

Overcoming the Challenges and Complexities of Researching a Vulnerable Population Within A Palliative Care Context

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Contributor Biographies

Natasha Nabi has previous experience of a year volunteering with male offenders in a secure forensic unit with learning difficulties.

Nicola Cogan completed her PhD in psychology and social policy/social work (University of Glasgow) and went on to work in specialist mental health services for children and young people before

completing a Professional Doctorate in Clinical Psychology (University of Edinburgh). She has over 15 years working at the front line of adult mental health services within NHS Scotland; most recently as a consultant clinical psychologist/clinical lead for a specialist veteran service. She recently joined the University of Strathclyde as a Lecturer in Psychological Sciences in Health.

Dr Leanne Fleming has 15 years' experience in working within hospital and healthcare settings delivering CBT for insomnia to patients with chronic illness. She developed the CBT intervention that will be used in this study and as such, is very experienced in understanding the key aspects of its implementation, particularly in those groups with co-morbid health complaints.

Stacey Moore has three years of experience volunteering as a young carers support worker with vulnerable children. She has also volunteered within Quarriers for 1 year as a dementia befriender and has completed some shadow shifts as an adult support worker.

Kate Tweats has collected data in a previous research study from vulnerable adults who have undergone therapy. She also has 1-year experience working as an adult support worker providing mental health care.

Amy McMurdo has volunteered for 10 months with forensic patients at a state hospital. She also has 3 years experience as a care assistant providing palliative care to individuals diagnosed with dementia.

Shivani Vani has collected data in a previous research study from vulnerable adults who were from low socio-economic areas and using mental health services in India.

Karen Logan has experience of working with vulnerable children and adults. She has worked with children in care for 6 years, as a family support worker for 1 year and has volunteered within the mental health outreach programme for 6 months.

*All authors involved have recently completed a Msc in Clinical Health Psychology at Strathclyde university and have gained experience within sleep psychology and palliative care.

Abstract

While previous studies have investigated sleep issues in chronic illness and the effectiveness of Cognitive Behavioral Therapy for Insomnia (CBT-I), this has not been examined within palliative care. High rates of sleep difficulties have been found in patients receiving palliative care. We aimed to explore the practical feasibility of implementing CBT-I among palliative patients using techniques such as stimulus control therapy, progressive muscle relaxation and guided imagery/thought blocking. However, issues such as the intervention protocols being relatively labor intensive and time consuming for participants that were receiving palliative care, involving completion of daily diaries and quantitative outcome measures, led to high non-completion rates among participants. Consequently, a shift in methodology was required and a qualitative approach was adopted to explore participants' experiences of sleep disturbance within palliative care. The aim was to gain an in-depth understanding of the specific issues and challenges within palliative care that impacted on sleep. Focus groups were conducted with patients, informal carers and hospice staff who all described how they experienced sleep difficulties. This provided a broader understanding of insomnia from multiple perspectives within palliative care. Furthermore, it helped inform how we will go about designing future studies in CBT-I in palliative care; having illuminated the appropriate adaptations required to current protocols. This case study will discuss the complexities and ethical issues we faced at each stage of the research process and how adopting both quantitative and qualitative approaches helped provide useful insights that will inform future research.

Learning Outcomes

By the end of this case, students should be able to:

- Recognise the complexities and ethical issues of carrying out a research study within palliative care

- Understand the needs of the client group when running an intervention study
 - Understand the challenges of undertaking research with vulnerable patients
 - Recognise the complex issues surrounding using focus groups as a data collection method
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Project Overview and Context

High rates of sleep-wake difficulties have been found in patients receiving palliative care (Bernatchez, Savard, Savard, Aubin, 2018). Prevalence estimates of sleep disturbance among patients within palliative care are estimated to be between 45% - 95% (Renom-Guiteras, Planas, Farriols, Mojal et al, 2014). However, research in this area is scarce. This wide-ranging prevalence is partly explained by inconsistencies in methods of sleep assessment and failure to utilise definitions of sleep disturbance that are based on diagnostic criteria (Luyster, Choi, Yeh, Imes et al, 2016). Therefore, research focusing on the sleep status of those receiving palliative care for an incurable illness should address these issues by utilising operational definitions and valid, reliable methods of assessment. That said, qualitative reports and clinical observations indicate that sleep disturbance is problematic for these patients. Therefore, this study was designed to assess the feasibility of implementing an intervention for poor sleep in this population.

