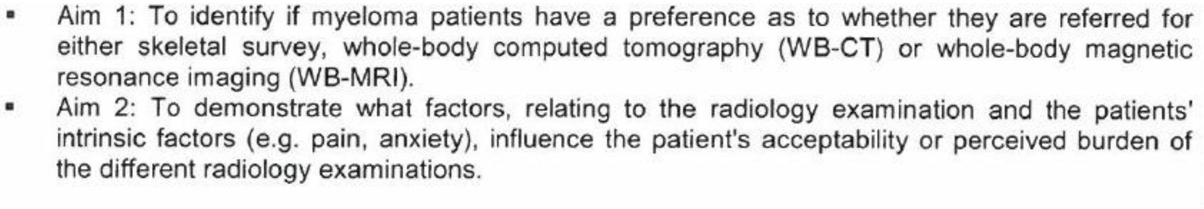
Adam Ryder

CoRIPS Research Grant 177

£1,715.46 awarded

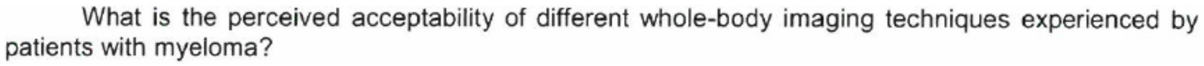
Title: A Survey Study to Investigate Patient Perceptions of Whole-Body Imaging Used in the Diagnosis of Multiple Myeloma

Principle Aim



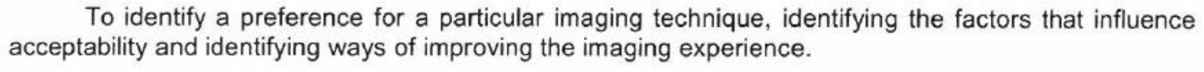
- Aim 1: To identify if myeloma patients have a preference as to whether they are referred for either skeletal survey, whole-body computed tomography (WB-CT) or whole-body magnetic resonance imaging (WB-MRI).
- Aim 2: To demonstrate what factors, relating to the radiology examination and the patients' intrinsic factors (e.g. pain, anxiety), influence the patient's acceptability or perceived burden of the different radiology examinations.

Primary research question



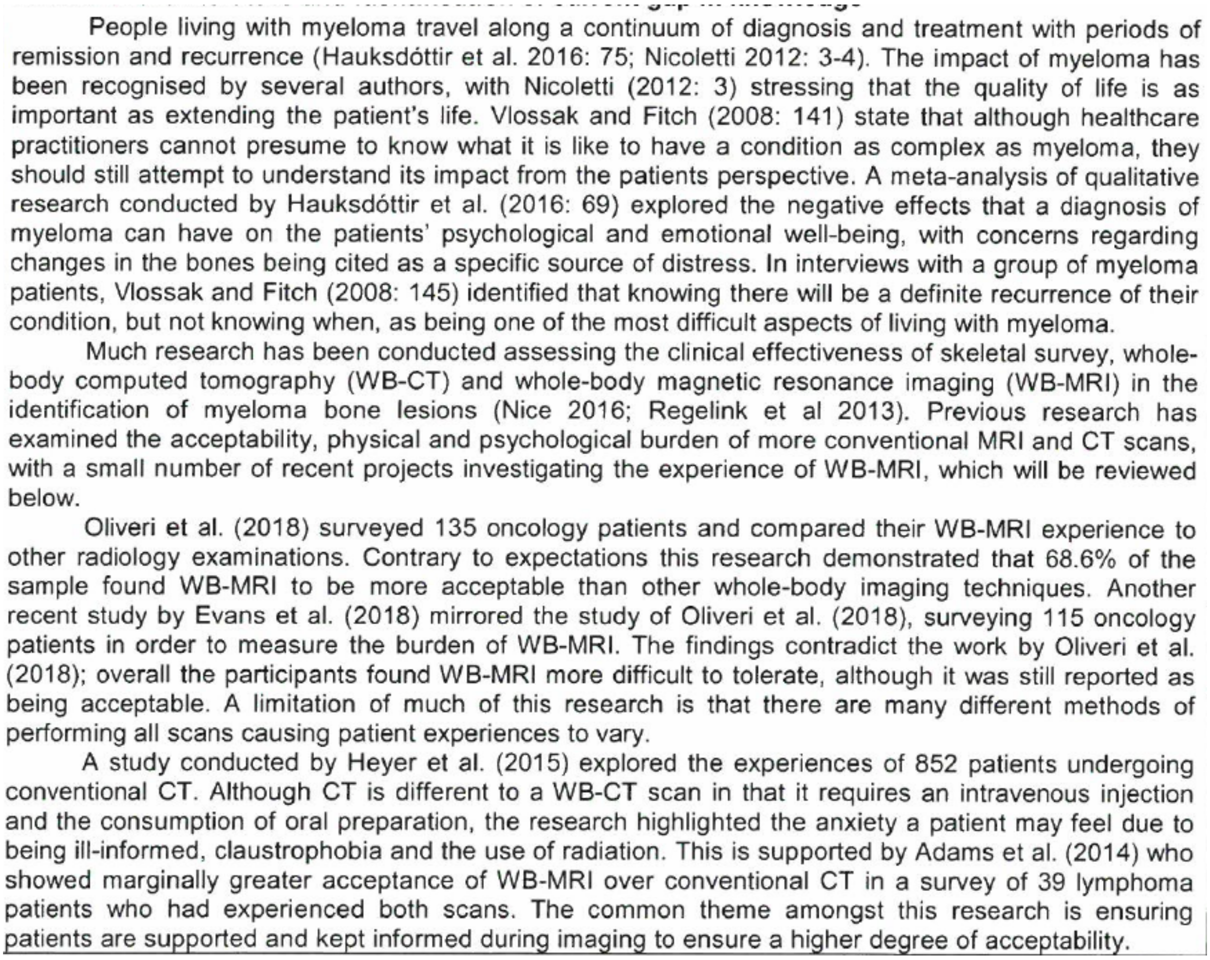
What is the perceived acceptability of different whole-body imaging techniques experienced by patients with myeloma?

