



Genetics in palliative oncology: a missing agenda? A review of the literature and future directions

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Abstract

Purpose In the palliative oncology setting, genetic assessment may not impact on the patient's management but can be of vital importance to their surviving relatives. Despite care of the family being central to the ethos of palliative care, little is known about how hereditary aspects of cancer are addressed in this setting. This review aims to examine current practices, identify practice barriers and determine the genetic information and support needs of patients, family members and health providers.

Methods Key databases were systematically searched to identify both quantitative and qualitative studies that addressed these aims. Data was extracted and coded using thematic analysis.

Results Eight studies were included for review. Suboptimal genetic practices were identified, with lack of knowledge and poor confidence amongst providers reported as barriers in both qualitative and quantitative studies. Providers expressed concern about the emotional impact of initiating these discussions late in the disease trajectory; however, qualitative interviews amongst palliative patients suggested there may be emotional benefits.

Conclusions All lines of evidence suggest that genetics is currently missing from the palliative agenda, signifying lost opportunities for mutation detection, genetic counselling and appropriate risk management for surviving relatives. There is an urgent need for interventions to improve provider knowledge and awareness of genetic referral pathways and for research into the genetic information and support needs of palliative care patients.

Keywords Hereditary · Genetic counselling · Palliative · End of life · Supportive care

It is estimated that up to 35% of all cancers (depending on cancer type) are attributable to underlying heritable factors [14, 31, 32]. The discovery of genes predisposing to cancer has enabled clinical translation of genetic testing in oncology, and genetic counsellors now play an integral role within the multidisciplinary cancer care team. Cancer genetic counselling involves the use of clinical and family history information

to identify individuals who have potentially increased risk of cancer [39]. For those at high risk, genetic counsellors provide education and counselling to promote informed decisions about genetic testing and risk management, whilst also attending to the psychosocial repercussions [39] (Fig. 1).

A familial risk assessment is most informative when genetic testing is performed on a family member affected by cancer who is likely to carry a mutation in a cancer predisposition gene (an index case). Identifying a mutation in an affected individual enables predictive genetic testing of the known mutation amongst family members [8]. For those carrying the familial mutation, risk management strategies—such as surveillance, prophylactic surgery and risk-reducing medication—can reduce cancer-specific morbidity and mortality [9, 12], whilst non-carriers are considered to be at population risk and reassurance can be provided. Given the potential presence of genes that are as yet unknown or undetectable [2, 10], genetic testing of unaffected family members without first identifying a pathogenic mutation in an index case does

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not provide full reassurance even when no mutation is detected.

In the palliative setting, genetic assessment does not usually impact on management decisions for the patient but may be vitally important to their surviving relatives. This may be the last opportunity to obtain a DNA sample, without which a familial mutation may go undetected until a new family member is diagnosed with an otherwise preventable cancer.

Whilst the challenges of counselling and decision-making have been well-described in the context of palliative treatment [11, 24, 40], there is a dearth of literature specifically related to the issues around genetic assessment (with or without genetic testing/DNA storage) of palliative oncology patients.

This review aims to (1) examine current genetic practices within the palliative oncology setting, (2) identify

practice barriers and (3) determine the genetic information and support needs of patients, families and health care providers. These aims are addressed in response to a significant gap in the literature and will highlight areas for future research.

Methodology

An initial, non-systematic search was performed to gain an appreciation of the available literature addressing the research question. This indicated a limited body of literature. As such, the review methodology was developed in favour of an inclusive approach, accommodating both qualitative and quantitative research methodologies (a mixed-method review).

