
<th>Significance</th>
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<tbody>
<tr>
<td></td>
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<td></td>
<td>Events (%) N</td>
<td></td>
<td>Events (%) N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean (SD) N</td>
<td></td>
<td>Mean (SD) N</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alim et al. (2016)</td>
<td>Up to discharge</td>
<td>N/A</td>
<td>6 (6.8) 622</td>
<td>N/A</td>
<td>6.3 (7.5) 627</td>
<td>N/A</td>
<td>-0.30 [-1.09 - 0.49]</td>
<td>NS</td>
</tr>
<tr>
<td>Lindley et al. (2017)</td>
<td>6 months</td>
<td>89 (14%) 623</td>
<td>9.3 (7.4) 622</td>
<td>82 (13%) 627</td>
<td>9.5 (7.9) 627</td>
<td>1.09 [0.83 - 1.44]</td>
<td>-0.20 [-1.05 - 0.65]</td>
<td>NS</td>
</tr>
<tr>
<td>Forster et al. (2012)</td>
<td>6 months</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>N/A</td>
<td>NS</td>
<td>Unclear LOS</td>
</tr>
<tr>
<td>Forster et al. (2013)</td>
<td>12 months</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>Still as not significantly different</td>
<td>N/A</td>
<td>NS</td>
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<tr>
<td>Kalra et al. (2004)</td>
<td>Stroke unit in days</td>
<td>N/A</td>
<td>30.8 (NR) 151</td>
<td>N/A</td>
<td>43.2 (NR) 149</td>
<td>N/A</td>
<td>-12.4 days [-19.5 to -5.6]</td>
<td>Sign. diff. LOS</td>
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<td>Patel et al. (2004)</td>
<td>12 months</td>
<td>Unclear</td>
<td>Unclear</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>-12.4 days [-19.5 to -5.6]</td>
<td>Sign. diff. LOS</td>
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<tr>
<td>Laitinen et al. (1996)</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
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<tr>
<td>Li et al. (2003)</td>
<td>Up to discharge</td>
<td>N/A</td>
<td>5.56 (2.71) 25</td>
<td>N/A</td>
<td>6.25 (2.15) 24</td>
<td>N/A</td>
<td>-0.69 [-2.06 -0.68]</td>
<td>NS</td>
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<td></td>
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<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
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N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval
<table>
<thead>
<tr>
<th>Study</th>
<th>Follow-up</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Results</th>
<th>Complications</th>
<th>Results</th>
</tr>
</thead>
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<td></td>
<td></td>
<td>N/A, not applicable</td>
<td>N/A, not applicable</td>
</tr>
<tr>
<td>Alim et al. (2016)</td>
<td>6 months</td>
<td>72 (12%)</td>
<td>86 (14%)</td>
<td>0.84 [0.63 - 1.13]</td>
<td>Pneumonia: 0.72 [0.23 - 2.25]</td>
<td>NS</td>
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<tr>
<td>Lindley et al. (2017)</td>
<td></td>
<td>623</td>
<td>627</td>
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<tr>
<td>Forster et al. (2012)</td>
<td>6 months</td>
<td>39 (8.6%)</td>
<td>34 (7%)</td>
<td>1.22 [0.78 - 1.89]</td>
<td>In-hospital falls: 1.07 [0.66 - 1.74]</td>
<td>NS</td>
</tr>
<tr>
<td>Forster et al. (2013)</td>
<td>12 months</td>
<td>53 (12%)</td>
<td>55 (12%)</td>
<td>1.02 [0.72 - 1.46]</td>
<td></td>
<td>NS</td>
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<tr>
<td>Kalra et al. (2004)</td>
<td>12 months</td>
<td>17 (11%)</td>
<td>16 (11%)</td>
<td>1.05 [0.55 - 2.00]</td>
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<td>NS</td>
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<tr>
<td>Patel et al. (2004)</td>
<td></td>
<td>151</td>
<td>149</td>
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<td>NR</td>
<td>NR</td>
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<td>Laitinen et al. (1996)</td>
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<td>NR</td>
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<tr>
<td>Li et al. (2003)</td>
<td>14 days</td>
<td>NR</td>
<td>NR</td>
<td>Days of confusion: In total 4 patients died. Not further specified 0.71</td>
<td>Days of confusion: 2.93 (3.45) 24</td>
<td>Days of confusion: P-value given =</td>
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</table>
| N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval
Table A3. Activities of Daily Living

