

BMJ Open Nurses' decision-making about cancer patients' end-of-life skin care in Wales: an exploratory mixed-method vignette study protocol

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To cite: Samuriwo R, Lovell-Smith C, Anstey S, *et al.* Nurses' decision-making about cancer patients' end-of-life skin care in Wales: an exploratory mixed-method vignette study protocol. *BMJ Open* 2020;**10**:e034938. doi:10.1136/bmjopen-2019-034938

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2019-034938>).

Received 11 October 2019
Revised 03 April 2020
Accepted 03 June 2020



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ABSTRACT

Introduction Patients with cancer are at high risk of developing pressure ulcers at the end of life as a result of their underlying condition or cancer treatment. There are many guidelines which set out best practice with regard to end-of-life skin care. However, the complexity of palliative cancer care often means that it is challenging for nurses to make the appropriate person-centred decisions about end-of-life skin care. This study seeks to explore the perceived importance that nurses place on different factors in their end-of-life skin care for patients with cancer. The utility, face validity and content validity of a prototype decision-making tool for end-of-life skin care will also be evaluated.

Methods and analysis A mixed-method design will be used to gather data from primary and secondary care nurses working in different hospitals and local authority areas across Wales. Clinical vignettes will be used to gather qualitative and quantitative data from nurses in individual interviews. Qualitative data will be subject to thematic analysis and quantitative data will be subject to descriptive statistical analysis. Qualitative and quantitative data will then be synthesised, which will enhance the rigour of this study, and pertinently inform the further development of an end-of-life skin care decision-making tool for patients with cancer.

Ethics and dissemination Ethical approval to undertake the study has been granted by Cardiff University School of Healthcare Sciences Research Governance and Ethics Screening Committee. Informed consent will be obtained in writing from all the participants in this study. The results of this study will be disseminated through journal articles, as well as presentations at national and international conferences. We will also report our findings to patient and public involvement groups with an interest in improving cancer care, palliative care as well as skin care.

INTRODUCTION

Poor decision-making by healthcare professionals about key aspects of skin care such as patient repositioning causes or contributes to pressure ulcer formation especially in patients approaching the end of life.^{1,2} Healthcare professionals often make challenging decisions about key aspects of

Strengths and limitations of this study

- Vignettes are an abstraction of reality, which are an effective way to explore ethically complex aspects of healthcare such as cancer patients' end-of-life skin care.
- Decisions based on a vignette may not reflect decisions in real life.
- Clinical vignettes that describe typical patients with cancer in clinical practice will be used to explore the impact of different factors on nurses' end-of-life skin care-related decision-making.
- Our mixed-method approach will provide an insight into the relative importance that nurses place on different factors in their end-of-life skin care decision-making for patients with cancer.
- This study will establish the face validity, content validity and utility of a prototype end-of-life skin care decision-making tool.

end-of-life skin care such as whether or not to reposition a patient which may inadvertently cause distress or discomfort in palliative care patients at the end of life.^{1,2} Uncertainty about the goals of treatment, inappropriate presumptions or a desire to adhere to the prevailing clinical ethos in a given context can precipitate flawed skin care-related decision-making concerning patients receiving palliative care.¹⁻³ There are many guidelines⁴⁻⁸ and publications^{9,10} which are designed to inform healthcare professionals' decisions about end-of-life skin care. These national and international guidelines⁴⁻⁸ set out the prevailing consensus on best practice with regard to end-of-life skin care, which maintains skin integrity for as long as possible and facilitates a dignified death that is in line with the patient's preferences. However, studies^{1,2} from different contexts have identified that there can be conflict between the goals of palliative care, and pressure ulcer prevention, such as different perspectives on the



frequency of patient repositioning, which contributes to poor decision-making and results in the delivery of inappropriate end-of-life skin care.