Outcomes



To identify a preference for a particular imaging technique, identifying the factors that influence acceptability and identifying ways of improving the imaging experience.

Review of literature and identification of current gap in knowledge

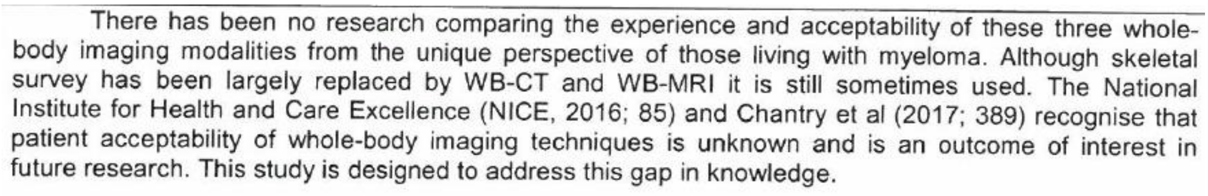


People living with myeloma travel along a continuum of diagnosis and treatment with periods of remission and recurrence (Hauksdóttir et al. 2016: 75; Nicoletti 2012: 3-4). The impact of myeloma has been recognised by several authors, with Nicoletti (2012: 3) stressing that the quality of life is as important as extending the patient's life. Vlossak and Fitch (2008: 141) state that although healthcare practitioners cannot presume to know what it is like to have a condition as complex as myeloma, they should still attempt to understand its impact from the patients perspective. A meta-analysis of qualitative research conducted by Hauksdóttir et al. (2016: 69) explored the negative effects that a diagnosis of myeloma can have on the patients' psychological and emotional well-being, with concerns regarding changes in the bones being cited as a specific source of distress. In interviews with a group of myeloma patients, Vlossak and Fitch (2008: 145) identified that knowing there will be a definite recurrence of their condition, but not knowing when, as being one of the most difficult aspects of living with myeloma.

Much research has been conducted assessing the clinical effectiveness of skeletal survey, whole-body computed tomography (WB-CT) and whole-body magnetic resonance imaging (WB-MRI) in the identification of myeloma bone lesions (Nice 2016; Regelink et al 2013). Previous research has examined the acceptability, physical and psychological burden of more conventional MRI and CT scans, with a small number of recent projects investigating the experience of WB-MRI, which will be reviewed below.

