COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	24
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	N/A
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	N/A
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5-6
Sample size	12	How many participants were in the study?	5,7,8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5-6
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5-6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	no
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4-8
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	5-6
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5-6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	5-6
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	6
Participant checking	28	Did participants provide feedback on the findings?	7
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	8-15
Data and findings consistent	30	Was there consistency between the data presented and the findings?	8-15
Clarity of major themes	31	Were major themes clearly presented in the findings?	8-15
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-15

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Interview-Guideline for Patients with severe ME/CFS

[Introduce yourself, introduce the study, "Rules of the interview (breaks, cancel...)", clarification of consent, clarify recording]

Introduction and Personal Narrative

- **Could you please start by introducing yourself and giving me a little bit of an idea of who I have in front of me?**
    - In other words, what are you currently doing in your life? What have you been doing in the past? What was your living situation (profession/in private) like before you became ill with ME/CFS?

- **How did it come about, that you are now in this situation, seriously ill with ME/CFS? (Please start telling me from the moment you became ill, about how and when you received your diagnosis and how has the disease progressed up until the present day. Please, take your time! Should I not understand something or if something is not clear to me, I will anyways ask you to clarify. I have also brought a few other questions with me as well.)**
    - Was there a triggering event and how long have you been affected? (aiming at being able to follow and understand the process, otherwise ask straight away)
    - What was the course before the illness? [Was it initially mild or were you severely affected immediately after the triggering event? Were there fluctuations in the disease progression; were there things/events/triggers that significantly improved or worsened the illness, even if only in the short term?]

      [Particularly in the case of infections as a trigger: What was the history of the disease beforehand? Were there long periods of illness beforehand, comparable conditions after other infections (which ones?).]

- **How does your severe form present itself? At the moment, what does a normal, typical day look like for you? Can you please describe it to me, from the morning onwards?**
    - What is functionally possible on a good day? What on a bad day?
      (Allow the person to describe their routines and always ask questions to understand who does what and when etc.)

      [ask about symptoms if not mentioned: cognitive capacity and weakness; lights and sounds; orthostatic intolerance (more simply: maintaining circulation when the person is standing); food intolerance, MCAS; pain, hypermobility (EDS); Psychological comorbidities (anxiety, hallucinations, psychotic phase); Joint mobility]

Symptom Management

- **How are you currently dealing with your symptoms?**

- **Which symptoms are the most distressing and limiting ones for you? [What is the severity of this illness? Food intake/digestion? Symptom cluster?]**
- **What does a "crash" look like in you? Which triggers do lead to a "crash"?**
- **What helps you to prevent the symptoms from getting worse? e.g. medication or care?** (What is difficult, what works well and for what symptoms?)
- **What do emergency situations look like? What do you do then and what would you need?**

Professional Care Experiences

- **What type of care [care/support/therapy] do you currently have? Is it what you need? [When you think/look at your care, support and therapy, what is going well at the moment? What's going less well?]**
    - When your symptoms get particularly severe, what additional care do you require?
    - Is there anything that is absolutely missing or that you are completely unsatisfied with, concerning the professional care you are receiving?
    - How well do assessments (e.g. DSQ-PEM or Funcap) capture your condition/illness?

Interactions with Professionals and Family Caregivers

- **How are your experiences with people who take care of you? [Skilled personnel?] What does work well, what does work less well/not well at all? Is communication working?**

Improvements in Nursing and Care

- **Are there ongoing check-ups with professionals for you? If possible at all, can you tell me any positive or negative examples? (let them tell you, then ask: was this the case often or is this a typical example if it hasn't been told before)**
- **What would be the optimal care and support, even if that is completely unattainable?** Secondary questions, only if person can comment on it:
    - Could symptoms or parameters be measured to detect and prevent your deterioration?
    - From your point of view, which care and support services could improve your quality of life? (e.g. telemedical support/care, home visits…)
    - What forms of insurance/coverage do you have? [Occupational disability pension, nursing allowance, degree of disability]
    - What are the costs for your care/support/therapy? [Do you receive public support for this?]
    - Are there any forms of support that you would like to receive but cannot afford?

Is there anything else you would like to tell us?

