

Appendix 1. Search strategy and search terms

EMBASE [1862]

'palliative therapy'/exp OR 'terminal disease'/exp OR 'death'/de OR 'dying'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp

(Palliation OR 'Supportive care'):ti,ab

((Palliative OR end-of-life OR terminal*) NEAR/3 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)):ti,ab

((terminal* OR hospice* OR 'end-of-life' OR 'end-stage' OR 'last year of life' OR LYOL OR 'lifes end') NEAR/5 (care OR caring)):ab,ti

('terminal* ill*' OR death* OR dying OR 'terminal stage of illness'):ti,ab

#1 OR #2 OR #3 OR #4 OR #5

('caregiver'/exp OR 'family'/exp OR 'legal guardian'/exp) AND 'decision making'/exp

'surrogate decision making'/exp

((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse? OR spousal OR sibling* OR wife OR husband OR 'legal guardian' OR relative*) NEAR/4 (Decide? OR decision? OR decision-mak* OR opinion* OR preference*)):ti,ab

#7 OR #8 OR #9

'patient decision making'/exp OR ('patient preference'/exp AND 'decision support system'/exp)

('patient'/exp OR 'patient preference'/exp) AND ('decision making'/exp OR 'decision support system'/exp)

((Patient* OR dyad*) NEAR/4 (Decide? OR decision? OR decision-mak* OR preference* OR opinion* OR choice*)):ti,ab

#11 OR #12 OR #13

(Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*):ti,ab

#6 AND #10 AND #14 AND #15

Medline [891]

exp palliative care/ OR exp Terminal Care/ OR exp Terminally Ill/

(Palliation OR Supportive care).ti,ab.

((Palliative OR end-of-life OR terminal*) adj3 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)):ti,ab.

((terminal* OR hospice* OR end-of-life OR end-stage OR last year of life OR LYOL OR lifes end) adj5 (care OR caring)).ti,ab.

(terminal* ill* OR death* OR dying OR terminal stage of illness).ti,ab.

or/1-5

(Caregivers/ OR exp Family/ OR exp Legal Guardians/) AND exp Decision Making/

((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR legal guardian OR relative*) adj4 (Decide? OR decision? OR decision-mak* OR opinion* OR preference*)).ti,ab.

or/7-8

(exp Patients/ OR "Patient Preference"/) AND (exp Decision Making/ OR exp Decision Support Techniques/ OR Decision Making, Shared/)

((Patient* OR dyad*) adj4 (Decide? OR decision? OR decision-mak* OR preference* OR opinion* OR choice* OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*)).ti,ab.

or/10-11

(Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*).ti,ab.

6 AND 9 AND 12 AND 13

CINAHL [754]

(MH "Terminal Care") OR (MH "Hospice Care") OR (MH "Palliative Care")

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)) OR AB ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*))

TI ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal* ill*" OR death* OR dying OR "terminal stage of illness") OR AB ("terminal* ill*" OR death* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

((MH "Caregivers") OR (MH "Family+") OR (MH "Guardianship, Legal+")) AND (MH "Decision Making")

(MH "Decision Making, Family")

TI ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)) OR AB ((Caregiv* OR care-giv* OR carer* OR famil* OR

surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)

S7 OR S8 OR S9

(MH "Decision Making, Patient+")

(MH "Patients+") AND ((MH "Decision Making") OR (MH "Decision Support Techniques") OR (MH "Decision Making, Shared"))

TI ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*)) OR AB ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*))

S11 OR S12 OR S13

TI (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*) OR AB (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*)

S6 AND S10 AND S14 AND S15

Web of Science [824]

TS =(((Palliation OR "Supportive care") OR ((Palliative OR end-of-life OR terminal*) NEAR/3 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)) OR ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end" OR "terminal stage of illness") NEAR/5 (care OR caring)) OR ("terminal* ill*" OR death* OR dying)) AND ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) NEAR/4 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)) AND ((Patient* OR dyad*) NEAR/4 (Decide* OR decision* OR decision-mak* OR preference* OR opinion* OR choice*)) AND (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*))