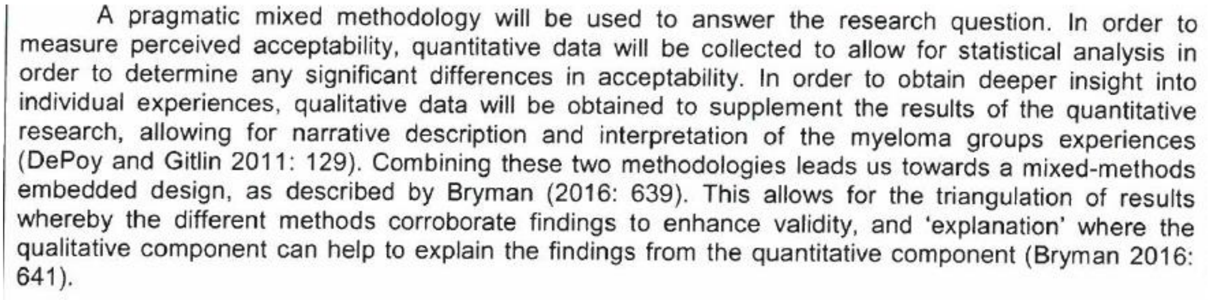
Oliveri et al. (2018) surveyed 135 oncology patients and compared their WB-MRI experience to other radiology examinations. Contrary to expectations this research demonstrated that 68.6% of the sample found WB-MRI to be more acceptable than other whole-body imaging techniques. Another recent study by Evans et al. (2018) mirrored the study of Oliveri et al. (2018), surveying 115 oncology patients in order to measure the burden of WB-MRI. The findings contradict the work by Oliveri et al. (2018); overall the participants found WB-MRI more difficult to tolerate, although it was still reported as being acceptable. A limitation of much of this research is that there are many different methods of performing all scans causing patient experiences to vary.

A study conducted by Heyer et al. (2015) explored the experiences of 852 patients undergoing conventional CT. Although CT is different to a WB-CT scan in that it requires an intravenous injection and the consumption of oral preparation, the research highlighted the anxiety a patient may feel due to being ill-informed, claustrophobia and the use of radiation. This is supported by Adams et al. (2014) who showed marginally greater acceptance of WB-MRI over conventional CT in a survey of 39 lymphoma patients who had experienced both scans. The common theme amongst this research is ensuring patients are supported and kept informed during imaging to ensure a higher degree of acceptability.

