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# Quality Assessment Scoring

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|   | Badger (2005) | Bailey et al. (2011) | Becker et al. (2017) | Chong & Abdullah (2017) | Gelinas et al. (2012) | Harris (2013) | Johansson & Lindahl (2012) | Jordan et al. (2014) | Källström Karlsson et al. (2008) |
| **Rater** | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| **CASP Questions** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Q.1**  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.2**  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.3**  | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.4**  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.5**  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.6**  | 0 | 0 | 0 | 0 | 2 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 2 | 2 | 0 | 0 |
| **Q.7** | 1 | 1 | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.8**  | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 |
| **Q.9** | 2 | 2 | 0 | 0 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.10** | 1 | 1 | 1 | 1 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 |
| **Total (Out of 20)** | 16 | 16 | 14 | 14 | 18 | 19 | 17 | 17 | 16 | 16 | 18 | 18 | 18 | 19 | 19 | 19 | 17 | 18 |
|
| **Score (%)** | 80 | 80 | 70 | 70 | 90 | 95 | 85 | 85 | 80 | 80 | 90 | 90 | 90 | 90 | 95 | 95 | 85 | 85 |
|
|

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|   |   | Kaup et al.(2016) | McCloskey & Taggert (2010) | McNamara et al. (1995) | Reid (2013) | Rose & Glass (2009) | Seed & Walton (2012) | Tunnah et al. (2012) | Wilkes et al., (1998) | Yang & Mcilfatrick (2001) |
| **Rater** |  | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 | 1 | 2 |
| **CASP Questions** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| **Q.1**  |  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.2**  |  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.3**  |  | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 |
| **Q.4**  |  | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.5**  |  | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.6**  |  | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 2 | 1 | 1 | 1 | 1 | 0 | 0 | 0 | 0 |
| **Q.7** |  | 2 | 2 | 2 | 2 | 0 | 0 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 1 |
| **Q.8**  |  | 2 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 |
| **Q.9** |  | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| **Q.10** |  | 1 | 1 | 1 | 1 | 1 | 1 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 1 |
| **Total (Out of 20)** |  | 18 | 18 | 15 | 15 | 12 | 12 | 17 | 17 | 18 | 17 | 19 | 19 | 19 | 19 | 16 | 17 | 16 | 16 |
|
| **Score (%)** |  | 90 | 90 | 75 | 75 | 60 | 60 | 85 | 85 | 90 | 85 | 95 | 95 | 95 | 95 | 80 | 85 | 80 | 80 |

# Quality Assessment

All studies recruited participants using a purposive sampling approach to include participants with particular characteristics who were better able to assist with the relevant research (Etikan et al., 2016). However, three of the 18 studies had omitted reporting participants’ demographic details (Bailey et al., 2011; Källström Karlsson et al., 2008; McCloskey & Taggart, 2010). Of the remaining 15 studies, two did not include gender details (Reid, 2013; Yang & Mcilfatrick, 2001), 11 had no information regarding participants’ ages (Bailey et al., 2011; Becker et al., 2017; Johansson & Lindahl, 2012; Jordan et al., 2014; Källström Karlsson et al., 2008; McCloskey & Taggart, 2010; Reid, 2013; Rose & Glass, 2009; Seed & Walton, 2012; Tunnah et al., 2012; Wilkes et al., 1998), and only two studies reported participants’ ethnic background (Badger, 2005; Harris, 2013). A lack of reporting on gender, and a gender bias in nursing research, may contribute to knowledge gaps and a lack of research generalisability (Polit & Back, 2009). Additionally, a lack of adequate demographic information may raise questions regarding inclusion and diversity issues, and a lack of clarity impacting any generalisation of findings for clinical practice or future research (Hughes et al., 2016; Jones et al., 2020).

Reflexivity has been recognised as a crucial strategy in qualitative research (Finefter-Rosenbluh, 2017; Naples & Sachs, 2000). Only three studies discussed bias and data validation or the relationship between the researcher and participants (Becker et al., 2017; Jordan et al., 2014; Rose & Glass, 2009). The absence of reflexive discussions in the other 15 studies means it is not possible to assess any risk of bias or potential impact on the validity of findings (Lazard, 2020; Reid et al., 2018).

The suitability or rigour of data analysis approaches within the studies was also highlighted. Seven of the studies lacked enough details to assess the quality of data analysis (Bailey et al., 2011; Jordan et al., 2014; Reid, 2013; Rose & Glass, 2009; McCloskey & Taggart, 2010; McNamara et al., 1995; Wilkes et al., 1998). The lack of clarity on theoretical positions and processes undertaken during data analysis limited the ability to assess the validity of studies’ findings or recommendations (Santiago-Delefosse et al., 2016; Twining et al., 2017).