PsycINFO & PsycARTICLES [325]

DE "Palliative Care" OR DE "Death and Dying" OR DE "Hospice" OR DE "Terminally Ill Patients"

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)) OR AB ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*))

TI ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal* III*" OR death* OR dying OR "terminal stage of illness") OR AB ("terminal* III*" OR death* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(DE "Caregivers" OR DE "Caregiving" OR DE "Family Members" OR DE "Family" OR DE "Adult Offspring" OR DE "Daughters" OR DE "Grandchildren" OR DE "Grandparents" OR DE "Siblings" OR DE "Sons" OR DE "Spouses" OR DE "Stepchildren" OR DE "Filial Responsibility") AND (DE "Group Decision Making" OR DE "Decision Making")

TI ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)) OR AB ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*))

S7 OR S8

(DE "Patients") AND (DE "Group Decision Making" OR DE "Decision Making")

TI ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*)) OR AB ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*))

S10 OR S11

TI (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*) OR AB (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*)

S6 AND S9 AND S12 AND S13

[Social Sciences Full Text \[47\]](#)

DE "Palliative treatment" OR DE "Hospice care" OR DE "Terminally ill" OR DE "Terminal care"

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)) OR AB ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*))

TI ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal* III*" OR death* OR dying OR "terminal stage of illness") OR AB ("terminal* III*" OR death* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(DE "Families of the terminally ill" OR DE "Families" OR DE "Caregivers" OR DE "Male caregivers" OR DE "Older caregivers" OR DE "Women caregivers" OR DE "Family relationships of caregivers") AND (DE "Decision making" OR DE "Group decision making")

TI ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)) OR AB ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*))

S7 OR S8

(DE "Patient participation" OR DE "Patients") AND (DE "Group Decision Making" OR DE "Decision Making")

TI ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*)) OR AB ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*))

S10 OR S11

TI (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*) OR AB (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*)

S6 AND S9 AND S12 AND S13

AMED [79]

(ZU "terminal care" or ZU "terminal illness" or ZU "palliative care" or ZU "palliative medicine" or ZU "palliative treatment" or ZU "hospice care")

TI (Palliation OR "Supportive care") OR AB (Palliation OR "Supportive care")

TI ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*)) OR AB ((Palliative OR end-of-life OR terminal*) N2 (care OR treatment* OR therapy OR therapies OR nursing OR approach*))

TI ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring)) OR AB ((terminal* OR hospice* OR "end-of-life" OR "end-stage" OR "last year of life" OR LYOL OR "lifes end") N4 (care OR caring))

TI ("terminal* ill*" OR death* OR dying OR "terminal stage of illness") OR AB ("terminal* ill*" OR death* OR dying OR "terminal stage of illness")

S1 OR S2 OR S3 OR S4 OR S5

(ZU "caregivers" or ZU "family" or ZU "legal guardians" or ZU "proxy" or ZU "spouses") AND (ZU "decision making")

TI ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*)) OR AB ((Caregiv* OR care-giv* OR carer* OR famil* OR surrogate* OR proxy OR spouse* OR spousal OR sibling* OR wife OR husband OR "legal guardian" OR relative*) N3 (Decide* OR decision* OR decision-mak* OR opinion* OR preference*))

S7 OR S8

(ZU "decision making") AND (ZU "patients")

TI ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*)) OR AB ((Patient* OR dyad*) N3 (Decide* OR decision* OR "decision mak*" OR preference* OR opinion* OR choice*))

S10 OR S11

TI (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*) OR AB (Concord* OR consensus OR concur* OR consent* OR dissent* OR discord* OR conflict* OR distress OR agree* OR disagree* OR congruence OR negotiat* OR prefer* OR mismatch* OR discrepant* OR disparit* OR accept* OR reject*)

S6 AND S9 AND S12 AND S13