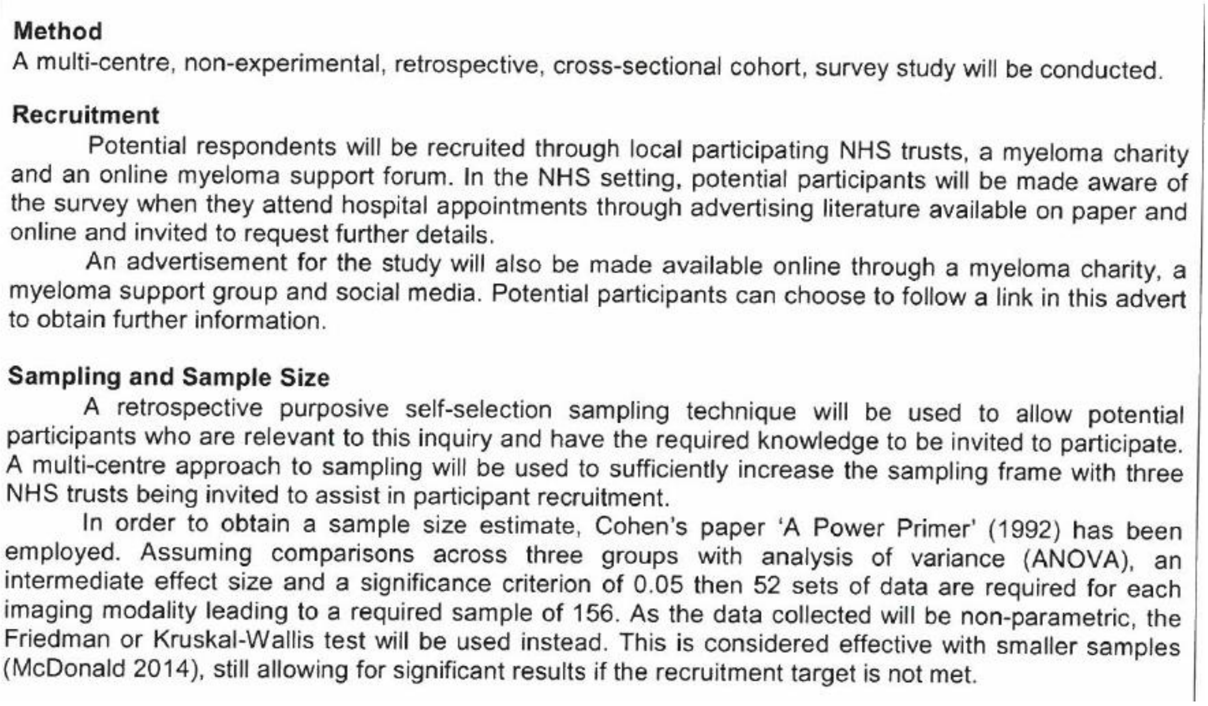


There has been no research comparing the experience and acceptability of these three whole-body imaging modalities from the unique perspective of those living with myeloma. Although skeletal survey has been largely replaced by WB-CT and WB-MRI it is still sometimes used. The National Institute for Health and Care Excellence (NICE, 2016; 85) and Chantry et al (2017; 389) recognise that patient acceptability of whole-body imaging techniques is unknown and is an outcome of interest in future research. This study is designed to address this gap in knowledge.

Methodology



A pragmatic mixed methodology will be used to answer the research question. In order to measure perceived acceptability, quantitative data will be collected to allow for statistical analysis in order to determine any significant differences in acceptability. In order to obtain deeper insight into individual experiences, qualitative data will be obtained to supplement the results of the quantitative research, allowing for narrative description and interpretation of the myeloma groups experiences (DePoy and Gitlin 2011: 129). Combining these two methodologies leads us towards a mixed-methods embedded design, as described by Bryman (2016: 639). This allows for the triangulation of results whereby the different methods corroborate findings to enhance validity, and 'explanation' where the qualitative component can help to explain the findings from the quantitative component (Bryman 2016: 641).



Method

A multi-centre, non-experimental, retrospective, cross-sectional cohort, survey study will be conducted.

Recruitment

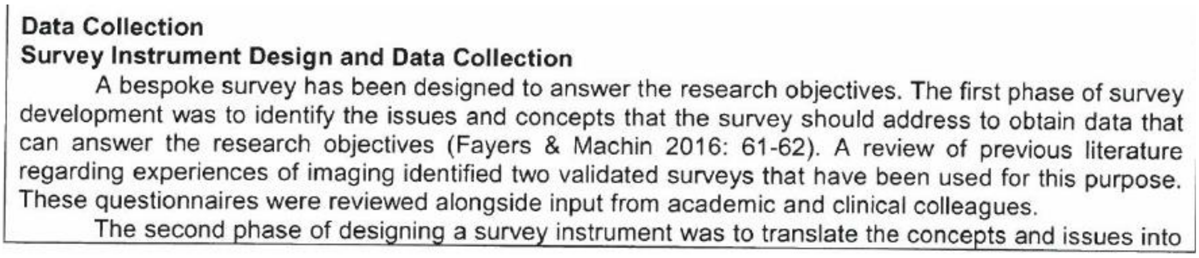
Potential respondents will be recruited through local participating NHS trusts, a myeloma charity and an online myeloma support forum. In the NHS setting, potential participants will be made aware of the survey when they attend hospital appointments through advertising literature available on paper and online and invited to request further details.

An advertisement for the study will also be made available online through a myeloma charity, a myeloma support group and social media. Potential participants can choose to follow a link in this advert to obtain further information.

Sampling and Sample Size

A retrospective purposive self-selection sampling technique will be used to allow potential participants who are relevant to this inquiry and have the required knowledge to be invited to participate. A multi-centre approach to sampling will be used to sufficiently increase the sampling frame with three NHS trusts being invited to assist in participant recruitment.

In order to obtain a sample size estimate, Cohen's paper 'A Power Primer' (1992) has been employed. Assuming comparisons across three groups with analysis of variance (ANOVA), an intermediate effect size and a significance criterion of 0.05 then 52 sets of data are required for each imaging modality leading to a required sample of 156. As the data collected will be non-parametric, the Friedman or Kruskal-Wallis test will be used instead. This is considered effective with smaller samples (McDonald 2014), still allowing for significant results if the recruitment target is not met.