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<th>Study</th>
<th>Follow-up</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Results</th>
<th>Intervention</th>
<th>Comparison</th>
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<tr>
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<td>Mean (SD) N</td>
<td>Mean Difference [95% CI]</td>
<td>Mean (SD) N</td>
<td>Mean (SD) N</td>
<td>Mean Difference [95% CI]</td>
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<td>BARTHEL SCORE</td>
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<tr>
<td>Alim et al. (2016)</td>
<td>Pre-discharge</td>
<td>43 (23.17) 614</td>
<td>43.2 (23.89) 618</td>
<td>-0.20 [-2.80 - 2.40]</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NS</td>
</tr>
<tr>
<td>Lindley et al. (2017)</td>
<td>3 months</td>
<td>76.1 (25.24) 543</td>
<td>74.8 (26.05) 525</td>
<td>1.30 [-1.78 - 4.38]</td>
<td>27.1 (17.21) 537</td>
<td>26.3 (17.31) 523</td>
<td>0.80 [-1.28 - 2.88]</td>
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<tr>
<td></td>
<td>6 months</td>
<td>82.1 (23.09) 533</td>
<td>82.6 (23.19) 512</td>
<td>-0.50 [-3.31 - 2.31]</td>
<td>31 (17.67) 527</td>
<td>31.2 (17.52) 509</td>
<td>-0.20 [-2.34 - 1.94]</td>
<td>NS</td>
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<tr>
<td>Forster et al. (2012)</td>
<td>6 months</td>
<td>14.1 (5.14) 323</td>
<td>13.9 (5.13) 346</td>
<td>-0.30 [-1.10 - 0.50]</td>
<td>27.4 (18.16) 330</td>
<td>27.6 (18.46) 348</td>
<td>-0.20 [-2.96 - 2.56]</td>
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<td></td>
<td>12 months</td>
<td>14.4 (5.07) 297</td>
<td>14.4 (5.02) 325</td>
<td>0.00 [-0.79 - 0.79]</td>
<td>29.6 (17) 301</td>
<td>29.1 (17.25) 330</td>
<td>0.50 [-2.17 - 3.17]</td>
<td>NS</td>
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<tr>
<td>Kalra et al. (2004)</td>
<td>3 months</td>
<td>Score &gt; 18 77 (54%) 141</td>
<td>Score &gt; 18 52 (37%) 140</td>
<td>1.47 [1.13 - 1.91]</td>
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<tr>
<td>Patel et al. (2004)</td>
<td>12 months</td>
<td>Score &gt; 18 93 (69%) 134</td>
<td>Score &gt; 18 75 (56%) 134</td>
<td>1.24 [1.03 - 1.50]</td>
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<td>Sign. diff</td>
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<tr>
<td>Li et al. (2003)</td>
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N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval; SD, standard deviation
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<th>Comparison</th>
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<th>Significance</th>
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<td>Mean (SD) N</td>
<td>Mean Difference [95% CI]</td>
<td>Mean (SD) N</td>
<td>Mean (SD) N</td>
<td>Mean Difference [95% CI]</td>
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<td>Mean (SD) N</td>
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<td>Alim et al. (2016)</td>
<td>HADS</td>
<td>3 months</td>
<td>4.8 (4.01) 536</td>
<td>4.9 (4.36) 520</td>
<td>-0.10 [-0.61 - 0.41]</td>
<td>6.5 (4.94) 536</td>
<td>6.6 (4.99) 520</td>
<td>-0.10 [-0.70 - 0.50]</td>
<td>NS</td>
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<tr>
<td>Lindley et al. (2017)</td>
<td></td>
<td>6 months</td>
<td>3.7 (3.74) 527</td>
<td>3.7 (4.19) 509</td>
<td>0.00 [-0.48 - 0.48]</td>
<td>5.3 (4.64) 527</td>
<td>5.3 (4.96) 509</td>
<td>0.00 [-0.59 - 0.59]</td>
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<td>Forster et al. (2012)</td>
<td>HADS</td>
<td>6 months</td>
<td>6.7 (3.95) 323</td>
<td>6.6 (3.87) 340</td>
<td>-0.20 [-0.82 - 0.42]</td>
<td>7.3 (3.95) 323</td>
<td>7.2 (3.87) 341</td>
<td>0.10 [-0.50 - 0.70]</td>
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<tr>
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<td></td>
<td>12 months</td>
<td>6.4 (3.94) 294</td>
<td>6.6 (3.92) 318</td>
<td>-0.20 [-0.82 - 0.42]</td>
<td>6.9 (4.28) 294</td>
<td>7.3 (4.47) 320</td>
<td>-0.40 [-1.09 - 0.29]</td>
<td>NS</td>
</tr>
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<td>HADS</td>
<td>12 months</td>
<td>Median: 3 IQR: 2-4</td>
<td>Median: 4.5 IQR: 4-6</td>
<td>N/A</td>
<td>Median: 3 IQR: 2-4</td>
<td>Median: 4 IQR: 2.5 – 5.5</td>
<td>N/A</td>
<td>Sign.diff (P &lt;0,01)</td>
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<tr>
<td>Patel et al. (2004)</td>
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<tr>
<td>Laitinen et al. (1996)</td>
<td>NR</td>
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<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
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<tr>
<td>Li et al. (2003)</td>
<td>Depression Scale</td>
<td>1-3 days</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>0.19 (0.36) 25</td>
<td>0.39 (0.44) 24</td>
<td>-0.20 [-0.43 - 0.03]</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td>(PDS)</td>
<td>before discharge</td>
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<td>NR</td>
<td>NR</td>
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<td>10-14 days after discharge</td>
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<td>0.36 (0.55) 55</td>
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<td>0.72 (0.89) 24</td>
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N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval; SD, standard deviation; HADS, Hospital Anxiety and Depression Scale.
Table A5. Informal caregivers’ psychological distress