Interview-Guideline for Patients with severe ME/CFS_self-recording

Introduction and Personal Narrative

- **Could you please start by introducing yourself and giving me a little bit of an idea of who I have in front of me?**

    - In other words, what are you currently doing in your life? What have you been doing in the past? What was your living situation (profession/in private) like before you became ill with ME/CFS?

- **How did it come about, that you are now in this situation, seriously ill with ME/CFS? (Please start from the moment you became ill, about how and when you received your diagnosis and how has the disease progressed up until the present day.)**

    - Was there a triggering event and how long have you been affected?

    - What was the course before the illness? [Was it initially mild or were you severely affected immediately after the triggering event? Were there fluctuations in the disease progression; were there things/events/triggers that significantly improved or worsened the illness, even if only in the short term?]

      [Particularly in the case of infections as a trigger: What was the history of the disease beforehand? Were there long periods of illness beforehand, comparable conditions after other infections (which ones?).]

- **How does your severe form present itself? At the moment, what does a normal, typical day look like for you? Can you please describe it, from the morning onwards?**

    - What is functionally possible on a good day? What on a bad day?

      [e.g. symptoms: cognitive capacity and weakness; lights and sounds; orthostatic intolerance (more simply: maintaining circulation when the person is standing); food intolerance, MCAS; pain, etc.]

Symptom Management

- **How are you currently dealing with your symptoms?**
- **Which symptoms are the most distressing and limiting ones for you? [What is the severity of this illness? Food intake/digestion? Symptom cluster?]**
- **What does a "crash" look like in you? Which triggers do lead to a "crash"?**
- **What helps you to prevent the symptoms from getting worse? e.g. medication or care?** (What is difficult, what works well and for what symptoms?)
- **What do emergency situations look like? What do you do then and what would you need?**

Professional Care Experiences

- **What type of care [care/support/therapy] do you currently have? Is it what you need? [When you think/look at your care, support and therapy, what is going well at the moment? What's going less well?]**

    - When your symptoms get particularly severe, what additional care do you require?
    - Is there anything that is absolutely missing or that you are completely unsatisfied with, concerning the professional care you are receiving?
    - How well do assessments (e.g. DSQ-PEM or Funcap) capture your condition/illness?

Interactions with Professionals and Family Caregivers

- **How are your experiences with people who take care of you? [Skilled personnel?] What does work well, what does work less well/not well at all? Is communication working?**

Improvements in Nursing and Care

- **Are there ongoing check-ups with professionals for you? If possible at all, can you tell me any positive or negative examples?**
- **What would be the optimal care and support, even if that is completely unattainable?**
  Secondary questions, only if you can comment on it:
    - Could symptoms or parameters be measured to detect and prevent your deterioration?
    - From your point of view, which care and support services could improve your quality of life? (e.g. telemedical support/care, home visits…)
    - What forms of insurance/coverage do you have? [Occupational disability pension, nursing allowance, degree of disability]
    - What are the costs for your care/support/therapy? [Do you receive public support for this?]
    - Are there any forms of support that you would like to receive but cannot afford?

Is there anything else you would like to tell us?

Interview-Guideline for Patients with very severe ME/CFS

[Introduce yourself, introduce the study, "Rules of the interview (breaks, cancel...)", clarification of consent, clarify recording]

Interview part with caregiver:

Introduction and Personal Narrative:

- **Could you please start by introducing XY and giving me a little bit of an idea of who this person is?**

    - In other words, what is XY currently doing in their life? What has XY been doing in the past? What was the living situation (professionally/in private) like before XY became ill with ME/CFS?

- **How did it come about, that XY is now in this situation, seriously ill with ME/CFS? (Please start telling me from the moment XY became ill, about how and when XY received their diagnosis and how has the disease progressed up until the present day. Please, take your time! Should I not understand something or if something is not clear to me, I will anyways ask you to clarify. I have also brought a few other questions with me as well.)**

    - Was there a triggering event and how long has XY been affected? (aiming at being able to follow and understand the process, otherwise ask straight away)

    - What was the course before the illness? [Was it initially mild or was XY severely affected immediately after the triggering event? Were there fluctuations in the disease progression; were there things/events/triggers that significantly improved or worsened the illness, even if only in the short term?]