Data Collection

Survey Instrument Design and Data Collection

A bespoke survey has been designed to answer the research objectives. The first phase of survey development was to identify the issues and concepts that the survey should address to obtain data that can answer the research objectives (Fayers & Machin 2016: 61-62). A review of previous literature regarding experiences of imaging identified two validated surveys that have been used for this purpose. These questionnaires were reviewed alongside input from academic and clinical colleagues.

The second phase of designing a survey instrument was to translate the concepts and issues into questions and decide the response format (Fayers & Machin 2016: 68-70). Due to the complexity of designing a new survey tool from the ground up, it was decided to base the survey on validated work by Schonenberger et al. (2007), and incorporate concepts from validated work conducted by Salmon et al. (1994). Both of their survey instruments have been employed to measure the experience of imaging in a number of research studies. The adapted survey tool for this study will use a labelled categorical scale for responses. This is to normalise individual responses and prevent respondents from applying a subjective value to the arbitrary 1-5 scale. A numeric rating scale (NRS) will be used for measuring pain, a concept that is very subjective, as it has been shown to be an accurate and reproducible measure. (Harrington et al. 2018: 84). Open-ended questions will be included to provide the respondent with the opportunity to elaborate on answers given in the closed questions, in addition to a comparison table of each imaging modality, designed by Schonenberger et al. (2007).

Phase three has consisted of pre-testing the survey (Fayers & Machin 2016: 74-75). This was initially done with clinical and academic colleagues, seven in total, to identify issues of ambiguity, wording, semantics and clarity. After revising the survey it was then given to a local NHS Patient and Public Involvement in Research group for further review and criticism, before final revisions made with further feedback from healthcare practitioners. This process has been important in ensuring the face and content validity of the proposed survey.

Data Analysis

The research question will be answered through statistical analysis of the ranked scores of the participants' acceptability of each imaging modality. The data will be analysed descriptively by calculating median values and the interquartile ranges for each question, and for each of the three imaging modalities being compared. These results will then be analysed using the Kruskal-Wallis test to demonstrate statistical differences between the three imaging modalities being investigated.

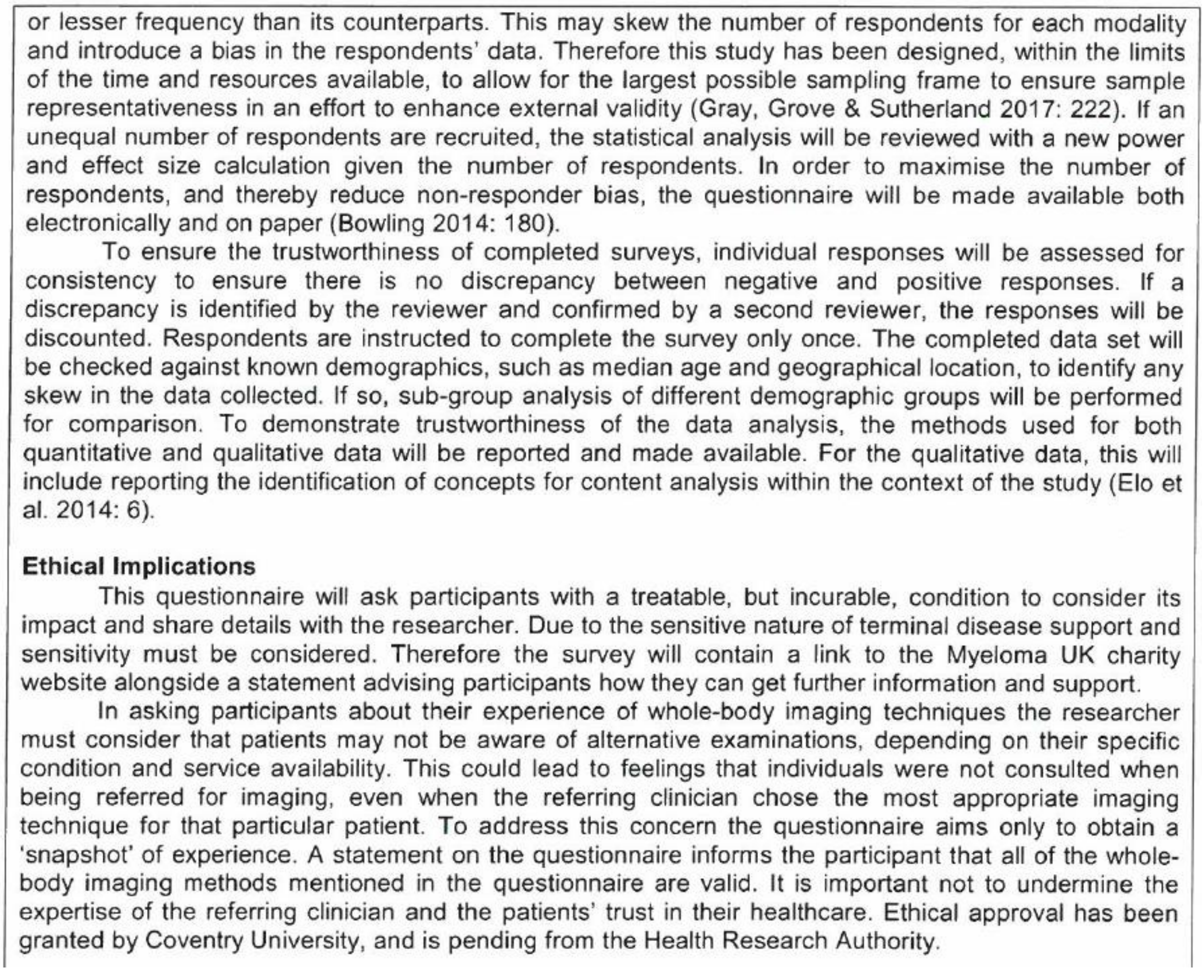
The qualitative data will be analysed through descriptive phenomenology, a method frequently used in healthcare research to complement a mixed methods approach (Bradshaw et al 2017). The qualitative data collected will be subject to content analysis to objectively analyse written communication and to group data into content-related categories which can then be further interpreted and reported upon. Content analysis will allow for a deductive approach whereby generalised theory can be made more specific whilst enhancing the quantitative data.