Patient care is delivered in healthcare systems that are inherently complex and adaptive, which can impinge on healthcare professionals' ability to make decisions about patient care in line with the guidelines for best practice.^{11–13} The complexity of clinical practice often makes it challenging for individual healthcare professionals to gather and marshal pertinent information with an appropriate mental focus to make the best possible decisions about patient care.^{12 13} Health professionals' decision-making at any point in the care trajectory is combination of judgements and decisions about the best course of action to maintain skin integrity with due respect for the patient's preferences.^{2 14} Nurses can find it challenging to make appropriate patient centred decisions about end-of-life skin care due to uncertainty about the goals of care, as well as undue concerns about unsettling or causing distress to the person receiving care and their family.^{1 2 15}

Patients receiving palliative care, especially those with cancer, are at high risk of developing pressure ulcers due to the underlying pathophysiology of the disease process, treatment side effects or therapeutic interventions.^{3 16–18} Clinicians' decisions about end-of-life patient care are influenced by a variety of factors relating to symptom management, the efficacy and/or acceptability of treatment interventions, the type/intensity of care that is required, as well as the wishes of the patient and family.^{19–22} Healthcare professionals are expected to make decisions that underpin the delivery of end-of-life care that is consistent with, and is a paramount factor regarding what the patient and their family consider to be a dignified death.^{23 24} Empirical evidence from a variety of studies^{25–28} demonstrates the utility of decision support tools and systems in fostering the consistent delivery of safe high-quality patient care. In a previous unpublished study,²⁹ we developed a prototype decision-making tool with key principles and maxims that can be used as an informative guide concerning the appropriate the end-of-life skin care for patients with cancer. The face and content validity, as well as the utility of this prototype end-of-life skin care decision-making tool for patients with cancer²⁹ needs to be established before the feasibility of integrating it into practice can be considered.

Aims

The aims of this vignette study are to:

1. Explore the perceived importance of different factors in nurses' end-of-life skin care-related decision-making for patients with cancer.
2. Establish the utility, face and content validity of a prototype end-of-life skin care decision-making tool.
3. Summarise the key factors to be integrated into a revised nurse decision-making tool for the end-of-life skin care of patients with cancer.

Theoretical framework

Skin care-related decision-making is influenced by a healthcare professional's expertise and ability to accurately assess the needs of the patient before selecting the most appropriate course of action.^{2 30} Making decisions about skin care and end-of-life care is often challenging and complex due to the variety of individual, organisational, contextual and patient-related factors that have to be taken into account.^{2 30–32} A significant consideration for any healthcare professional or person making a decision about some aspect of end-of-life care is how to deliver care which maximises the quality of life for the patient and facilitates a dignified and 'good death'.^{33 34} However, the delivery of end-of-life skin care can be challenging because there is uncertainty about the extent to which some measures to maintain skin integrity such as regular repositioning can have unintended consequences such as distress or discomfort which are not compatible with a dignified 'good death'.^{1 2} Defining what constitutes a good death is subjective as perceptions of dying well are socially and culturally mediated.^{32 34}

The term good death serves as an organising construct which can be understood in different ways depending on the socio-cultural, philosophical and intellectual perspective that is adopted.^{35–37} Given that dying well and a good death are socially constructed, we have adopted a philosophical position that we feel is the most appropriate to inform the design of this study. This study will be undertaken in the critical realist paradigm with a realist ontology and abductive epistemology.^{38–40} In line with our philosophical stance, this study will integrate empirical data with an interpretive outlook and a focus on theoretical abstraction. Data collection and analysis in this study will be informed by information processing theory,^{41 42} which conceptualises decision-making as being subject to the limits of a person's memory, knowledge and expertise. The use of information processing theory is congruent with the aim of this study as it focuses on understanding the basis of nurses' end-of-life skin care-related decision-making with due recognition of their differing levels of knowledge and expertise.

METHODS AND ANALYSIS

Design

We will conduct a concurrent mixed-method study^{38 43 44} that will use clinical vignettes to:

- Explore the perceived importance of different factors in nurses' end-of-life skin care-related decision-making for patients with cancer.
- Establish the utility, face and content validity of a prototype end-of-life skin care decision-making tool.
- Summarise the key factors to be integrated into a revised nurse decision-making tool for the end-of-life skin care of patients with cancer.

Patient and public involvement

This protocol was co-produced with patient and public involvement (PPI) in line with standards^{45–47} for best

practice in research. The design of this study was informed by research priorities developed through wider PPI in relation care,⁴⁸ pressure ulcer prevention,⁴⁹ and end-of-life care.⁵⁰ The PPI representative on the research team (CL-S) has also been involved in every aspect of the study including the formulation of the research question and study design. CL-S' expertise as the family member of a patient with cancer that received palliative care will underpin our analysis and interpretation of the data. The contribution of CL-S is fundamental to this study as the overarching focus of palliative care, including end-of-life skin care, is on facilitating what the patient and their family consider to be a dignified death.^{23 24} We will discuss our preliminary results with national and regional cancer care PPI groups such as the North Wales Cancer Patient Forum⁵¹ which functions as a voice for patients with cancer and carers in a Welsh region. We will use the feedback from these PPI groups to inform our interpretation of the study results.