Insomnia is defined as difficulty with sleep initiation and/or duration that results in daytime impairment (American Psychiatric Association, 2013). Previous research and NICE guidelines have demonstrated that Cognitive Behavioural Therapy for Insomnia (CBT-I) is the appropriate treatment for insomnia (Trauer, Qian, Doyle, Rajaratnam et al, 2015). CBT-I has also been found to have significant and durable effects on daytime functioning, specifically negative mood, self-control and increased job satisfaction (Barnes, Miller & Bostock, 2017). Moreover, CBT-I reduces clinical levels of fatigue, anxiety and depression in cancer patients, providing evidence that CBT-I offers benefits beyond improving sleep. (Fleming, Randell, Harvey, Espie, 2014). Despite this effectiveness data,

little work has been implemented within the palliative care context. A recent study by Bernatchez et al (2018) was designed to explore the feasibility and acceptability of a cognitive-behavioural and environmental intervention to improve insomnia and hypersomnolence in cancer patients receiving palliative care (Bernatchez et al, 2018). Results demonstrated that although participant adherence and satisfaction towards the CBT-E intervention were variable, participants found CBT-E easy to apply and was not rated as impossible to use because of their health conditions (Bernatchez et al, 2018).

Given the lack of research exploring the effectiveness of CBT-I within palliative care, our aim was to assess the feasibility of conducting such research on an outpatient population from a local hospice. Ensuring participant safety was our prime concern, so careful consideration of our inclusion and exclusion criteria was required. We collaborated with senior palliative care clinicians and agreed that eligible participants should be 18 years and over, be actively accessing the hospice's outpatient services and currently experience symptoms of insomnia. The ability to attend appointments and engage with the CBT-I protocol were also used as a guide for eligibility. Participants were ineligible for the study if their prognosis was less than six months (in order to ensure a reasonable level of physical functioning) or, if they were currently misusing alcohol or substances. Finally, if participants reported a sleep problem other than insomnia (i.e. restless leg syndrome, sleep apnea), they were ineligible for our study but were referred to their clinical specialist for onward assessment. It was also essential that participants had the capacity to provide informed consent and to be able to understand and follow the data protection guidelines that were in place. Eligibility screening was conducted by the clinical team at the hospice. Ethical approval for this study was granted by the University of Strathclyde's Ethics Committee.

Section Summary

- Research within palliative care is limited. However, previous research has shown that the prevalence of sleep disturbance among patients receiving palliative care is between 45% - 95%.
 - CBT-I is effective in improving sleep latency, wake time after sleep onset and sleep efficiency. It also improves comorbid symptoms of anxiety, low mood and fatigue
 - Our study was designed to test the feasibility of delivering a CBT-I technique within a palliative care setting
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Research Design

We designed an intervention study to test the feasibility of delivering a CBT-I sleep management protocol to adults receiving palliative care for an incurable illness within a hospice setting. The study recruited participants from the hospice outpatient service. A gatekeeper, who was a senior occupational therapist within the day therapy unit in the hospice, informed eligible participants about the study and put those interested in taking part in contact with the research team. At this stage, a study researcher made telephone contact with the participants to arrange an initial meeting. This allowed us to establish a relationship with potential participants, to clarify eligibility and to organise a convenient time and location for the initial interview. Participants were provided with participant information sheets in advance of this interview to provide further details about the study.

We planned to meet participants at the hospice outpatient clinic, at a convenient date and time. This was so we could match our appointments with the scheduled clinical appointments in order to minimise participant burden. The purpose of this appointment was to obtain informed consent and conduct the semi-structured interview. The interview was designed to establish further details about the participants' sleep, including quality, duration and any methods currently used to aid sleep. The interview also assessed symptoms of depression, anxiety, fatigue and pain.