Reliability and Validity

Confirming the criterion validity of a survey instrument is a process of assessing it against a known true value (Fayers & Machin 2016: 94). As surveys measure subjective concepts, measuring this survey against the results of an established survey instrument can be a reliable method of confirming agreement and therefore criterion validity. As stated previously, the adapted survey being employed in this study is based on a validated survey measuring patient experiences of imaging. Therefore it is reasonable to assume that criterion validity is established. Given the scale of this project and the resources available, asking a proportion of respondents to repeat the questions seems to offer little advantage but could increase questionnaire fatigue and burden.

Due to the barriers in confirming construct validity, it is important to confirm that this adapted survey will measure the constructs that it has been designed for, described as construct validity (Fayers & Machin 2016: 96-98). To achieve this, convergent validity and discriminant validity will be measured. This is done by identifying related or opposing concepts within the survey and calculating their correlation coefficients, confirming the surveys validity in measuring constructs by ensuring internal consistency. As a mixed-method approach is being used, then further correlation of quantitative and qualitative data becomes possible to ensure consistency of results, a process frequently referred to as triangulation (Bryman 2016: 641).

The three imaging modalities being investigated are unlikely to have been experienced by an equal number of patients for reasons such as availability and healthcare provider preference. Although difficult to predict accurately, it is likely that one of the three imaging modalities is employed with greater



or lesser frequency than its counterparts. This may skew the number of respondents for each modality and introduce a bias in the respondents' data. Therefore this study has been designed, within the limits of the time and resources available, to allow for the largest possible sampling frame to ensure sample representativeness in an effort to enhance external validity (Gray, Grove & Sutherland 2017: 222). If an unequal number of respondents are recruited, the statistical analysis will be reviewed with a new power and effect size calculation given the number of respondents. In order to maximise the number of respondents, and thereby reduce non-responder bias, the questionnaire will be made available both electronically and on paper (Bowling 2014: 180).

