Table 1: Study characteristics

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| Author (year) | Country | Sample size | Participant characteristics | | | Method of diagnosis | Sampling method | Main method of data collection | Setting (place of recruitment) | Data analysis method | JBI 7+ |
|  |  |  | Age range (years) | Gender | Ethnicity |  |  |  |  |  |  |
| Ware, 1992 | Boston, USA | 50 | 23-66 | 80% female | 92% white | 80% met U.S., British or Australian operational case definition | convenience | Semi-structured interviews | primary care clinic in hospital | Not stated |  |
| Wheeler, 1992 | Santa Barbara, USA | 10 | Not stated | 100% female | Not stated | Not stated (medically diagnosed) | snowball | open-ended interview | Not stated | Not stated |  |
| Anderson and Ferrans, 1997 | Chicago, USA | 22 | 31-67 | 50% female | Not stated | Physician; 1988 CFS criteria | purposive from a convenience sample | Face-to-face or telephone semi-structured interviews | recruited through various routes | Unclear – coding guided by study aims |  |
| Ax et al., 1997 | London, UK | 18 | 16-68 | 78% female | Not stated | diagnosis of ME, CFS, or PVFS by a  medical practitioner. | Not stated | Face to face semi-structed interviews | recruited from several London ME support groups | content analysis |  |
| Cooper, 1997 | Essex, England, UK | 10 | Not stated (19-60 years from six quotes; one 14 year old mother's account.) | 70% female | Not stated | Not stated | convenience | Face to face interviews | recruited via local ME group organiser and local newsletter | narrative analysis | Y |
| Ware, 1998 | New England, USA | 66 | 27-72 | 80% female | 94% white | CDC case definition of CFS | Not clear | Face to face and telephone interviews | primary care clinic in hospital | thematic analysis | Y |
| Holloway and Pinikahana, 1999 | Perth, Australia | 25 | 8-65 (most 40-50) | Not stated | Not stated | Not stated | Not clear | Face to face interviews | recruited from CFS support groups | Not clear |  |
| Lovell, 1999 | London, UK | 12 | 27-61 | 42% female | Not stated (7 from Africa; 2 from Nepal; 3 from each of South America, Burma, Singapore) | GP/medical consultant & fulfilled oxford CFS criteria | convenience | face-to-face interviews or written reports | recruited through a travel health clinic | Grounded theory | Y |
| McCue, 2004 | North East England, UK | 14 | 21-70 | 100% female | Not stated | diagnosed by GP of specialist consultant but recovered from CFS | Purposive | Face-to-face semi-structured interviews | recruited via CFS/ME support groups | Grounded theory | Y |
| Taylor, 2005 | USA | 47 | Mean= 46.9 | 96% female | 17% (8) minority; 83% (39) non-minority | Fukuda et al. (1994) criteria  for CFS used | Not stated | Focus groups, progress notes | recruited via various means (CFS self-help groups, physicians specialising in CFS, adverts in media) | Comparative method (Grounded theory) | Y |
| Reynolds and Vivat, 2006 | UK | 3 (case studies) | 51-62 | 100% female | 100% white | Not stated | convenience | Semi-structured interviews | recruited via adverts in national arts magazines | Thematic analysis | Y |
| Dickson et al., 2007 | Scotland, UK | 14 | 21-68 | 57% female | Not stated | GP or consultant | Purposive | Face-to-face semi-structured interviews | recruited via alternative therapy clinic or personal contacts | IPA | Y |
| Edwards et al., 2007 | England, UK | 8 | 37-55 | 100% female | 75% White (6); 12.5% (1)Chinese; 12.5% (1) mixed race | diagnosed by GP or consultant | convenience | Face to face semi-structured interviews | recruited via ME self-help group | IPA | Y |
| Guise et al., 2007 | Edinburg, Scotland, UK | 56  (49 internet and 7 face-to-face) | Not stated | Not stated | Not stated | Not stated | Not stated | Focus groups; online support groups interview; online individual interviews | recruited from internet-based ME/CFS support group | discourse analysis | Y |
| Arroll and Senior, 2008 | South East of England, UK | 8 | 35-67 | 75% female | Not stated | Not stated | Convenience | Telephone semi-structured interviews | recruited via CFS/ME support groups | IPA | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 24 patients | 25-78 | 54% female | 100% white | diagnosed by Oxford inclusion criteria | Purposive | Face to face semi-structured interviews | recruited from those participating in an RCT | Thematic analysis | Y |
