

Supplementary Table 1. Quality assessment using a critical appraisal checklist for qualitative studies [18]												
Study	Appraisal Criteria										Total 'Yes'	Quality: high = ++ moderate = + low = -
	Clear statement of study aim	Appropriate qualitative methodology	Appropriate research design to address aims	Appropriate recruitment strategy to address aims	Data collection method addressed research issue	Adequate consideration of relationship between the researcher and participant	Ethical issues considered	Data analysis sufficiently rigorous	Clear statement of findings	Research is valuable addition to current understanding		
Clayton et al., 2005. [21]	Yes	Yes	Yes	Yes	Yes	Yes	In part - ethical consent gained but no other discussion of ethical issues.	Yes	Yes	Yes	10	++
Enyert & Burman, 1999. [22]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	++
Hawker et al., 2006. [23]	Yes	Yes	Yes	Yes	Yes	No	Yes – clear information on ethical approval, safe practice and supportive services	Yes	Yes	Yes	9	++

							for participant s.					
Herz, McKinnon & Butow, 2006. [24]	Yes	Yes	Yes	Yes	Yes	In part – some discussion surrounding the role of the MND Association when collecting research, but no discussion around the role of the researchers.	Yes – stated that ethical approval gained and that a counsellor was present during the focus groups.	Yes	Yes	Yes	9	++
Koop & Strang, 2003. [25]	Yes	Yes	Yes	Yes	Yes	Yes	In part - ethical consent gained but no other discussion of ethical issues.	Yes	Yes	Yes	9	++
Lee, Woo & Goh, 2013. [26]	Yes	Yes	Not clear – research design was highly likely to be appropriate, but was not	Yes	Yes	Not clear – some discussion surrounding data collection, but no real	Yes	Yes	Yes	Yes	8	+ Some justifications and explanations lacking

			justified.			discussion surrounding potential bias and influence of researchers.							
Linderholm & Friedrichsen, 2010. [27]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	++
McGrath, 2002. [28]	Yes	Yes	Not clear - research design was highly likely to be appropriate, but unclear justification.	Yes	Yes	No - no discussion of researchers' role.	Yes	Yes	Yes	Yes	Yes	8	+ Necessary components of each criteria largely present. Some areas of critical appraisal have little consideration.
Milberg et al., 2003. [29]	Yes	Yes	Yes	Yes	Yes	Yes	In part - ethical consent gained but no other discussion of ethical issues.	Yes	Yes	Yes	Yes	9	++
Mok et al., 2003. [30]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	++
Neergaard et	Yes	Yes	Yes	Yes	Yes	Yes	In part –	Yes	Yes	Yes	Yes	10	++

al., 2008. [31]							ethical approval gained, discusses issues such as why terminally ill patients were not included within the study.					
O'Brien et al., 2012. [32]	Yes	Yes	Yes	Yes	Yes	Not clear – some discussion of establishing rigour within qualitative methodology , but no real discussion of researchers' role.	Yes	Yes	Yes	Yes	9	++
Perreault, Fothergill-Bourbonnais & Fiset, 2004. [33]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	++
Stajduhar & Davies, 2005. [34]	Yes	Yes	Yes	Yes	Yes	Yes	Yes – describes obtaining both informed	Yes	Yes	Yes	10	++

							consent from participants and ethical approval.					
Stajduhar et al., 2008. [35]	Yes	Yes	Yes	Yes	Yes	Not clear – some discussion of coding independently, but no real discussion surrounding researchers’ role.	In part – ethical approval gained, but no discussion of ethical issues.	Yes	Yes	Yes	8	+ Some justifications and explanations lacking
Thomas, Morris & Clarke, 2004. [36]	Not clear – within introduction, no specific aims stated, but does describe findings.	Yes	Not clear – research design was highly likely to be appropriate, but was not justified.	Yes	Yes	No	Yes – ethical approval gained and discussed how informed consent was ensured.	Yes	Yes	Yes	6	+ Some criteria with vague description, appear to have little consideration.
Topf, Robinson & Bottorff, 2013. [37]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9	++
Wennman-Larsen &	Yes	Yes	Not clear – research	Yes	Yes	No - no discussion of	Yes	Yes	Yes	Yes	8	+ Some

Tishelman, 2002. [38]			design was highly likely to be appropriate, but was not justified			researchers' role.						justifications and explanations lacking
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