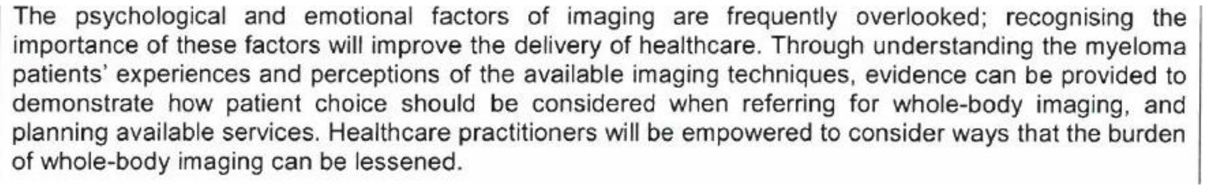
To ensure the trustworthiness of completed surveys, individual responses will be assessed for consistency to ensure there is no discrepancy between negative and positive responses. If a discrepancy is identified by the reviewer and confirmed by a second reviewer, the responses will be discounted. Respondents are instructed to complete the survey only once. The completed data set will be checked against known demographics, such as median age and geographical location, to identify any skew in the data collected. If so, sub-group analysis of different demographic groups will be performed for comparison. To demonstrate trustworthiness of the data analysis, the methods used for both quantitative and qualitative data will be reported and made available. For the qualitative data, this will include reporting the identification of concepts for content analysis within the context of the study (Elo et al. 2014: 6).

Ethical Implications

This questionnaire will ask participants with a treatable, but incurable, condition to consider its impact and share details with the researcher. Due to the sensitive nature of terminal disease support and sensitivity must be considered. Therefore the survey will contain a link to the Myeloma UK charity website alongside a statement advising participants how they can get further information and support.

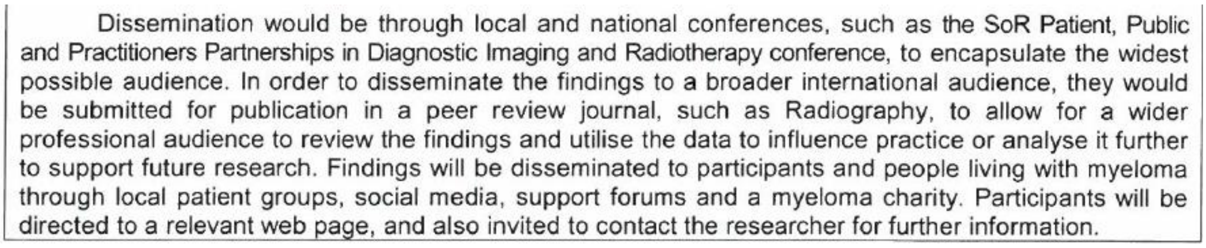
In asking participants about their experience of whole-body imaging techniques the researcher must consider that patients may not be aware of alternative examinations, depending on their specific condition and service availability. This could lead to feelings that individuals were not consulted when being referred for imaging, even when the referring clinician chose the most appropriate imaging technique for that particular patient. To address this concern the questionnaire aims only to obtain a 'snapshot' of experience. A statement on the questionnaire informs the participant that all of the whole-body imaging methods mentioned in the questionnaire are valid. It is important not to undermine the expertise of the referring clinician and the patients' trust in their healthcare. Ethical approval has been granted by Coventry University, and is pending from the Health Research Authority.