| Dickson et al., 2008 | Scotland, UK | 14 | 21-68 | 57% female | Not stated | diagnosed by GP or medical consultant plus CDC (Fukuda 1994) criteria | Convenience | Face-to-face semi-structured interviews | recruited from an alternative therapy clinic or through personal contacts | IPA | Y |
| Gilje et al., 2008 | Norway | 12 | 22-54 | 83% female | Not stated | Physician diagnosis | Purposive | Focus group | recruited via local patient organisation | systematic text condensation |  |
| Reynolds et al., 2008 | London, England, UK | 13 | 34-62 | 100% female | Not stated | Own diagnosis (patients themselves) | Convenience | Semi-structured interviews or lengthy written answers to interview guide | recruited via adverts in national arts magazines and via a support group | IPA | Y |
| Travers and Lawler, 2008 | Australia | 19 | 20–75 | 74% female | Not stated | diagnosed by a medical practitioner; self-identified  as ‘affected with CFS’ or ‘recovered’ | convenience, snowball and finally purposeful | Face to face semi-structured interviews | recruited by various methods | Grounded theory | Y |
| Ward et al., 2008 | UK | 25 | 23-65 | 84% female | Not stated | Physician diagnosis | Convenience | Unstructured telephone interviews | recruited by patient support groups | Thematic analysis | Y |
| Donalek, 2009 | Chicago, USA | 8 (eight families with each having one parent living with CFS | 36-75 | 75% female | Not stated | healthcare professional diagnosed plus Fukuda et al. (1994) criteria | Convenience and snowball | Face to face semi-structured interviews plus family interviews | recruited by various methods | Thematic analysis | y |
| Guise et al., 2009 | Online international support group – UK predominant | 38 (but based on 6 responders to a specific question) | Not stated | Not stated | Not stated | Not stated | Convenience | Asynchronous online discussion | recruited from an internet-based ME/CFS support group | discourse analysis | Y |
| Reynolds and Vivat, 2010 | UK | 13 | 34-62 | 100% female | Not stated | patients' reports of medical diagnosis that was not independently verified by researchers | Convenience | Face to face  semi-structured interviews (10) or written answers to interviews guide (3) | recruited via national arts magazine and a support group | Thematic analysis | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 19 | 20-61 | 68% female | Not stated | fulfilled the Oxford inclusion criteria | Purposive | Face to face semi-structured interviews | recruited from patients participating in an RCT | Thematic analysis | Y |
| de Carvalho Leite et al., 2011 | England, UK | 35 | 18 ≥ 56 | 77% female | 77% white British; 2.9% each of German-Jewish, Portuguese, Chinese, African, White-black African mixed; White-black Caribbean mixed; Chinese-White mixed; white-Asian mixed | Not stated | Purposive | Focus group; Face-to-face semi-structured interviews | recruitment via various routes | Thematic analysis | y |
| Larun and Malterud, 2011 | Norway | 10 | 40-64 | 80% female | Not stated | diagnosed by GP (3) and specialist (7) | Purposive | Focus group | recruitment from adults attending a 6-week treatment programme | systematic text  condensation | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 20 | 22–60 | 85% female | Not stated | specialist doctor (GP with special  interest in CFS/ME) | Convenience | Semi-structured telephone interviews | recruitment from patients referred to specialist CFS/ME service | constant comparative analysis | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 46 | 20-73 | 72% female | Not stated | GP using Oxford inclusion criteria for CFS | Purposive | Face-to-face semi-structured interviews | recruited from patients taking part in an RCT | thematic analysis | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 16 patients (other participants) | 28-71 | 69% female | 38% white British, 31% south Asian, 12.5% black British, 12.5% Indian, 6.3% other white | Not stated | purposive | Face to face semi-structured interviews | recruited by various methods | Thematic analysis | Y |
| Best and Butler, 2013 | Australia and Canada (and worldwide) | 107 | Not stated | Not stated | Not stated | Not stated | convenience | Participant observation, interviews and focus groups | online recruitment | Thematic analysis |  |
| Anderson et al., 2014 | Chicago-Illinois, USA | 19 | mean 51 (SD 11) | 84% female | 42.1% White; 31.6% Hispanic or Latino; 15.8% African American; 10.5% Asian or Pacific Islander | Physician/Fukuda criteria | Purposive | Face-to-face or telephone semi-structured interviews | recruited from a community-based epidemiological study | Grounded theory | Y |