# Characteristics of the Literature

Four studies were conducted in the UK (Bailey et al., 2011; McCloskey & Taggart, 2010; Reid, 2013; Tunnah et al., 2012), and in the United States (Badger, 2005; Becker et al., 2017; Harris, 2013; Seed & Walton, 2012), three in Sweden (Johansson & Lindahl, 2012; Källström Karlsson et al., 2008; Kaup et al., 2016) and Australia (McNamara et al., 1995; Rose & Glass, 2009; Wilkes et al., 1998), one in Canada (Gélinas et al., 2012), Malaysia (Chong & Abdullah, 2017), South Africa (Jordan et al., 2014), and Taiwan (Yang & Mcilfatrick, 2001).

Studies were varied in their approaches to data collection, with focus group interviews (Gélinas et al., 2012; Harris, 2013; McCloskey & Taggart, 2010), semi structured interviews (Chong & Abdullah, 2017; Johansson & Lindahl, 2012; Jordan et al., 2014; Källström Karlsson et al., 2008; Kaup et al., 2016; Reid, 2013; Seed & Walton, 2012; Tunnah et al., 2012; Yang & Mcilfatrick, 2001), and open-ended questionnaires (Becker et al., 2017) all being used. Five studies combined qualitative data collection approaches. This included combining focus group interviews, informal conversations, and observations (Badger, 2005), observations and semi structured interviews (Bailey et al., 2011; McNamara et al., 1995), semi-structured interviews and reflective journaling (Rose & Glass, 2009), and open-ended questionnaires and semi-structured interviews (Wilkes et al., 1998).

 Participants were all nurses working in services that provided PC including: hospital inpatient (Badger, 2005; Bailey et al., 2011; Becker et al., 2017; Chong & Abdullah, 2017; Gélinas et al., 2012; Johansson & Lindahl, 2012; Jordan, et al., 2014; Källström Karlsson et al., 2008; Yang & Mcilfatrick, 2001), community hospices (Harris, 2013; McNamara et al., 1995; Seed & Walton, 2012), and community/home-based PC services (Kaup et al., 2016; Reid, 2013; Rose & Glass, 2009; Tunnah et al., 2012; Wiles et al., 1998). Participants from McCloskey and Taggart (2010) came from hospital, hospice, and community teams. Seven studies reported participant ages which ranged from 22 to 62 years (Badger, 2005; Chong & Abdullah, 2017; Gélinas et al., 2012; Harris, 2013; McNamara et al., 1995; Kaup et al., 2016; Yang & Mcilfatrick, 2001).

 All studies apart from five (Bailey et al., 2011; Källström Karlsson et al., 2008; McCloskey & Taggart, 2010; Reid, 2013; Yang & Mcilfatrick, 2001) reported gender, which included 240 females (93%) and 18 males (7%).

# Analysis Stage One: Coding text



# Analysis Stage two: Developing descriptive themes (visual mapping)



# Analysis Stage three: The development of 'analytical' themes

# Additional Quotes

**Main Theme – When work becomes personal**

*“Laughter is often used to mitigate the tension that results from toxic interactions with “pain-in-the-ass families and patients.” For example, “we’ll go into the backroom” and “say that the family is full of a bunch of nuts…they are all crazy.”* (Badger, 2005, p. 66)

*“In addition, families may have difﬁculty understanding the information provided by the physician and will turn to the nurses for explanation. This situation added to the stress of having to be the bridge between the family and the physician. As a consequence of these communication difﬁculties, nurses sometimes received complaints from one or another of the parties. In half of the focus groups, nurses said that they found it stressful to receive critical comments from the family…”* (Gélinas et al., 2012, p. 30)

*“This means not allowing relations with the patients and families to become too private and requires the ability to strike a balance between closeness and distance: … So you don’t get too close and personal”* (Johansson & Lindahl, 2012, p. 2,037)

*“The informants experienced some meetings with the patients and their families as extra demanding. They said it was difficult for them to leave them and move on. They felt exhausted. One described the feeling she had after a difficult meeting, saying that she felt as if she was going to fall into pieces. Several informants also felt that it was quite risky, as those feelings could accumulate if they did not have a chance to process them.”* (Kaup et al., 2016, p. 567)

**Main Theme – The burden on mind and body**

**Subtheme –** *Emotional impact*

*“The nurses clearly, and sometimes tearfully, articulated the personal impact of the episode. ‘… whole emotional rollercoaster that the parents were on … you were riding that yourself ... [it was] emotionally wearying.’”* (Reid, 2013, p 543)

*“Three emotional stressors were addressed: value conﬂicts, lack of emotional support, and dealing with patient and family suffering.”* (Gélinas et al., 2012, p. 31-32)