A semi-structured interview format was deemed to be the most suitable approach as it allowed us to explore sleep in-depth, by facilitating the participant's own frames of reference. The advantage of conducting the interview in person allowed us further insight into the participants' behavioural responses to the questions asked, which would not have been apparent from a telephone conversation. We envisaged that this one to one contact would also allow us to offer information and contact details of support agencies (where required), as well as offer a comfort break if the interview triggered an emotional response. Finally, we made every effort to avoid the use of clinical jargon during the participant interviews to ensure a friendly and relaxed approach.

Once the participant completed the interview, the researcher provided an overview of each of the available CBT-I techniques. These included stimulus control therapy, guided imagery/thought blocking and progressive muscle relaxation. Each participant was informed that, once they had selected the CBT-I component that they wished to try first, the researcher would provide guidance throughout the implementation phase of the study. The researcher also explained that materials would be provided to support the participant at home. Discussion would take place about the 3 interventions proposed and participants would then pick the intervention most suitable for them. They would then carry out their chosen intervention for a 2-week implementation phase, filling out a diary every day to assess anxiety, depression, fatigue and pain and wear an Acti-watch to record their sleep pattern and activity levels. Finally, we had planned a second meeting with participants approximately 2 weeks later to conduct the post-treatment assessment. At this point, the participant was given the option to stop participating in the study or to continue. Participants were given a further 3 options – continue using the same chosen technique for another 2 weeks, continue with the same technique and choose an additional technique to try or stop their current technique and choose technique another to try. Following these 2 weeks, participant would be invited back to conduct another post assessment interview, and again would be given the same options if they wished to continue or exit the study.

Section Summary

- Researchers were in contact with a gatekeeper, who was a senior occupational therapist within the day unit. She was responsible for participant recruitment
 - Semi-structured interviews were designed to explore participants' sleep quality, duration and use of sleep aids.
 - Participants were asked to choose one of three different CBT techniques to help their sleep and were asked to complete daily dairies and wear an Acti-watches to monitor activity levels during the 2-week intervention phase.
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Difficulty recruiting and attrition

Recruitment was one of the biggest issues we faced in this study. We attempted to anticipate potential difficulties with recruitment of these participants by using a gatekeeper (on-site senior occupational therapist within the day therapy unit) and whilst there were many advantages of having a gatekeeper (i.e. direct access to hospice staff and participants), there were also consequences. Abrams (2010) noted that researchers are forced to rely on gatekeepers, who follow rules and institutional regulations, rather than researchers' needs or goals. The gatekeeper did not have a pre-prepared script to follow when the study was first mentioned to the participant, so we were unsure what information was passed on. Also, the gatekeeper had clinical and administrative priorities, which understandably were more important than recruitment for the study. Therefore, recruitment became a lengthy and difficult process.

In the initial stages of the study, there seemed to be a great deal of interest amongst potential participants, indicating that sleep disturbance is of concern to this cohort. However, recruitment of participants was very poor and there were various reasons for this. Participant's health and hospital appointments made it difficult to organise pre and post interview meetings. One participant informed the researcher at the initial interview they had not read the participant information sheet properly, so they were not fully aware of what the study entailed. The fact that the intervention took

place over a 2 week period, made it seem long and intense for the participants, resulting in them dropping out. Other reasons included participant's health deteriorating, causing the initial interview to be cancelled. It is possible that participants' complex health issues may have adversely impacted upon their ability to carry out their chosen CBT-I techniques. Participants reported that they found it difficult to engage with the intervention due to the multiplicity of hospital appointments they were required to attend and so consequently, they were unable to complete the study.

