

Supplementary Material 6. Outcome categories and measures within studies assessing effectiveness of interventions for carers

Study, design	Outcome category	Outcome measure	Definition/scale items if reported or identified
Improving staff information, knowledge and skills			
Mador (2004) RCT	Satisfaction with care	Postal questionnaire using a 5-point scale asking how satisfied family caregivers were with the nursing and overall care	Satisfaction from next of kin with the care provided to the patient. Outcome rated as next of kin satisfaction satisfied or very satisfied
Beernaert (2017) cRCT	Satisfaction with care	Satisfaction With Care at the End-of-Life in Dementia scale (range 10-40)	<p>Satisfaction with care during the last 48 hours of life assessed by the family carer; higher total score suggesting more satisfaction with care.</p> <p>Items of SWC-EOLD:</p> <ol style="list-style-type: none"> 1. I felt fully involved in all decision making 2. I would probably have made different decisions if I had had more information* 3. All measures were taken to keep my care recipient comfortable 4. The health care team was sensitive to my needs and feelings 5. I did not really understand my care recipient's condition* 6. I always knew which doctor or nurse was in charge of my care recipient's care 7. I feel that my care recipient got all necessary nursing assistance 8. I felt that all medication issues were clearly explained to me 9. My care recipient received all treatments or interventions that he or she could have benefited from 10. I feel that my care recipient needed better medical care at the end of his or her life* <p>*Reverse coded for calculation of the total score</p>
	Quality of communication (between staff and family; between staff and patients)	<p>Questionnaire with 14 items assessing quality of communication;</p> <p>Questionnaire with 4 items assessing quality of communication</p>	<p>Communication between clinical staff and <i>family carers</i> in the last 48 hours of life assessed by family carers:</p> <ol style="list-style-type: none"> 1. Told loved one is in the last days of life (yes) 2. Info about what to expect (totally agree/agree) 3. Understood info about what could be expected (totally agree/agree) 4. Doctor spoke about wishes for medical treatment at end of life (totally agree/agree) 5. Always informed about loved one's condition (totally agree/agree)

6. Doctor always understood what family or loved one was going through (totally agree/agree)
7. Doctor always listened to what you, family or loved one had to say about medical treatment and end of life care (totally agree/agree)
8. Always had opportunity to ask questions about loved one's care
9. In the last 48 hours of life of your loved one, given the opportunity to talk about issues that were important to you at that time (yes, more or less)
10. In the last 48 hours of life of your loved one, were involved in decisions about the medical treatment of your loved one (involved in all or some decisions vs not involved)
11. In the last 48 hours of life of your loved one, did you feel sufficiently involved in decisions about medical treatment? (yes)
12. In the last 48 hours of the life of your loved one, someone ask you when you wanted to be contacted about their impending death (yes)
13. In the last 24 hours of the life of your loved one, did you receive information about the care that was delivered to them (eg about the treatment of specific symptoms)? (yes)
14. Did you feel supported by the professional caregivers immediately after the death of your loved one? (yes)

Communication between clinical staff and *patients* in the last 48 hours of life assessed by family carers:

1. Someone of the professional caregivers told your loved one that they were in the last days of their life (yes)
2. Your loved one was given the opportunity to talk about issues that were important to them at that time (e.g. specific wishes, feelings, belief, norms and values) (yes, more or less)
3. In the last 48 hours of life, your loved one was involved in decisions about their medical treatment (involved in all or some decisions vs not involved)
4. In the last 48 hours, your loved one felt sufficiently involved in decisions about medical treatment (Yes or did not want to be involved)

Luxford (2015) BA	Quality of communication (satisfaction with clinician communication)	Survey questions for carers with recollection of previous admission to same facility	Recollection of a previous admission to the same facility: 1. Satisfaction that staff made carer feel comfortable to provide information about the patient 2. Satisfaction that staff listened and took notice of information provided by carer
------------------------------	--	--	---

Special care units

Goldberg (2013) RCT	Satisfaction with care	Likert scales measuring 10 dimensions of care (overall, admission, car parking, nutrition, medical management, being kept informed, dignity and respect, meeting the needs of a confused patient, discharge arrangements, timing of discharge).	Items for dimensions of care taken from an Alzheimer Society report on acute hospital care. Carers' satisfaction with hospital care was ascertained through telephone calls 1 to 3 weeks after discharge (% very/mostly satisfied, mostly/very dissatisfied)
	Carer mental health (strain)	Carer strain index (range 0-13)	13 items about common stressors are included in index as "a list of things which other people have found to be difficult in helping out after somebody comes home from the hospital" Link to paper describing index: https://academic.oup.com/geronj/article/38/3/344/555870
	Carer mental health (wellbeing)	General health questionnaire (GHQ-12, range 0-36)	GHQ is a measure of current mental health. The questionnaire covers the following items: <ol style="list-style-type: none">1. Able to concentrate2. Lost much sleep3. Playing useful part4. Capable of making decisions5. Under stress6. Could not overcome difficulties7. Enjoy normal activities8. Face up to problems9. Feeling unhappy and depressed10. Losing confidence11. Thinking of self as worthless12. Feeling reasonably happy
Support for carers			
Catic (2013) BA	Satisfaction with care	Satisfaction With Care at the End-of-Life in Dementia scale (range 10-40)	See above description in Beernaert (2017)
	Quality of communication (with hospital providers)	Quality of Communication scale (range 0-130)	Higher scores indicating better communication (original scale not provided in paper or obtained through other resources)