*“Like Anna, Shae’s impaired emotional wellbeing also had an impact that affected others. Shae recalled: If I’m unbalanced everybody knows it. I talk about [the issue] a lot. I can’t let it go. I’m teary, I’m emotional, I’m impulsive. I say and make rash decisions that I wouldn’t do if I felt balanced which ends me up in more strife ... I put myself in the ﬁring line sometimes unnecessarily. I don’t sleep well, I’m anxious. I’m looking for the next thing to go wrong. I come from a real negative base. I am expecting the worst instead of expecting the best..”* (Rose & Glass, 2009, p. 189)

*“'It's very sad really, you know when it comes to the end of their life it can hit you emotionally, but I don't take it home and think about it for hours.’”* (Tunnah et al., 2012, p. 287)

*“In most cases when talking of these constructs the nurses described the cause and effect of the stress on themselves. As one nurse stated: ‘It’s emotional, overload, I find myself constantly thinking about the client, crying, having disturbed sleep’”* (Wiles et al., 1998, p. 17)

*“It seemed to be difficult to avoid thinking about the patients. After work, when the nurses felt that they had done everything in their power but had still been unable to relieve the patients’ suffering, it was difficult to let go of their feelings. Furthermore, the nurses would dream about the patients, which was emotionally exhausting.”* (Källström Karlsson et al., 2008, p. 228)

*“The majority of the participants expressed mixed emotions of sadness, grief and anger when caring for patients who presented with end-of-life issues. One participant explained it as follows: ‘Guilt, anger... helplessness, because... you want to fix it, but you can’t. That’s kind of sadness obviously...extreme sadness...”* (Jordan et al., 2014, p. 78)

*“This sense of fear and guilt was coupled with a sense of powerlessness and frustration relating both to nurses’ inability to alter the ultimate outcome for patients or take away the family’s grief”* (Yang & Mcilfatrick, 2001, p. 437)

**Subtheme –** *Physical impact*

*“Physical tension, distress, sadness, restlessness and irritability were reported. Mind racing, sleeplessness and worrying caused ongoing effects leaving some nurses depleted of energy.”* (Rose & Glass, 2009, p. 189)

*“…as identiﬁed by our study ﬁndings, over time this could be exhausting. If nurses were not supported to reach the ﬁnal stage of the model, they were at risk of developing ineffective and potentially harmful coping mechanisms that could lead to stress, ill-health and withdrawal from practice”* (Bailey et al., 2011, p. 3,368)

*““Sometimes I cry once I get home, from being so exhausted.””* (Gélinas et al., 2012, p. 33)

*“Many nurses try this kind of nursing and leave within months, others 'burnout", but many stay despite the physical, emotional, ethical, social and spiritual problems they encounter through the course of their work.”* (McNamara et al., 1995, p. 228)

*“‘I do feel quite burnt out you know. How much compassion have I left? I do feel very tired. In the past year I have seriously thought about giving up nursing completely so I am obviously stressed and burnt out, and I have never done that before.’”* (McCloskey & Taggart, 2010, p. 238)

**Main Theme – Finding meaning and connection**

**Subtheme –** *Feeling fulfilled*

*“…caring for the terminally ill and their families means getting a lot back in return, which means experiencing afﬁrmation and stimulation in the work. This helps the nurses to gain the strength to care and ﬁnd meaning in what they do.”* (Johansson & Lindahl, 2012, p. 2,038)

*“Job satisfaction was identified as an important determinant of the nurses' stress levels. Several of the nurses discussed the merits of 'making a difference': 'When you've walked in and there's a crisis, the patient is in pain, family in distress, they are not coping, they are frightened. By the time you have left the home, having sorted out the pain, the symptom control issues and you've calmed the waters ... the families are happy.'”* (Tunnah et al., 2012, p. 286)

*“…nurses indicated that providing comfort, respecting patient wishes and having empathy for patients and families could help balance their own emotional reactions or stress: ‘I provide the optimal nursing care to the patients who are approaching death. I just want all of them to feel very comfortable and this is what I can do for them at that time… It can make me feel better when the patients die.”* (Yang & Mcilfatrick, 2001, p. 439)

**Subtheme** – *Connection with others*

“…it became clear through the discussions that most viewed the relationships with their coworkers as much more than a professional connection. For some, there was consensus that it was ‘‘more than a family,’’ whereas others agreed that the relationship was much ‘‘more personalized and they were able to share more with one another.’” (Harris, 2013, p. 449)

*“…registered nurses found that they supported each other, which aided in their coping. They expressed that these support systems in the intensive care unit were very beneficial and helped them as illustrated by the following quote: So it’s nice in this ICU, because we support each other a lot. If you’ve got a problem you never sit alone with a dying patient. There will be times that someone will pat your shoulder, ask how you are, or ask if they can bring you a cup of coffee or do something for you.” (*Jordan et al., 2014, p. 80)

*“Although the nurse's social networks may be broad and represent the totality of resources they may draw upon for support, the personal networks developed between family, friends and colleagues feature most strongly as both a source of stress and support for hospice nurses.”* (McNamara et al., 1995, p. 232).