We had planned to recruit 30 participants but only managed to recruit 5 participants in total. Of these 5 participants, participant 1 only completed half the study. This participant did not complete the post-intervention assessment interview. This was due to other commitments and hospital appointments, which made it difficult to organise the post-intervention assessment interview. As only the pre-interview assessment was completed, it was unclear whether any difference was made to this participant's levels of anxiety, depression fatigue and pain. Moreover, although feedback from participant 1 was mostly positive as he stated the intervention was helping him, it would still be unclear whether the intervention would be feasible within this cohort in general. In terms of the other participants, the main reason for non-completion seemed to be the daily diary which participants were required to fill out every day. Participant 2 found the process of recording their responses in the daily diary to be too lengthy and time-consuming. Participant 3 complained of the Acti-watch being uncomfortable and reported that they would forget to click the Acti-watch button when they needed to. She also found the daily diary to be lengthy and time consuming and complained it was becoming too much. In the initial interview, participant 4 admitted to not reading the participant information sheet properly. Once having the details of the study and explaining the daily diary and Acti-watch, they did not wish to proceed with the study. Finally, participant 5, due to health reasons had to opt out of the study before the initial interview took place.

Given these issues, we had to consider how to adapt our protocol. This involved us revisiting and revising our study aims. Rather than assessing the feasibility of a CBT-I intervention in a palliative

care setting, we decided to explore the types of sleep difficulties that arise within a palliative care context and to understand their etiology. A qualitative approach seemed most appropriate for answering these questions.

We recognise the necessity of sleep research and the need for sleep interventions in this cohort, as most of the participants reported sleep issues and were unable to access adequate resources to resolve them. While participants reported that there were various programmes in the hospice targeting overall well-being and reducing stress and anxiety, there were no sleep-specific interventions available. Therefore, whilst our revised protocol would not specifically intervene to improve their sleep problems, we felt there was merit in trying to understand the nature of sleep difficulties from the lived experiences of patients, staff and carer's. Our hope was that this may inform future sleep intervention studies within palliative care contexts.

Section Summary

- Gatekeeper had clinical and administrative priorities resulting in slow study recruitment. Therefore, recruitment was much slower than anticipated and non- completion rates were high
 - Daily Dairy was found to be lengthy, time-consuming and labor intensive. Health related issues may have impacted on participants engaging with the intervention and completing the study
 - Adaptations were made to the study protocol to better understand the difficulties regarding sleep within a palliative care context.
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Change in protocol and methodology

We recognise that whilst our attempts to conduct an intervention study for insomnia within a palliative care setting was a valuable aim, it was perhaps premature. We therefore decided to gain an in-depth understanding of the specific issues and challenges faced by palliative care staff, patients and informal carers that impact upon sleep.

Practice-based research suggests that focus groups are equal to, or better than, individual interviews for generating themes on sensitive health topics (Hyde, Hawlett, Drennon, 2005). Recent empirical evidence compared focus groups and individual interviews which collected data on help seeking behaviour. It was found that personal disclosures were more likely in focus group settings (Guest, Namey, Taylor, McKenna, 2017). With this in mind, we decided to use focus groups to capitalise on group dynamics, to stimulate discussion and gain in-depth data on the experience of insomnia within a palliative care setting (Rothwell, Anderson & Botkin, 2016). We asserted that the interpersonal and interactive nature of focus groups would allow for the generation of discussion that might not have occurred from individual interviews (Kaplowitz, & Hoehn, 2001). The direct observation of focus group discussion can provide a rich source of contextual data, with interaction between multiple participants offering the opportunity for individuals to become aware of their own thoughts and feelings (Tomkins & Eatough, 2010; Wilkinson, 2004).

We decided to run focus groups to explore the challenges and difficulties faced by patients, informal carers and hospice staff who described how they experienced sleep difficulties. Involving multiple perspectives gave us a broader understanding of sleeping difficulties within the palliative care setting. Previous research has generally supported the notion that those who work in hospices, carers and patients do experience some form of sleeping difficulty (Hawkins, Howard & Oyeboode, 2005).

Section Summary

- Change in project and methodology was required

- Direct observation of focus group discussion can provide a rich source of contextual data, with interaction between multiple participants offering the opportunity for individuals to become aware of their own thoughts and feelings
 - Decided to run focus groups to explore the challenges and difficulties faced by patients, informal carers and hospice staff who reportedly experienced sleeping difficulties
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Research Practicalities

Ethical Issues Regarding Palliative Research

The safety of both the researchers and the participants was of utmost importance throughout the development and implementation of this study. All interviews were conducted face-to-face within the hospice to ensure a safe and familiar environment with on-site clinical staff if required.