| (XXX anonymis-ed for blinded review) | (XXX anonymis-ed for blinded review) | 11 | Not stated | Not stated | 100% British minority ethnic groups | Not stated | Purposive | Face-to-face semi-structured interviews | recruited through CFS/ME support groups and South Asian community groups | Hybrid thematic analysis in line with modified grounded theory | Y |
| Brooks et al., 2014 | North of England, UK | 2 | Adults: mid-50s | 100% male | Not stated | CDC criteria for CFS/ME | Convenience | Face to face semi-structured interviews | recruited from hospital immunology clinic | IPA | y |
| Gladwell et al., 2014 | UK | 76 | <30 - 50+ | 82% female | Not stated | Not stated | purposive | Free text reply to online survey | online recruitment | Thematic analysis |  |
| Lingard and Court, 2014 | Australia | 5 couples (one CFS/ME in each couple) | Not stated | Unclear how many of 5 females have CFS/ME | Not stated | medical practitioner diagnosed | purposive and convenience | Semi-structured interviews – not stated if face to face | recruited from survey (from various routes) | excerpts from transcripts categorized according to SLQFC heading |  |
| Lian and Nettleton, 2015 | Norway | Not stated: 14 websites run by 13 women and 1 man | Not stated: above 16 years | Not stated | Not stated | Not stated | purposive selection of text and images | Group discussions on CFS/ME online forums | based on internet sites | discourse analysis | Y |
| Pinxsterhuis et al., 2015a | Oslo, Norway | 6 | 28-46 | 83% female | Not stated | medical practitioner diagnosed | Convenience | Focus group | recruited to trial via HCP and patient support groups | Thematic analysis | Y |
| Pinxsterhuis et al., 2015b | South-East Norway | 10 | 32-57 | 80% female | Not stated | Canadian diagnostic criteria  (Carruthers et al., 2003); Centers for Disease Control and Prevention criteria  (Fukuda et al., 1994) for CFS. | convenience | Focus group | recruited from participants in an intervention study | Thematic analysis | y |
| Stormorken et al., 2015 | Norway | 26 | 26-59 | 73% female | 100% white | diagnosed with PIFS according to international criteria for CFS | purposive | Face-to-face semi-structured interviews | recruited via a clinic | content analysis | Y |
| Bayliss et al., 2016 | North West England, UK | 11 patients | 27-71 | 79% female | Not stated | Not stated | Convenience | Face to face semi-structured interviews | recruited from participating GP practices | Thematic analysis | Y |
| Lian and Rapport, 2016 | Norway | 10 | 26-58 | 60% female | Not stated | Not stated | purposive | Autobiographic stories with text and photographs | Recruited from the community as part of a big survey | Thematic analysis | Y |
| Ryckeghem et al., 2016 | East  and West Flanders, Belgium | 15 | 33-59 | 93% female | Not stated | Diagnosis of CFS after multidisciplinary  discussion | purposive | Face to face semi-structured interviews | recruited via hospital department | Thematic analysis | Y |
| Williams et al., 2016 | Southern England, UK | 10 | 25-60 | 90% female | Not stated | To have had a diagnosis of CFS/ME by a registered  general practitioner (GP) for a minimum  of 3 years | convenience | Semi-structured telephone interviews | recruited via support group | Thematic analysis | Y |
| Broughton et al., 2017 | England, UK | 16 | 24–62 | 88% female | Not stated; BME underrepresentation noted as a limitation in the discussion | Diagnosed by specialist physicians | Convenience | Face-to-face or telephone semi-structured interviews | recruited via 3 outpatients NHS specialist CFS/ME services | Thematic analysis | Y |
| Brown et al., 2017 | UK | 16 | Not stated | 69% female | Not stated | Not stated – recovered from CFS/ME | convenience and snowball | Face to face semi-structured interviews | recruited via various routes | Grounded theory | Y |
| Picariello et al., 2017 | London, UK | 13 | 18-64 | 85% female | 85% white; 15% Black or Black British | Not stated | consecutive | Face-to-face or telephone semi-structured interviews | recruited from a specialist outpatient clinic | Thematic analysis | Y |

JBI: the Joanna Briggs Institute (JBI) QARI Critical Appraisal Checklist for Interpretive & Critical Research (Joanna Briggs Institute Reviewers’ Manual. 2014, Adelaide: Joanna Briggs Institute). IPA: Interpretative Phenomenological Analysis. RCT: Randomised Controlled Trial.