Study population and sample

We will recruit palliative, oncology tissue viability and district nurses with experience of delivering end-of-life skin care to patients with cancer from 19 hospitals and 8 local authorities in Wales. A stratified purposive sample^{43 44} of nurses across different professional bands will be recruited from a diverse range of clinical settings in order to generate the broadest possible insights. We intend to recruit 20–30 palliative, oncology, tissue viability and district nurses but the exact number of participants will be determined by the point at which we have recruited a sufficiently diverse sample of participants with insight into end-of-life care from the study population to enhance the applicability of our results to nurses working in different clinical settings as well in line with best practice in mixed-method research.^{38 43 44} The projected sample size for this study is in keeping with the number of participants that have been used to successfully develop and refine decision-making tools in other studies.^{25 52} Potential participants will be sent details about our study together with a participant information sheet via email by the research and development department in each organisation. Nurses who are interested in taking part in the study will be asked to email or telephone the chief investigator (RS) to make suitable arrangements to get their written informed consent and gather data.

Data collection

Semi-structured individual interviews will gather data about nurses' decision-making concerning end-of-life skin care for patients with cancer in a general sense and in relation to clinical vignettes (see [table 1](#)). Participants will be interviewed at a pre-arranged date and time that is convenient for the participants in a room away from the clinical setting to ensure privacy and confidentiality. The interviews, which are expected to last for 30–45 min, will be digitally audio recorded and transcribed verbatim.

Table 1 Exemplar vignette

NB: The information in this vignette is hypothetical and any similarities to an actual patient are purely coincidental

Name	Rhys
Gender	Male
Age	70
Medical history	Lung cancer with metastatic spinal cord compression (T4 and T5) Ischaemic heart disease Chronic obstructive pulmonary disease Catheterised
Key information	The patient has been deemed to be approaching the end of life and his care is being informed by national guidelines and quality standards for care of the dying. This patient is not for cardio-pulmonary resuscitation. The patient is on a syringe driver with cyclizine, midazolam and hyoscine. He has a grade 2 pressure ulcer on sacrum and heels for dressing changes every 3 days. The patient does not have any immediate family and he previously stated that he wishes to receive care that enhances his quality of life.

Participants will be asked questions about their experiences about the delivery of end-of-life skin care and to rate the relative importance of different factors in decisions about this aspect of patient care using a numerical rating scale. Five vignettes and a prototype decision-making tool will also be used to explore the participants end-of-life skin care-related decision-making. The interview schedule, items to be rated and the clinical vignettes have all been informed by an earlier as yet unpublished study.²⁹ Data will be gathered during the interviews with five vignettes as this has been shown to be the optimal number needed to gather data in other decision-making studies.^{53 54} Vignettes are a good way of gathering data about different elements of healthcare professionals' decision-making.^{25 53} The process of data collection is summarised in the flow diagram in [figure 1](#).

In order to establish the face validity, content validity and utility of the prototype decision-making tool, half of the participants will be given the prototype decision-making tool alongside the vignettes and asked to decide how best to deliver end-of-life skin care in relation to each vignette. The participants that are asked to use the prototype decision-making tool to inform their decisions about end-of-life skin care will be asked additional questions about its face validity, content validity, utility and relevance. The other half of the participants will be given the vignettes and asked to decide how best to deliver end-of-life skin care using their clinical judgement. The

