

Supplementary Table 1 Medline and CENTRAL database search strategy

Medline and CENTRAL:

1. Withholding Treatment/
2. exp Respiration, Artificial/
3. Ventilator Weaning/
4. Airway Extubation/
5. (((Ventilat* or respirat*) adj2 wean*) or (Terminal adj2 (wean* or extubat*)) or (((Withdraw* or extubat* or remov* or withhold* or cessation) adj3 ((Mechanic* or artificial* or assist*) adj2 (ventilat* or respirat* or breath*))) or (Life adj2 sustaining adj2 treatment*))) .ti,ab,kw.
6. (1 and 2) or 3 or 4
7. 6 or 5
8. Intensive care units/ or Respiratory care units/ or "Life Support Care"/
9. Critical Care/
10. (((intensive or critical or respiratory) adj2 (unit or units or care or ward)) or icu or itu).ti,ab,kw.
11. 8 or 9 or 10
12. Palliative Care/
13. (end* adj3 life).ti,ab,kw.
14. (last year of life or LYOL).ti,ab,kw.
15. palliat*.ti,ab,kw.
16. Terminally Ill/
17. hospice*.ti,ab,kw.
18. (terminal* adj3 (car* or ill* or diseas*)).ti,ab,kw.
19. (terminal-stage* or terminal stage* or dying or (close adj4 death)).ti,ab,kw.
20. exp Terminal Care/
21. Hospice Care/
22. (dying adj3 care).ti,ab,kw.
23. ((end-stage* or end stage* or incurable or advanced) adj5 (disease* or ill* or care or cancer* or malignan*)).ti,ab,kw.
24. or/12-23
25. adolescent/ or exp child/ or exp infant/

26. (infant* or neonat* or newborn* or baby or child* or paediatric or pediatric or girl or girls or boy or boys or kid or kids or teen* or young* or youth or youths or preadolescen* or adolescen* or preschooler or school age* or schoolchild*).ti,ab,kw.

27. 25 or 26

28. 7 and 11 and 24

29. 28 not 27

30. limit 29 to (yr="2007 -Current" and (english or french or greek))