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**ANXIETY**

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**DEPRESSION**

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**CAREGIVER BURDEN**

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N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval; SD, standard deviation; IQR, interquartile range; HADS, Hospital Anxiety and Depression Scale
Table A6. Patients and informal caregivers’ quality of life

<table>
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<th>Comparison</th>
<th>Intervention</th>
<th>Comparison</th>
<th>Results</th>
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<tbody>
<tr>
<td>Alim et al. (2016)</td>
<td>EuroQol 5-D overall health</td>
<td>3 months</td>
<td>Intervention</td>
<td>Mean (SD) N</td>
<td>Comparison</td>
<td>Mean Difference [95% CI]</td>
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<tr>
<td>Lindley et al. (2017)</td>
<td>EuroQol 5-D overall health</td>
<td>6 months</td>
<td></td>
<td>63.2 (21.21)</td>
<td>539</td>
<td>-0.60 [-3.13-  1.93]</td>
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<td>Forster et al. (2012)</td>
<td>EuroQol 5-D overall health</td>
<td>6 months</td>
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<td>0.44 (6.07)</td>
<td>319</td>
<td>0.00 [-0.95, 0.95]</td>
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<td>EuroQol 5-D overall health</td>
<td>6 months</td>
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<td>0.47 (5.9)</td>
<td>334</td>
<td>0.00 [0.284, 0.79, 0.21]</td>
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<td>Kaif et al. (2004)</td>
<td>EuroQol 5-D overall health</td>
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<td>0.473 (5.92)</td>
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<td>0.00 (0.95, 0.96)</td>
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<td>EuroQol 5-D overall health</td>
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<td>0.47 (5.99)</td>
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<td>0.00 [0.284, 0.79, 0.21]</td>
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<td>Laitinen et al. (1996)</td>
<td>NR</td>
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<td>IQR: 55-80</td>
<td>0.02 [-0.01 - 0.05]</td>
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<td>Median: 65</td>
<td>IQR: 55-80</td>
<td>0.02 [-0.01 - 0.05]</td>
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N, number; N/A, not applicable; NR, not reported; NS, not significant; 95% CI, 95% confidence interval; SD, standard deviation; IQR, interquartile range.