Table 2: Key/recurring, first and second order concepts

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| Key/recurring concepts – translation across studies | First order concepts (example quote) | Second order concepts (example quote) | All source papers |
| 1. **Invisible illness**:

People with CFS/ME are often denied support because illness is not physically identifiable or verifiable through diagnostic tests. Invisibility of illness made worse by being seen by others on their ‘good’ days. Additionally, they may avoid places, objects or people perceived to aggravate their illness. | I think one thing between me and my GP is complete lack of awareness of how I am when I'm really ill… (**Hannon et al. 2012**).  | They described visiting their GP on ‘a good day’, when they had the energy to leave the house… (**Hannon et al. 2012**). | Ware, 1992; Ware, 1998; Anderson and Ferrans, 1997; Cooper, 1997; Holloway and Pinikahana, 1999; Lovell, 1999; Reynolds and Vivat, 2006; Dickson et al. 2007; Edwards et al. 2007; Chew-Graham et al., 2008; Reynolds et al., 2008; Travers and Lawler, 2008; Chew-Graham et al. 2011; de Carvalho Leite et al. 2011; Hannon et al. 2012; Best and Butler, 2013; Anderson et al. 2014; Brooks et al. 2014; Stormorken et al., 2015; Ryckeghem et al. 2016 Williams et al. 2016; Lian, 2016; Picariello et al., 2017  |
| 1. ‘**Outed’ – hiding or exposing illness**:

In an attempt to avoid being stigmatised (shamed), people with CFS/ME hide the diagnosis of CFS/ME or they hide their symptoms. Support can encourage the disclosure of diagnosis or. Hiding illness may limit access to help. | They [colleagues] rang up to say why wasn’t I at my appointment and my husband said, ‘‘she’s gone out.’’ He couldn’t bring himself to say she’s passed out on the bed. (**Travers and Lawler, 2007**). | Families were deeply concernedthat disclosure of illness would discourage present and future customers (**Donalek, 2009**). | Ware, 1992; Norma C Ware, 1998; Travers and Lawler, 2008; Donalek, 2009; Best and Butler, 2013; Brooks et al. 2014; Pinxsterhuis et al., 2015b; Broughton et al. 2017; |
| 1. **Legitimisation and validation**:

CFS/ME is a contested illness because diagnosis is by exclusion and test results return normal. People with CFS/ME want symptoms, impairments and limitations to be taken seriously by professionals and society, and recognised as a genuine illness. They do not want their symptoms being trivialised. | At the end of the examination, he said ‘I can’t find anything wrong with you, you must have ME, but I don’t believe in it’, … (**Mc Cue P, 2004**). | … a sense that the condition and its associated symptoms were trivialised by outside others (**Brooks et al. 2014**). | Ware, 1992; Wheeler, 1992; Ax et al. 1997; Cooper, 1997; Holloway and Pinikahana, 1999; Lovell, 1999; Mc Cue, 2004; Taylor, 2005; Reynolds and Vivat, 2006; Dickson et al. 2007; Guise et al. 2007; Edwards et al. 2007; Chew-Graham et al., 2008;Dickson et al. 2008; Gilje et al. 2008; Travers and Lawler, 2008; Donalek, 2009; Guise et al. 2009; Chew-Graham et al. 2011; de Carvalho Leite et al. 2011; McDermott et al. 2011; Peters et al. 2011; Hannon et al. 2012; Anderson et al. 2014; Bayliss et al. 2014; Brooks et al. 2014; Lian and Nettleton, 2015; Bayliss et al. 2016; Ryckeghem et al. 2016; Williams et al. 2016; Broughton et al. 2017; Picariello et al., 2017;  |
| 1. **Psychologisation**:

People with CFS/ME do not want their illness to be viewed as predominantly psychological at the exclusion of physical symptoms. They want their physical symptoms treated, and psychological symptoms e.g. depression to be regarded and treated as a consequence of their CFS/ME. Acknowledging the physicality of illness can enable the exploration of mind-body interaction safely. | The only message you get is that it is psychic and sits in yourhead (**Lian and Nettleton, 2015**) | Much of the misunderstanding, as far as the patients were concerned, stemmed from doctors' misunderstanding their symptoms as mere depression (**Cooper, 1997**). | Ware, 1992; Wheeler, 1992; Ax et al. 1997; Cooper, 1997; Holloway and Pinikahana, 1999; Lovell, 1999; Mc Cue, 2004; Taylor, 2005; Reynolds and Vivat, 2006; Dickson et al. 2007; Guise et al. 2007; Chew-Graham et al., 2008; Gilje et al. 2008; Ward et al. 2008; Donalek, 2009; Guise et al. 2009; de Carvalho Leite et al. 2011; Chew-Graham et al. 2011; McDermott et al. 2011; Hannon et al. 2012; Lian and Nettleton, 2015; Broughton et al. 2017; Brown et al., 2017; Picariello et al., 2017;  |
| 1. **Illness at a cost**:

CFS/ME has serious financial implications due to the cost of treatment, loss of employment, and cost of practical help. The cost of the illness is amplified by stigma, limited access to employment or disability benefits and lack of work adaptability. | Every cent of my pension goes into keeping me functioning…(**Holloway and Pinikahana, 1999**). | CFS sufferers invariably end up with little income, most of which is subsequently spent on expensive treatments (such as naturopathic), inability to gain any kind of employment, and difficulties in accessing disability pensions… (**Holloway and Pinikahana, 1999**). | Anderson and Ferrans, 1997; Cooper, 1997; Ware, 1998; Holloway and Pinikahana, 1999; Taylor, 2005; Reynolds and Vivat, 2006; Dickson et al. 2007; Edwards et al. 2007; Donalek, 2009; Guise et al. 2009; de Carvalho Leite et al. 2011; McDermott et al. 2011; Anderson et al. 2014; Stormorken et al., 2015;Ryckeghem et al. 2016;  |
| 1. **Seeking person-centred care**:

People with CFS/ME want to be listened to, believed, shown empathy, individualised treatment strategies, relationships with professionals and shared understanding of their illness. They may need support to accept that symptoms may be long standing but that some people might recover. They appreciate self-management strategies that enable adequate coping.  | ’…I think first and foremost who she was, her empathic nature, was her greatest skill, anything else for me came secondarily’ (**Peters et al. 2011**). | …building a therapeutic alliance to engage patients, in particular, explaining the rationale for the treatment and listening to and validating patients’ illness experience. This was highly valued by patients (**Peters et al. 2011**).  | Wheeler, 1992; Ax et al. 1997; Cooper, 1997; Lovell, 1999; Taylor, 2005; ; Dickson et al. 2007;Edwards et al. 2007; Arroll and Senior, 2008; Chew-Graham et al., 2008; Gilje et al. 2008; Reynolds et al., 2008; Travers and Lawler, 2008; Ward et al. 2008; Donalek, 2009; Guise et al. 2009; Chew-Graham et al. 2011; de Carvalho Leite et al. 2011; Larun and Malterud, 2011; McDermott et al. 2011; Peters et al. 2011; Hannon et al. 2012; Bayliss et al. 2014; Brooks et al. 2014; Gladwell et al. 2014; Lian and Nettleton, 2015; Pinxsterhuis et al., 2015a; Pinxsterhuis et al., 2015b; Bayliss et al. 2016; Ryckeghem et al. 2016; Broughton et al. 2017; Brown et al., 2017; Picariello et al., 2017  |
| 1. **‘Catch 22’ – needing help to get help**:

People with CFS/ME need help to get the few services/help that are available to them. They found it exhausting to justify the need for help to others, and to do things by themselves because they were too exhausted to ask for help. | I am constantly in a ‘Catch-22’ between always overextending myself to please others and facing people’s disbelief and judgment when I can’t go on or have to ask for help (**Taylor, 2005**). | …participants were extremelyambivalent about the process of getting others to make allowances for them, setting limits, or asking for help (**Taylor, 2005**). | Taylor, 2005;Edwards et al. 2007; Ward et al. 2008; de Carvalho Leite et al. 2011; Gladwell et al. 2014; Ryckeghem et al. 2016; Williams et al. 2016; Broughton et al. 2017; Picariello et al., 2017;  |
| 1. **Searching for alternatives**:

People with CFS/ME search for alternative options in response to perceived inadequate services in mainstream healthcare. Alternative/complementary therapy came at significant financial costs to people with CFS/ME. Searching for alternatives also included GP swapping, private practitioners, searching the internet and for self-help groups. | I started out with acupuncture, and I did that for over a year. It gave me a sort of energy boost, and it was quite relaxing (**Ax et al. 1997**). | For many, this was a move away from dependence on the medical profession (**Edwards et al. 2007**). | Ware, 1992; Anderson and Ferrans, 1997; Ax et al. 1997; Holloway and Pinikahana, 1999; Lovell, 1999; Taylor, 2005; Dickson et al. 2007; Edwards et al. 2007; Arroll and Senior, 2008; Chew-Graham et al., 2008; Reynolds et al., 2008; Guise et al. 2009; de Carvalho Leite et al. 2011; ; Larun and Malterud, 2011; McDermott et al. 2011; Hannon et al. 2012; Anderson et al. 2014; Bayliss et al. 2014; Picariello et al., 2017;  |
| 1. **Shrinking (then rebuilding) social circle**:

People with CFS/ME lose many of the friends/social circle they formed prior to illness due to lack of acceptance of symptoms or loss of reciprocity. They then formed new relationships post illness that were perceived to be more understanding or accepting. | By doing a thing like this [working with a youth support group] I’m developing another circle of friends through CFS it’s budding, it’s opening up again (**Travers and Lawler, 2008**). | Most people had lost most if not all of their previous relationships (**Anderson and Ferrans, 1997**). | Anderson and Ferrans, 1997; Holloway and Pinikahana, 1999; Taylor, 2005; Reynolds and Vivat, 2006; Dickson et al. 2007; Dickson et al. 2008; Travers and Lawler, 2008; Edwards et al. 2007; Donalek, 2009; Reynolds and Vivat, 2010; de Carvalho Leite et al. 2011; Best and Butler, 2013; Anderson et al. 2014; Lingard and Court, 2014;  |
| 1. **Positive activity and identity reconstruction:**

These include strategies and activities that people with CFS/ME employed to reinvent themselves, or which they sought refuge in, or which improved their ability to cope . Some of these provide financial support and emotional expression. Examples include hobbies, artmaking, spirituality, recalibrating life expectations, virtual world, natural environments, ‘places’ or ‘homes’. |  I felt for a while that I had no identity apart from just being a sick, non-person and I’d lost all my former roles…I think I’ve managed to get that back again (**Reynolds and Vivat, 2010**). | Art-making seemed to offer each participant a means of restoring or transforming identity…(**Reynolds and Vivat, 2010**). | Wheeler, 1992; Holloway and Pinikahana, 1999; Lovell, 1999; Reynolds and Vivat, 2006; Reynolds et al., 2008; Travers and Lawler, 2008; Ward et al. 2008; Donalek, 2009; Reynolds and Vivat, 2010; Best and Butler, 2013; Anderson et al. 2014; Lingard and Court, 2014; Bayliss et al. 2014; Lian, 2016; Broughton et al. 2017;  |
| 1. **The role of significant others**:

Includes partners/spouses, carers, children, people with CFS/ME, and could be positive or negative role at different times. Supportive roles involve taking on supporting activities of daily living, health care needs, emotional help, social participation and financial support. | My husband has been a tower of strength and he understands, and he’s never questioned…He understands and that has been very supportive (**Reynolds and Vivat, 2006**). | The question often arose of whether the current help received, and the people currently relied upon would be available in the future, generating immense anxiety and worry *(***Williams et al. 2016**). | Anderson and Ferrans, 1997; Norma C Ware, 1998; Lovell, 1999; Taylor, 2005; Reynolds and Vivat, 2006; Dickson et al. 2007; Edwards et al. 2007; Guise et al. 2007; Travers and Lawler, 2008; Donalek, 2009; de Carvalho Leite et al. 2011; ; Larun and Malterud, 2011; Hannon et al. 2012; Anderson et al. 2014; Bayliss et al. 2014; Brooks et al. 2014; Lingard and Court, 2014; Bayliss et al. 2016; Williams et al. 2016; Broughton et al. 2017;  |
| 1. **Sharing stories**:

People with CFS/ME want to share their experiences with other people. This might be for validation, i.e. that the illness is genuine, or to gain hope for the future, e.g. by sharing with other people with CFS/ME who recovered or coped positively. Some of those who recovered support other people with active illness and this can provide a sense of achievement.  |  “Listening to other people’s stories and realising um that other people were experiencing exactly the same thing and I wasn’t imagining it …” (**Broughton et al. 2017**). | The majority of participants recalled group sessions positively, with benefits including ..having their own personal experiences and symptoms validated and normalized (**Broughton et al. 2017**). | Wheeler, 1992; Ax et al. 1997; Cooper, 1997; Taylor, 2005; Edwards et al. 2007; Chew-Graham et al., 2008; Reynolds and Vivat, 2010; McDermott et al. 2011; Anderson et al. 2014; Lian and Nettleton, 2015; Pinxsterhuis et al., 2015a; Pinxsterhuis et al., 2015b; Bayliss et al. 2016; Ryckeghem et al. 2016; Broughton et al. 2017; Brown et al., 2017;  |
| 1. **Support that is flexible, adaptable, and understanding**:

People with CFS/ME desire support that is based on an understanding of their illness and its associated limitations. They want support to accommodate the fluctuating levels of their symptoms and needs. | I can spread my work out over 7 days a week. If I feel particularly tired at 2:00 in the afternoon, I can come home and take a nap and finish my work after supper. (**Ware, 1998**). | Finding Flexibility. Finally, workers with CFS remain active members of the labor force despite their particular limitations by finding flexibility on the job. (**Ware, 1998**). | Norma C Ware, 1998; Taylor, 2005; Dickson et al. 2007; Edwards et al. 2007;de Carvalho Leite et al. 2011; Larun and Malterud, 2011; Peters et al. 2011; Hannon et al. 2012; Anderson et al. 2014; Ryckeghem et al. 2016; Williams et al. 2016; Broughton et al. 2017; Picariello et al., 2017;  |
| 1. **Equity in support**:

Women, and black and minority ethnic group people living with CFS/ME, report more delegitimising experiences, and find it more difficult to receive appropriate care and support. In some Asian and African cultures, people with CFS/ME, particularly women, especially struggle to obtain support from their family, and may avoid medical support. | I know if I happened to be a white person the story will be different… (**de Carvalho Leite et al. 2011**). | …a woman’s role to prioritise and care for her family often meant that there may be no time or support to seek medical advice for non-specific symptoms such as fatigue (**Bayliss et al. 2014**). | Ware, 1992; Wheeler, 1992; Cooper, 1997; Arroll and Senior, 2008; Gilje et al. 2008;de Carvalho Leite et al. 2011; Bayliss et al. 2014;  |
| 1. **Ongoing support – ‘having flown the nest’, ‘a safety net’**:

People with CFS/ME appreciate the positive outcomes following CFS/ME specialist services. However, many of them wanted ongoing care they could fall back on if needed. Continuity of care was also desired.  | You’ve kind of flown the nest [laughs] you’re being set free.... (**Broughton et al. 2017**). | Some patients believed it was important … to have an established relationship with their family physician (**Chew-Graham et al., 2008**). | Chew-Graham et al., 2008;Gilje et al. 2008; Guise et al. 2009; Pinxsterhuis et al., 2015b; Bayliss et al. 2016; Broughton et al. 2017; Ryckeghem et al. 2016; Williams et al. 2016; Picariello et al., 2017; |
| 1. **Support in all aspects of practical and social care**:

Some people with CFS/ME need support in most aspects of practical care and social life provided by significant others, family, friends, social workers, work colleagues. | I needed complete rest and somebody to do the shopping, to do the cooking …so I needed complete care really (**de Carvalho Leite et al. 2011**). | …practical support for personal care, family roles, independent living and support for carers was…seen as extremely important … *(***de Carvalho Leite et al. 2011**). | Anderson and Ferrans, 1997; Norma and Ware, 1998; Edwards et al. 2007; de Carvalho Leite et al. 2011; Larun and Malterud, 2011; McDermott et al. 2011; Stormorken et al., 2015; |