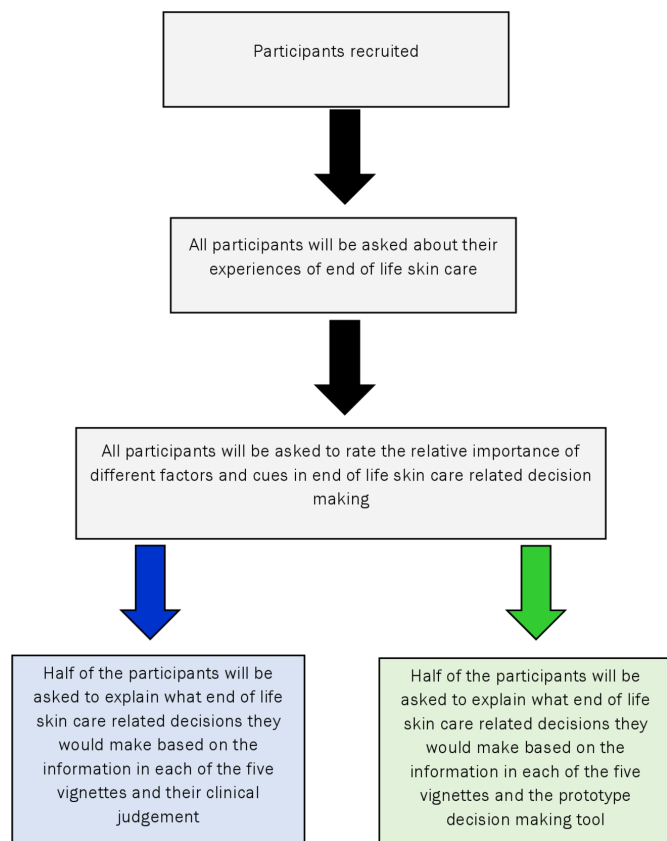


Figure 1 Data collection flow diagram.

participants who are asked to use their clinical judgement in reviewing the vignettes will be asked to explain how they made their decision, as well as what they think an end-of-life skin care decision-making tool should look like, and to describe the elements that would enhance its face validity, content validity, utility and relevance.

The use of two groups, one with a prototype decision-making tool and the other without has been shown to be an effective way of ascertaining the content validity, face validity and utility of a decision-making tool in previous research.²⁵ In order to ensure that the participants set out their views as honestly as possible, all of the participants will be informed that the *focus of this study is not on* the accuracy of their decision-making about the delivery of skin care at the end of life; but the specific focus of this study is on how they make decisions. The relatively small number of participants in this exploratory mixed-method study limit the extent to which we can make any meaningful statistical comparisons between the participants in the two groups. Therefore, we will look for differences in content validity, face validity and perceived utility of the prototype decision-making tool between the participants in the two groups in our synthesis of qualitative and quantitative data which can be further examined in subsequent research.

Data analysis

Our mixed-method approach study^{38 43 44} is designed to ascertain if the end-of-life skin care-related decision-making

factors identified in an earlier study,²⁹ are pertinent and relevant to nurses working in other contexts through qualitative data, while the quantitative data will provide an insight into to their perceived relative importance of different factors. It is important to establish the factors that nurses take into account in end-of-life skin care-related decision-making as this may be linked to the reported shortcomings in patient care.¹² In line with our mixed-method approach^{38 43 44} and the aims of this exploratory study, data will be analysed in a three step process:

1. *Thematic analysis* to provide an insight of the perceived important of different factors in nurses' end-of-life skin care-related decision-making for patients with cancer. The thematic analysis help to ascertain the utility, face and content validity of a prototype end-of-life skin care decision-making tool.
2. *Descriptive statistical analysis* to generate descriptive summaries of the rankings of different factors that influence nurses end-of-life skin care-related decision-making.
3. *Synthesis and interpretation* to compare the numerical rankings and the narrative provided by each the participants about the relative importance of different factors in relation to end-of-life skin care-related decision-making. This in turn will enable us to summarise the key factors to be integrated into a revised nurse decision-making tool for the end-of-life skin care of patients with cancer.

This approach to data analysis and triangulation will enable us to achieve our aims in line with the underpinning philosophy of this study and will inform the further development of our prototype end-of-life skin care decision-making tool for the end-of-life skin care of patients with cancer. We will now set out each step of data analysis in more detail.

Stage 1: thematic analysis

We will undertake thematic analysis^{55 56} of qualitative interview data and field notes informed by information processing theory.^{41 42} Thematic analysis will be facilitated by the qualitative computer analysis package NVivo V.11. Our thematic analysis of qualitative data generated is apt, as it generates insights into the themes and relationships that underpin the functioning, organisation or impact of the phenomena under investigation.^{43 56} Our thematic analysis will focus on the perceived importance of different factors in nurses' end-of-life skin care-related decision-making for patients with cancer and establishing the face validity, content validity and utility of a prototype end-of-life skin care decision-making tool. This focus in thematic analysis will enable us to summarise the key factors to be integrated into a revised nurse decision-making tool for the end-of-life skin care of patients with cancer.