      [Particularly in the case of infections as a trigger: What was the history of the disease beforehand? Were there long periods of illness beforehand, comparable conditions after other infections (which ones?).]

- **How does XY's very severe form present itself? At the moment, what does a normal, typical day look like for XY? Can you please describe it to me, from the morning onwards?**

    - What is functionally possible on a good day? What on a bad day?
      (Allow the person to describe their routines and always ask questions to understand who does what and when etc.)

      [ask about symptoms if not mentioned: cognitive capacity and weakness; lights and sounds; orthostatic intolerance (more simply: maintaining circulation when the person is standing); food intolerance, MCAS; pain, hypermobility (EDS); Psychological comorbidities (anxiety, hallucinations, psychotic phase); Joint mobility]

Symptom Management:

- **Which symptoms do you think are most distressing and limiting for XY? [Food intake/digestion? Symptom cluster?]**
- **What does a "crash" of XY look like? Which triggers do lead to a "crash"?**
- **What do emergency situations look like?** What does XY do then and what would XY need?

Interactions with Professionals:

- **What form of care [care/support/therapy] does XY currently have? What would be the care that XY needs? [If you think of care, support and therapy, what is currently going well for XY? What's going less well?]**
  - If symptoms are particularly severe, what additional care/care does XY need?
  - Is there anything that is absolutely missing? Something XY is completely unsatisfied with? [in medical, nursing or therapeutic care?]
  - How well do assessments (e.g. DSQ-PEM or Funcap) capture the condition/illness of XY?

Improvements in Nursing and Care:

- **Are there ongoing check-ups with professionals for XY? If possible at all, can you tell me any positive or negative examples? (let them tell you, then ask: was this the case often or is this a typical example if it hasn't been told before)**

Secondary questions (only if person can comment on it):

- Could symptoms or parameters be measured in XY to detect and prevent deterioration?
- From XY's point of view, which care and support services could improve their quality of life? (e.g. telemedical support/care, home visits…)
- What forms of insurance/coverage does XY have? [Occupational disability pension, nursing allowance, degree of disability]
- What are the costs for the care/support/therapy of XY? [Does XY receive public support for this?]
  Are there any forms of support that XY would like to receive but cannot afford?

Is there anything else you would like to tell us about XY?

Interview part with person with very severe ME/CFS:

Introduction and Personal Narrative:

Who were you before the illness? [pay attention to whether XY wants to answer this or emotionally too difficult]

What does a good day look like (functionally)? What about a bad one?

Symptom Management:

- **What is the worst symptom or limitation?**
- **What is a "crash" like? [Trigger?]**
- **What helps to prevent the symptoms from getting worse?**
- **What do emergency situations look like?** [What do you do then and what would you need?]

Interactions with professionals/caregivers:

- **How are your experiences with people who take care of you? [Skilled personnel?] What does work well, what does work less well/not well at all? Is communication working?**

Improvements in Nursing and Care:

- **What would be the care and support you need?**
- **How can we recognize possible deterioration in you?**

Is there anything else you would like to tell us?

Interview-Guideline for Family Caregivers

[Introduce yourself, introduce the study, "interview rules (breaks...)", clarify consent, explain recording]

Introduction and Personal Narrative

Could you please start by introducing yourself and giving me a little bit of an idea of who I have in front of me?

> In other words, what are you currently doing in your life? What have you been doing in the past? What were your living situation and activities like before XY fell ill with ME/CFS and you became a caregiver? Who is this person you are providing care for?

How did it come about, that you are now in this situation of looking after and caring for XY?
(Please start telling me from the moment your family member became ill, about how they received their diagnosis and the course of their disease up until the present day. Please, take your time! Should I not understand something or if something is not clear to me, I will anyways ask you to clarify. I have also brought a few other questions with me as well.

How is XY affected by ME/CFS?

[ask about symptoms if not mentioned: cognitive capacity and weakness; lights and sounds; orthostatic intolerance (more simply: maintaining circulation when the person is standing); food intolerance, MCAS; pain, hypermobility (EDS); Psychological comorbidities (anxiety, hallucinations, psychotic phase); Joint mobility]

How long have you been in this situation as a caregiver and has this situation changed for you over time?

At the moment, what does a normal, typical day look like for you? Can you please describe it to me, from the morning onwards? How do communicate with XY?