Supplementary Table 2 Studies' appraisals

Qualitative studies: CASP																					
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?											
Aita & Kai (2010)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Out of 10										
Hadders (2009)	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Can't tell	10 Yes										
Wiegand & Petri (2010)	Can't tell	Can't tell	Can't tell	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Can't tell	7 Yes, 2 No, 1 Can't tell										
Wiegand (2015)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	4 Yes, 6 Can't tell										
Wiegand et al. (2019)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	9 Yes, 1 Can't tell										
Surveys AXIS																					
	1. Were the aims/objectives of the study clear?	2. Was the study design appropriate for the stated aim(s)?	3. Was the sample size justified?	4. Was the target/reference population clearly defined? (Is it clear who the research was about?)	5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	7. Were measures undertaken to address and categorise non-responders?	8. Were the risk factor and outcome variables measured appropriate to the aims of the study?	9. Were the risk factor and outcome variables measured correctly using instruments/m-essurements that had been trialled, piloted or published previously?	10. Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	12. Were the basic data adequately described?	13. Does the response rate raise concerns about non-response bias?	14. If appropriate, was information about non-responders described?	15. Were the results internally consistent?	16. Were the results presented for all the analyses described in the methods?	17. Were the authors' discussions and conclusions justified by the results?	18. Were the limitations of the study discussed?	19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	20. Was ethical approval or consent of participants attained?	
Cottereau et al. (2016)	Yes	Yes	No	Yes	Yes	Yes	Don't know	Yes	Yes	No	Yes	Yes	Don't know	No	Yes	Yes	Yes	Yes	No	Yes	Out of 20
Dean et al. (2010)	Yes	Yes	No	Yes	Yes	Yes	Don't know	Yes	Don't know	No	No	Yes	Don't know	No	Yes	Don't know	Yes	No	Don't know	Don't know	14 Yes, 4 No, 2 Don't know
Grandhige et al. (2016)	Yes	Yes	No	Yes	Don't know	Don't know	Don't know	Yes	Yes	No	Yes	Yes	Don't know	No	Yes	Yes	No	Yes	Don't know	Don't know	9 Yes, 5 No, 6 Don't know
Groselj et al. (2014)	Yes	Yes	No	Yes	Yes	Yes	Don't know	Yes	Don't know	Yes	Yes	Yes	Don't know	No	Yes	Yes	Yes	Yes	No	Yes	11 Yes, 4 No, 5 Don't know
Observational studies (team developed appraisal tool)																					
	1. Was the research question or objective in this paper clearly stated?	2. Was the study population clearly specified and defined?	3. Was the participation rate of eligible persons at least 50%?	4. Were all the subjects selected or recruited from the same or similar populations (same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	5. Was a sample size justification, power, precision, or variance and effect estimates provided?	6. Was the analysis of data appropriate?	7. Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)	8. Are outcomes and variables described well?	9. Were the data collectors trained and blinded (if applicable)?	10. Were the basic data adequately described?	11. Does the response rate raise concerns about non-response bias? If applicable	12. Is missing data reported? Is it addressed?	13. Were the results presented for all the analyses described in the methods?	14. Were the findings discussed in relation to existing literature?	15. Were the limitations of the study discussed?	16. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	17. Was ethical approval or consent of participants attained?				
Bloomer et al. (2010)	No	Yes	N/A	Yes	No	Can't tell	Can't tell	Yes	Can't tell	Yes	N/A	Yes	Yes	Yes	Yes	Can't tell	No				Out of 17
Cooke et al. (2010)	Yes	Yes	N/A	Yes	No	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	No	Can't tell				8 Yes, 3 No, 3 Can't tell, 2 N/A
Epker et al. (2011)	Yes	Yes	N/A	Yes	No	Yes	No	Yes	Can't tell	Yes	N/A	No	Yes	Yes	Yes	No	No				13 Yes, 1 No, 1 Can't tell, 2 N/A
Epker et al. (2015)	Yes	Yes	N/A	Yes	No	Yes	No	Yes	Can't tell	Yes	N/A	No	Yes	Yes	Yes	No	No				10 Yes, 4 No, 1 Can't tell, 2 N/A
Gerstel et al. (2008)	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	No	Yes				10 Yes, 2 No, 1 Can't tell, 2 N/A
Huynh et al. (2013)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	N/A	No	Yes	Yes	Yes	No	No				14 Yes, 2 No, 2 N/A
Kross et al. (2011)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes				16 Yes, 1 No, 0 N/A
Long et al. (2015)	Yes	Yes	N/A	Yes	No	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Yes	Yes	Yes	No	Yes				14 Yes, 1 No, 2 N/A
Mazer et al. (2011)	Yes	Yes	N/A	Yes	No	Yes	Yes	Yes	Can't tell	Yes	N/A	No	Yes	Yes	Yes	No	Yes				12 Yes, 2 No, 1 Can't tell, 2 N/A
Robert et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes				16 Yes, 1 No, 0 N/A
Robert et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes				16 Yes, 1 No, 0 N/A
Thellier et al. (2017)	Yes	Yes	N/A	Yes	No	Yes	Yes	Yes	Can't tell	Yes	N/A	No	Yes	Yes	Yes	No	Yes				12 Yes, 2 No, 1 Can't tell, 2 N/A
van Beinum et al. (2016)	Yes	Yes	N/A	Yes	No	Yes	N/A	Yes	Can't tell	Yes	N/A	Yes	Yes	Yes	Yes	No	Yes				12 Yes, 1 No, 1 Can't tell, 3 N/A
White et al. (2009)	Yes	Yes	N/A	Yes	No	Yes	Yes	Yes	Can't tell	Yes	N/A	No	Yes	Yes	Yes	No	Yes				12 Yes, 2 No, 1 Can't tell, 2 N/A
Quasi-Experimental JBI																					
	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?												
Campbell et al. (2015)	Yes	Yes	Yes	Yes	Yes	N/A	Yes	Unclear	Yes	7 Yes, 1 Unclear, 1 N/A											
Delphi Technique (based on CREDES)																					
	1. Was there a clear statement of the aims of the research?	2. Is a Delphi methodology appropriate (authors provide rationale)?	3. Are the criteria for panel selection transparent?	4. Are response rates reported for each round?	5. Are all the preparations for each round of Delphi adequately described?	6. Is it comprehensible how consensus was achieved?	7. Are results reported for each round?	8. Is the interpretation and processing of results insightful?	9. Are the limitations of the study reported?	10. Are the conclusions adequately reflecting the outcomes of the Delphi?											
Downar et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10 Yes										