Thematic analysis will be conducted in an iterative process that is set out in a linear format in figure 2. The iterative collection and thematic analysis of qualitative data will facilitate the development of theoretical and conceptual insights about nurses' end-of-life skin care decision-making

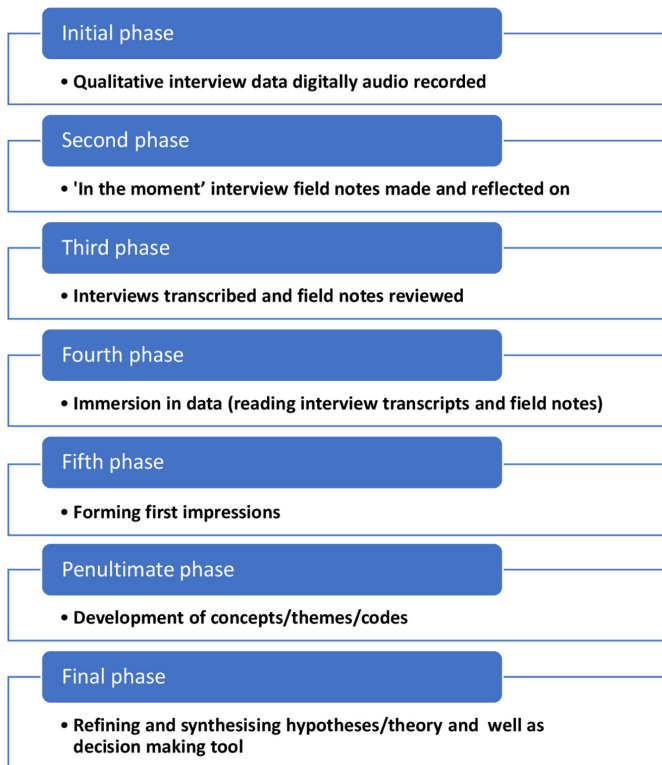


Figure 2 Flow chart for thematic analysis.

which can be further developed as data collection progresses. Qualitative data generated in this study will be coded at the lowest level possible according to the tenets of thematic analysis to offset the danger of forcing data to fit codes and broad vague themes that do not relate to the topic of.^{43 57} Initial data analysis will be undertaken by the chief investigator (RS) and independently reviewed by the other members of the research team to verify the primary researcher's interpretation. Any differences of opinion with regards to the analysis or interpretation of qualitative data will be resolved by negotiation until a consensus is reached. The analysis of qualitative data will enable us to explore the utility face and content validity of the prototype end-of-life skin care decision-making tool.

Reflexivity

The researcher's expertise influences the analysis and interpretation of qualitative data.^{44 58} Reflexivity surfaces the impact of the researcher's influence on qualitative research, which aids evaluation of the credibility and transferability of a study.^{43 44 58} Reflexive journals and team meetings also enhance the rigour of qualitative studies.^{43 59} A reflexive journal will be kept by the researcher (RS) conducting the interviews and initial data analysis. The research team will also hold reflexive meetings where the impact of their differing perspectives on the interpretation of the qualitative data will be discussed. This is important as the members of our research team possess expertise in different areas, that is, decision-making (RS), patient and public perspective (CL-S) as well as cancer, palliative and supportive care (SA, CJ, JH).

Table 2 Key factors for end-of-life skin care decision-making adapted from Samuriwo *et al*²⁹

Factors	Rating
1. (Nurse) Beliefs (about pressure ulcers and end-of-life skin care)	
2. (Nurse) Emotions and feelings	
3. (Nurse) Expertise and education	
4. Advice from colleagues	
5. (Nursing) Care co-ordination	
6. Clinical routine and medical devices	
7. (Pressure ulcer and end of life) Documentation	
8. (Pressure ulcer related) Quality assurance processes	
9. Severity of pressure ulcer	
10. (Nurse) Workload	
11. (Patient) Comfort	
12. (Patient) Dignity	
13. (Patient) Emotional well-being	
14. (Patient) Autonomy	
15. Patient preference	
16. (Patient) Physiological status	
17. Conversations (with patient's family) and care delivery	
18. (Family) Emotions and views	
19. (Family) Participation in care	

What do you think is the relative importance of these different factors in nurses' decision-making about end-of-life skin care on a scale of 1–10 if one is the least important and 10 is the most important? (Please bear in mind that you can give the same rating to more than one factor or cue).