> Allow the person to describe their routines and always ask questions to understand who does what and when etc.

Medical and Nursing Care at Home

Could you please describe the medical and nursing support that is currently being provided, respectively has been provided in the past, for XY?

- How do you experience the contact/support/treatment from healthcare professionals? What is helpful? What does not work?
- Are there any non-existent or non-available nursing services you would wish for? What would they look like?
- Can you name reasons for the possible lack of support?

Challenges and Gaps in Care

o How do you cope with the daily demands of high-intensity care?

- What challenges do you face?
- How easy or difficult is it for you to understand how XY deals with the illness?

Symptom Management and Prevention of Exacerbations

- **Which symptoms do you think are most distressing and limiting for XY? [Food intake/digestion? Symptom cluster?]**
- **Which symptoms are the most stressful or challenging for you in nursing and care?**
- **Have there been moments when symptoms (unexpectedly) worsened? Or health problems that occurred apart from ME/CFS? How did you deal with these situations?**
- What are your experiences with the measurement of symptoms or parameters? (Positive or negative experiences in this context)
- Are there any measurable symptoms or parameters indicating worsening?
- What are your strategies to prevent symptoms from worsening?

- **Are there emergency situations? Can you describe these situations and how do you deal with it?**

Support for Family Caregivers

What kind of support do you get as a family caregiver?
(in nursing, regarding information, financial, emotional – financed by whom and how?)

- Would you like more support with something?
- Do you currently need more support in dealing with certain symptoms of XY?
- more support in your role for nursing and care work (when dealing with authorities, etc.)
- more support for your own needs (e.g. to talk about difficult things...)
- More support to arrange tasks related to nursing and care work with your professional activity

Need for Training and Information

How do you get information so that you can fulfil your role as a family caregiver?

- Who or what supported you when it came to collecting information, or when it came to how you to deal with the situation and the illness in terms of care and nursing at home?

Closing Thoughts

Is there anything left you would like to tell us?

Interview-Guideline for Healthcare Professionals

(Introduce yourself, introduce the study, "interview rules (breaks..)", clarify consent, explain recording)

Can you please introduce yourself and tell us about your experiences you have with patients who are (very) severely affected by ME/CFS?

How do you experience both the (very) severe stage of ME/CFS?

[ask about symptoms if not mentioned: cognitive capacity and weakness; lights and sounds; orthostatic intolerance (more simply: maintaining circulation when the person is standing); food intolerance, MCAS; pain, hypermobility (EDS); Psychological comorbidities (anxiety, hallucinations, psychotic phase); Joint mobility]

Can you describe the typical care regimen you recommend for a severely affected ME/CFS patient at home?

1. **Medical and Nursing (/Therapeutical) Care at Home**
    - Please describe the situation of home care for your patients with ME/CFS
    - How do you adapt your measures, particularly to prevent symptoms from worsening in these patients? [Go through symptoms]
    - Do you know of care situations for ME/CFS not being done at home?

2. **Challenges and Gaps in Healthcare/Nursing Care**
    - What are the biggest challenges you face in providing care? What are the challenges you encounter in providing home care to ME/CFS patients?
    - How do you address the complexities in a home setting?
    - What is the first priority in medical/nursing/therapeutical care?
    - Would you like to see hospital-at-home-care? When? For what conditions or symptoms?

3. **Symptom Management and Exacerbation Prevention**
    - In your experience, which symptoms are the most distressing for ME/CFS patients?
    - Which symptoms (-constellations/-developments) are the most worrying for you in those affected? [symptom cluster]
        - Are there measurable symptoms, conditions and parameters that can detect and prevent deterioration? Have you had positive experiences measuring these?
    - Do you have an example of a patient where symptoms unexpectedly worsened? How did you handle the situation?
    - Are there acute emergency situations that you have experienced among those affected? What options are available in these situations and how do you/did you deal with them?

4. **Collaboration and Coordination**
    - **How do you collaborate with other health-care professions/services?**
        a) routinely
        b) give me an example where extraordinary collaboration happened?
    - What would you say works well in the collaborations/what would need to be improved? (and how)
    - What additional resources or supports would enhance your ability to provide effective care?

5. **Closing Thoughts**
    - Is there anything else you would like to share with us?