Potential impact



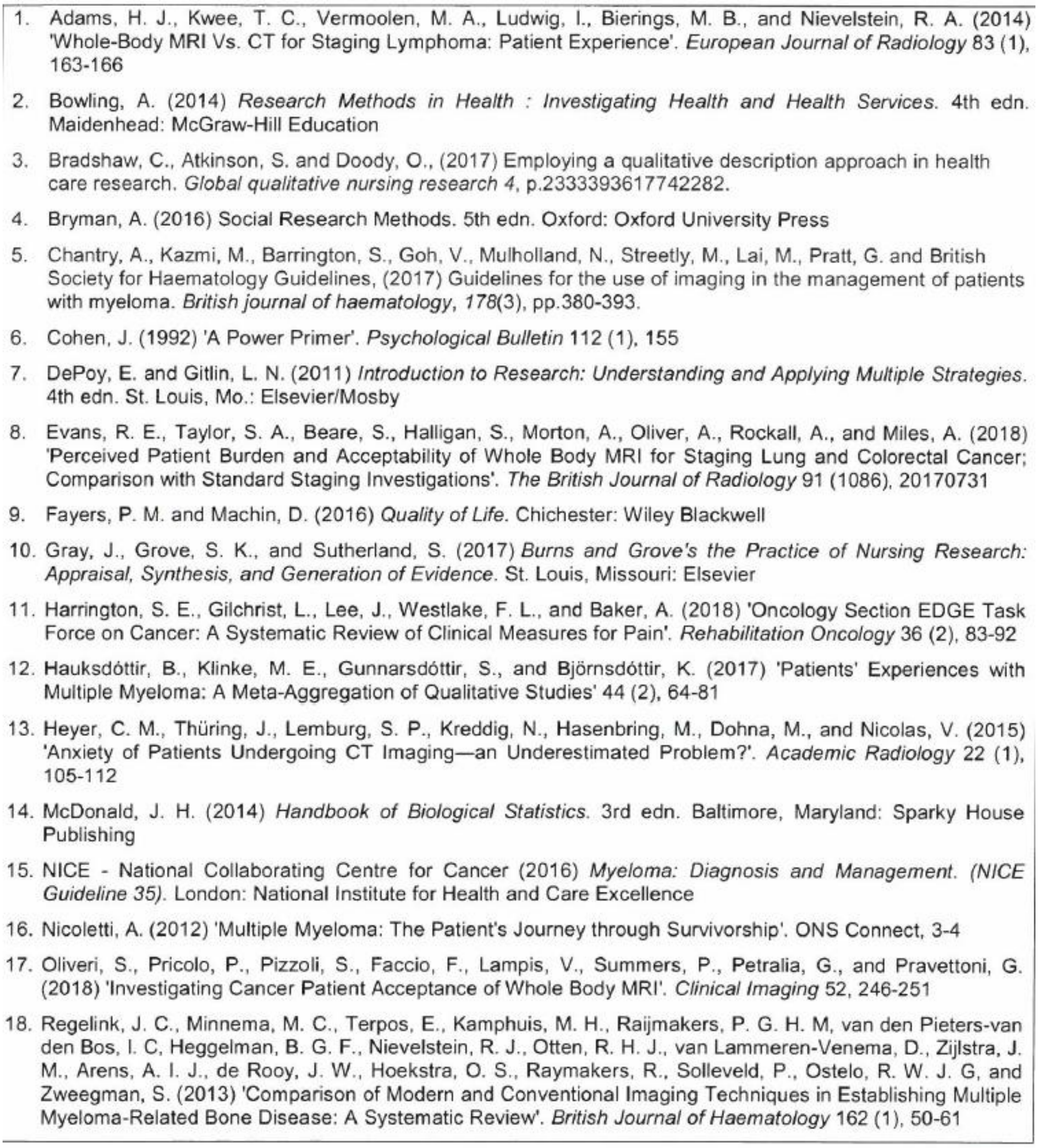
The psychological and emotional factors of imaging are frequently overlooked; recognising the importance of these factors will improve the delivery of healthcare. Through understanding the myeloma patients' experiences and perceptions of the available imaging techniques, evidence can be provided to demonstrate how patient choice should be considered when referring for whole-body imaging, and planning available services. Healthcare practitioners will be empowered to consider ways that the burden of whole-body imaging can be lessened.

Dissemination Strategy



Dissemination would be through local and national conferences, such as the SoR Patient, Public and Practitioners Partnerships in Diagnostic Imaging and Radiotherapy conference, to encapsulate the widest possible audience. In order to disseminate the findings to a broader international audience, they would be submitted for publication in a peer review journal, such as Radiography, to allow for a wider professional audience to review the findings and utilise the data to influence practice or analyse it further to support future research. Findings will be disseminated to participants and people living with myeloma through local patient groups, social media, support forums and a myeloma charity. Participants will be directed to a relevant web page, and also invited to contact the researcher for further information.

References



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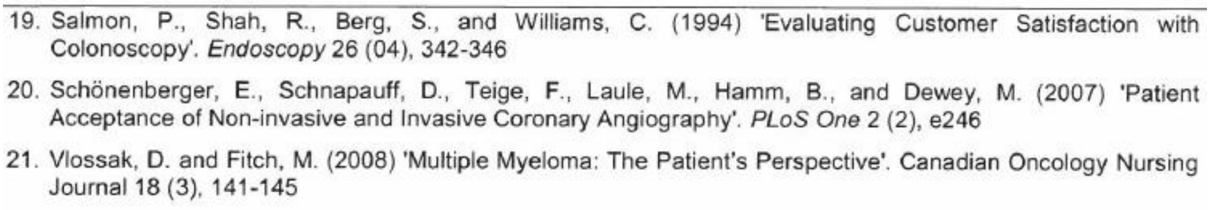

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