Stage 2: descriptive statistical analysis

We will conduct descriptive statistical analysis^{60–63} of quantitative ranking data facilitated by SPSS V.23^{63–65} in order to describe and summarise the relative importance that the participants place on different factors. Participants will be asked to rate the relative importance of different end-of-life skin care-related factors from an earlier study²⁹ with palliative care nurses working in a specialist cancer care setting, using a series of vignettes using a numerical rating scale (see [table 2](#)). This rating exercise will generate quantitative data about the perceived relative importance of different end-of-life skin care-related factors in nurse decision-making.

Our descriptive statistical analysis^{60–63} will generate descriptive summaries of the rankings that the participants place on different factors in nurses' end-of-life decision-making (see [table 2](#)). This exploratory study has a small sample of participants, which makes it challenging to make any meaningful comparisons between the group of nurses who use clinical judgements and the nurses who use the prototype decision-making tool. Consequently, our descriptive quantitative analyses will

seek to report any differences that merit exploration in a subsequent study with a larger and more representative sample. The descriptive statistical analyses of the numerical ratings given to different factors will identify those with the highest and lowest scores, thus providing an insight into their perceived relative importance. In line with the tenets of descriptive analysis,^{60–63} salient elements of the data will be presented in descriptive summaries in relation to each factor which will highlight the relative importance of different factors in relation to frequency, mean, median and range. The data summaries for each individual factor will be presented in graphs that will be presented as appendices to the main paper.

Stage 3: synthesis and interpretation

In the final stage of our mixed-method^{43 44} data analysis approach, the themes identified in the qualitative data will be integrated with the descriptive summaries generated from the quantitative ranking. In this stage, rich qualitative data will be synthesised with the quantitative descriptive summaries of rankings in a coherent non-statistical discussion of the results on related hypotheses. Our approach to synthesis is congruent with the triangulation of qualitative and quantitative data in a concurrent mixed-method study.^{38 43 44}

Our approach to synthesis is consistent with the principle of triangulation in concurrent mixed-method research^{38 43 44} which enhances the validity and completeness of the results. In other words, our synthesis of qualitative and quantitative data is in keeping with the principles of concurrent mixed-method research^{38 43 44}, which is designed to enable us to interpret all of the results from both sets of data in order to develop internally confirmed conclusions about the perceived relative importance of different factors in nurses end-of-life skin care-related decision-making. Triangulation of qualitative and quantitative data in this manner has been used in other mixed-method studies^{25 66 67} to develop and refine decision-making tools. The synthesis of data in this manner will generate insights into the face validity, content validity and utility of the prototype decision-making tool. The synthesis of qualitative and quantitative data will also enable us to summarise the key factors to be integrated into a revised nurse decision-making tool for the end-of-life skin care of patients with cancer.

We will also seek to establish if there are any patterns between the roles of the nurses who take part in this study and the ratings that they give to different factors. In other words, the rationale provided by the participants for their rankings in the qualitative data will be compared with their numerical rankings in the quantitative descriptive summaries. Triangulating qualitative and quantitative data in this manner during synthesis will highlight if there are any differences in the numerical rankings given by the participants as a result of their role or any other aspects of their practice that merit further exploration in subsequent research. The comparison between the qualitative and quantitative data relating to

the rankings during synthesis will also provide us with a more detailed insight into the utility of the tool in their decision-making.

Synthesis of the two types of data in this manner has added importance because the extent to which people think that they make undertake decisions in a rational or intuitive manner often differs from how they make decisions especially about end-of-life care.^{31 68 69} Triangulating qualitative and quantitative data in mixed-method studies provides a more complete internally confirmed insight into phenomenon of interest,^{38 43 44} which in this case is the face validity, content validity and utility of the prototype decision-making tool. Simply put, combining the qualitative and quantitative data in this manner will highlight if there are any differences in the numerical rankings given by the participants as a result of their role or any other aspects of their practice that merit further exploration in subsequent research.

Ethics and dissemination

Written informed consent will be obtained from all participants in this study. Every participant will be provided with information about the study in a participant information sheet that will provide details about how they can raise any concerns about the study to the Cardiff University School of Healthcare Sciences Research Governance and Ethics Screening Committee. The participant information sheet will fully outline the potential benefits and burdens associated with study participation, and the informed consent process will ensure that this has been further understood. If any specific difficult issues or concerns related to care or their individual participant experiences are identified during the interviews, participants will be offered the opportunity to debrief after the interviews using a reflective approach to explore any issues relating to best practice in dealing with clinical experiences related to end-of-life care. Participants will also be signposted to support services for nurses provided by organisations such as the Royal College of Nursing.