Researcher wellbeing was a potential concern due to our inexperience of working with palliative care patients, so various procedures were implemented to minimise the risk of harm. For example, close supervision was provided by two chief investigators (LF and NC) who both have extensive experience of supervising junior researchers in clinical settings. Both chief investigators monitored for any signs of distress through in-person meetings and frequent contact using email/telephone communications. They also provided debrief sessions following hospice visits and signposting to relevant service (University Counselling Service) if needed. In addition, supervision was offered by an allocated Clinical Nurse Specialist within the hospice for the duration of the study. Given that the hospice is a research-oriented establishment, the nurse was experienced in offering this type of mentorship and support. Further to this, the hospice counselling service was accessible, if required by any member of the research team.

In term of ensuring participant wellbeing, we made sure that all had access to the hospice counselling service if their participation in the study lead to any consequent distress. They were also given contact details and information of relevant external support agencies on the participant

information sheet (e.g. Samaritans and the National Sleep Foundation) and were provided with a debrief session with clinical staff within the hospice. With such safeguards in place, we were able to conduct research in this complex and sensitive field, without any undue stress to those involved.

Section Summary

- Various ethical issues needed to be considered during the implementation of this study
- Chief investigators supervised junior researchers and counselling services were made available should any researcher distress arise
- Participants had access to counselling services within the hospice and were provided with information regarding external support agencies

Focus Groups in Action

As discussed previously, we decided the best way forward was to undertake a qualitative study to collect data using focus groups. Due to the change in methodology, we thought it would be feasible to include informal carers and staff in the project as this would give a broader perspective of the sleep issues experienced within palliative care. Three focus groups were conducted separately, one with patients, one with staff and one with informal carers. Each of the focus groups consisted of 9 participants (n = 27 in total). We conducted the focus groups within the outpatient service of the hospice to ensure that participants were in a familiar and comfortable environment. Two researchers were allocated to each of the focus groups, enabling one researcher to facilitate the session whilst the other took notes and asked any additional questions not covered during the discussion. The sessions were recorded using a digital audio-recording device and each session lasted between 45 minutes to 1 hour.

As qualitative research requires a smaller number of participants and are therefore, more explorative in nature, we hoped to identify new avenues for future intervention research. In

particular, to gain insight into how best to develop future intervention study protocols to best meet the needs of the participants.

After conducting the focus groups, multiple observations were made:

- There was a 'strength in numbers' atmosphere where participants were relaxed and confident within the focus group settings. They encouraged each other to share their experiences, which helped make the focus groups feel less like an interview and more like a conversation. This approach facilitated further sharing and in-depth discussion
- Participants in each group empathised with the others in their groups and were supportive of each other and their struggles. They also tried to help each other by sharing their own experiences and the solutions they found to their issues
- Given that focus groups were held at a location participants were familiar with, it further helped to ease them into free-flowing conversation. They felt more comfortable knowing their surroundings, having visited the hospice multiple time

Section Summary

- By incorporating the perspectives of patients, informal carers and hospice staff, a broader understanding of sleep difficulties within a palliative care context was gained
 - Strength in numbers, empathy and familiarity with the location were important factors in the smooth running of the focus groups, allowing participants to feel more comfortable about sharing their experiences
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Practical Lessons Learned