Our approach to dissemination will be multifaceted to ensure that the results of this study are shared with as many different people as possible. The results of this study will be reported to national and regional cancer care PPI groups. We will also disseminate our results through presentations at local, national and international conferences as well as a paper submitted to a peer reviewed journal. We will share our provisional findings with national and regional cancer care PPI groups who will advise us on how best to present our findings with due consideration of the perspective of patients with cancer and their families. We will also prepare a plain English summary of this study that will be disseminated to the public through charities and organisations that engage with the public in improving the quality of cancer and wound healing care. A press release of the study will be shared with the public via news, print and online media to raise awareness about our findings.

Data storage and retention

This study will adhere to research governance guidance and the law on data protection legislation with regards to the storage and retention of data. All study data will be anonymised and stored in university computers that are password protected or in locked cabinets in secure university buildings.

Data sharing

Data from this study will be available on request in line with research governance policy and data protection legislation in response to a reasonable request.

DISCUSSION

This exploratory vignette study will inform the further development of a decision-making tool that can be used in primary and secondary care to enable nurses to make the most appropriate end-of-life skin care-related decisions for patients with cancer. Ultimately, this study will generate knowledge that can be used to inform and underpin efforts to improve nurses' ability to deliver person-centred end-of-life skin care for patients with cancer who are at high risk of developing pressure ulcers during the dying process.^{3 16} It will address some of the reported issues^{1 2 15} relating to nurse decision-making, which result in unwarranted variations or shortcomings in end-of-life skin care.

This study will ascertain the relative importance of different factors that influence nurses' end-of-life skin care-related decision-making for patients with advanced cancer. This study will also explore the utility, face and content of a prototype decision-making tool. Consequently, we contend that this study will address a key gap in knowledge and generate conceptual insights that can be used to improve the end-of-life skin care of patients with cancer. This is the first study undertaken, to the best of our knowledge, that has sought to further develop an end-of-life skin care decision-making tool specifically designed for use by nurses who look after patients with cancer.

In our view, this exploratory study will provide novel insights that can be used by nurses to consistently make the most appropriate decisions about the end-of-life skin care for patients with cancer. Further research will be needed to establish the feasibility and acceptability of using the revised end-of-life skin care decision-making tool by nurses, patients with cancer and their families. It is also envisaged that subsequent research will need to consider how a revised end-of-life skin-related decision-making tool can be integrated into the wider organisation and delivery of palliative care to patients with cancer. We anticipate that our study will have wider significance, and potentially an international impact, in informing efforts to improve end-of-life skin care for all patients.

Current status of the study

Data collection began in April 2019 and results are expected in September 2020

Acknowledgements We would like to thank Dr David Gillespie for providing guidance on statistical analysis which informed the design of this study. We are also grateful to Dr Andrew Carson-Stevens for the conversations and discussions which inspired this study.

Contributors First draft of the manuscript written by RS and CL-S. RS, SA, CL-S, CJ and JH are co-applicants on the grant that funds this study. The study was conceived and designed by RS, SA, CL-S and JH. CL-S is a patient and public involvement (PPI) representative who contributed to the study design. RS, SA, CL-S and JH contributed to the development of the vignettes and rating exercise that will be used to gather data. Every author contributed to the drafting of this manuscript. This manuscript was agreed by RS, SA, CL-S, CJ and JH.

Funding This work was funded by the Aneurin Bevan and Cwm Taf Morgannwg University Health Boards under Health and Care Research Wales' Pathway to Portfolio Funding scheme. However, the views and opinions expressed therein are those of the authors and do not necessarily reflect those of Aneurin Bevan or Cwm Taf Morgannwg University Health Boards. No funding bodies had any role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Cardiff University School of Healthcare Sciences Research Governance and Ethics Screening Committee. The protocol for this study was reviewed by Health and Care Research Wales (HCRW) (reference number 18/HCRW/0014/IRAS project ID253097) and granted research governance approval by participating Welsh healthcare organisations.

Provenance and peer review Not commissioned; externally peer reviewed.

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