The Importance of Collaboration

There are many benefits of collaboration for effective research. For example, collaboration involves the enrolment of a diverse group of participants and can result in improvements in the study design and project (Kimmey & Rich, 2014). Collaboration contributes to the quality of findings as those involved can relate to the lives of the participants, using their experienced knowledge of working with vulnerable adults (Nierse, Schipper, Zavelhoff, Griendt, et al, 2011). Furthermore, one of the main advantages of collaboration is that gatekeepers and staff can help with recruitment and in the setting up times for conducting research meetings and focus groups (Nierse et al, 2011). In our case, it was beneficial to recruit participants through the gatekeeper as they were able to identify participants that were eligible to take part in our study following clinical screening. Drawing upon staff's extensive knowledge of working with vulnerable adults, we were able to conduct the study in a professional and efficient manner. However, although there are benefits of collaboration, there were also challenges. Research has previously found communication is central to alleviating barriers and producing high quality interactions. However, communication barriers can occur (Giest-Martin, Bollinger, Weichert, Plump, et al, 2016). During the early stages of this study, some participants who initially agreed to take part then withdrew, as they reported not having read the participant information sheet properly at the outset. Communication is an integral part of working with vulnerable participants. It is important for all collaborators involved to be fully up to date and knowledgeable of the study being conducted. Collaboration in research is important to get the relevant information across to all staff members and patients (Kars, Thiel, Graaf, Moors et al, 2016). This is so all members involved within the research know how to answer any potential participant queries as accurate as they can, so when they come to the initial interview for the study, participants are aware what the study is about and what may be required from them. From here, participants may then be able to decide whether they would like to take part in the study.

Being Flexible and Adapting According to Participant Need

A key lesson learned from this study was the importance of being flexible and adaptable according to the participants' needs. From the initial feedback we received from participants from the intervention phase of the study, we learned that we would need to simplify and reduce the intensity of intervention protocols in future intervention research within palliative care. We also learned that through involving both staff and informal carers in future CBT-I studies, we would be able to gain better support for participants to implement the intervention protocol. Recognising that sleep difficulties were widespread within the palliative care context, helped us consider how future intervention studies could also be explored with informal carers and staff as well as patients within palliative care.

Section Summary

- Collaboration is essential for research as it involves the enrolment of a diverse group of participants and produces improvements in the study design and project
- Experienced staff who work with vulnerable participants often have great insight into participant's needs and in turn provide the best, most comfortable environment when participating in research
- Effective communication is essential throughout the conduct of research
- Adaptions to current protocol would need to be considered for future work in this area

Conclusion

Conducting interventional research for sleep difficulties within palliative care produced many challenges. However, we remain convinced that this is an extremely important area for future research. Although many issues were faced, we learned a great deal about insomnia within palliative care and the experience of adopting various research methods throughout the process. The importance of collaboration, flexibility and adapting research protocols in order to be responsive to participants' needs were important lessons learned. Such insights will inform the development of

future intervention studies, not only within palliative care, but also in other clinical and community-based settings.

Section Summary

- Research in palliative care is complex and involves collaboration and flexibility
 - It is important to be able to adapt research protocols according to participants' needs
 - The lessons learned from the current research will inform future intervention research within clinical and community-based settings
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Classroom Discussion Questions

1. Taking into consideration the challenges faced when conducting this research, how would you alter future research for palliative care?
 2. Provide a detailed description of the ethical issues that need to be considered when conducting research within palliative care.
 3. Critically appraise the different types of methods used in the research study
 4. Describe the pro's and con's of quantitative and qualitative approaches to collecting data within palliative care.
 5. Critically evaluate the need for future research on insomnia within palliative care
 6. Taking into consideration the challenges faced by the current research team when conducting palliative research, how would you respond to the difficulties faced in conducting intervention research?
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Multiple Choice Quiz Questions

1. What kind of research method provides in depth and detailed knowledge about a certain topic being investigated?
 - a. Quantitative Methodology
 - b. Observational Methodology
 - c. Qualitative Methodology

2. Why is it important to have ethical considerations in place when working with a vulnerable population?
 - a. To ensure safety for all parties involved (researchers, participants, chief investigators etc.). Any distress which may be caused, appropriate services and contact details should be made available.
 - b. Ethic's is not a concern as long the participants are not aware of what you are doing
 - c. To make sure you behave in a professional, consistent and empathic manner towards the vulnerable population.

3. What should you NOT do in regards of ethical research
 - a. Treat any human or animal participants with care and respect adhering to ethical guidelines
 - b. Deceive any participant involved by giving them misleading/false information
 - c. Respect participant confidentiality

4. What is the advantage of using focus groups?

- a. You can gain in depth and detailed information about personal/group feelings, perceptions and opinions
 - b. They are not time consuming
 - c. Inexpensive and fast
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Declaration of Conflicting Interests

The authors declare that there is no conflict of interest

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