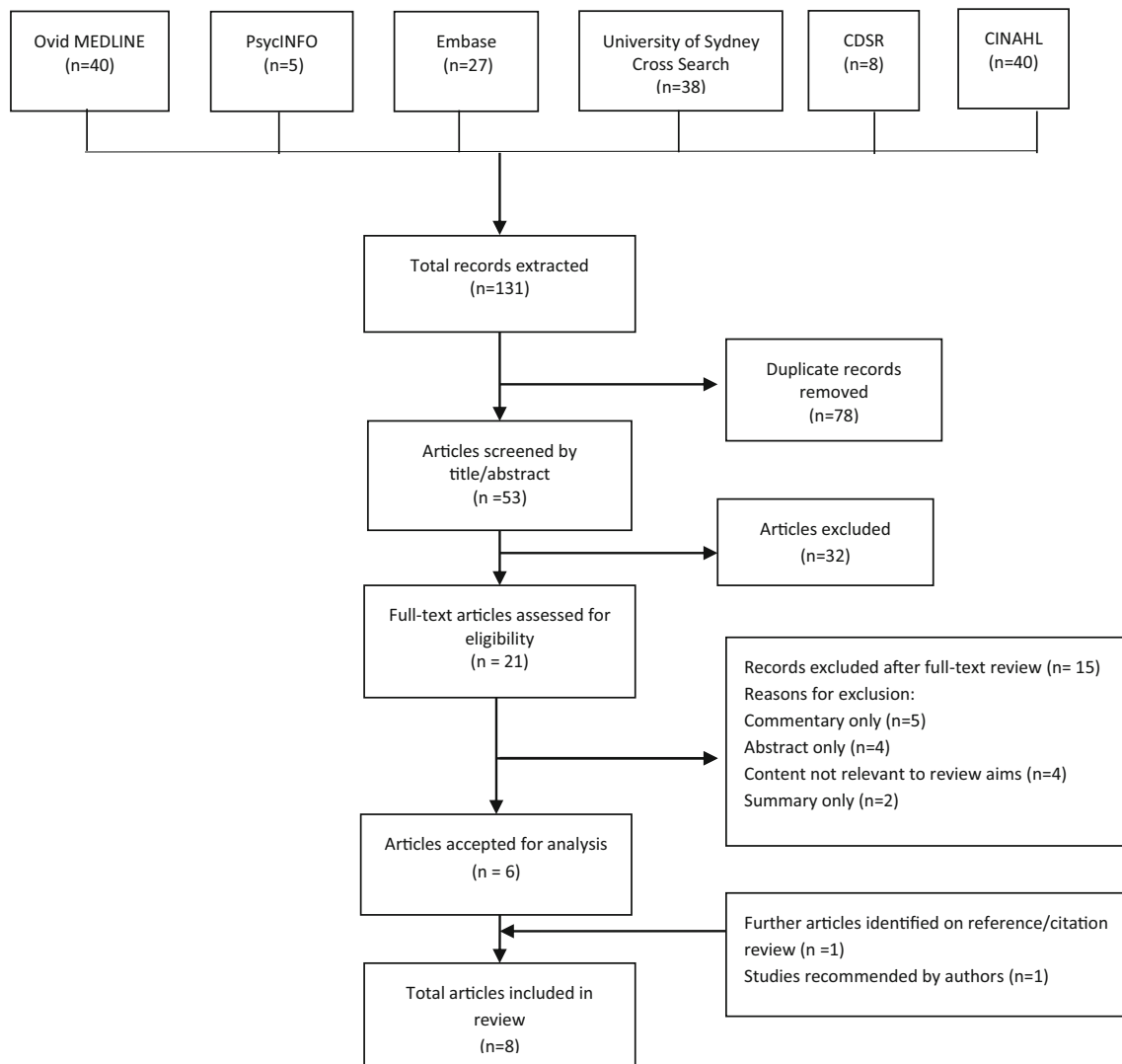


Fig. 1 Article selection flowchart

Literature search

The databases PsycINFO, Embase, Ovid MEDLINE, University of Sydney Cross Search, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Cochrane Database of Systematic Reviews (CDSR) were queried using key terms to identify articles. The search terms “genetics”, “genetic testing”, “genetic counselling”, “germline”, “sequencing”, “family history”, “familial cancer”, “hereditary” or DNA, combined (using Boolean term “AND”) with “palliative or advanced cancer”, “terminal cancer”, “end of life”, “hospice” or “dying” were used.

Inclusion and exclusion criteria

Both quantitative and qualitative studies were included if they explored any aspect of genetic practices within the palliative oncology setting including the provision of genetic information, facilitation of germline testing/DNA storage or family history assessment. Studies assessing the role of both genetic and non-genetic health providers were included, as were studies assessing the information and support needs of patients, family members and non-genetic health care providers. Given the limited number of studies in this area, relevant case studies were included, as well as conference abstracts containing original research findings. Opinion pieces and commentaries were excluded.

Titles and abstracts were reviewed against the inclusion/exclusion criteria by two independent reviewers. Full text review of the remaining articles was undertaken to assess eligibility. Reference lists of eligible articles were backward searched, and Google Scholar was used to forward search for citing articles to identify additional literature.

Given the few studies eligible for inclusion, the “grey literature” (work of potential high-quality but published outside peer-reviewed sources) was also searched. Key palliative care journals, including the *Journal of Palliative Care*, *Palliative Medicine*, *Journal of Palliative and Supportive Care*, *Supportive Care in Cancer* and *European Journal of Palliative Care*, were manually searched. Authors who have contributed to this field were contacted via email regarding relevant follow-up studies or unpublished work.

Data extraction and quality assessment

The following data were extracted: study characteristics and methodology, independent variables affecting genetic practices in palliative care and study outcomes. For qualitative studies, results sections were open-coded by a single reviewer (AM) and grouped into themes and subthemes using deductive thematic analysis according to Braun and Clarke [3]. The themes were discussed and refined with an additional reviewer (KT).

Quality was assessed using the pre-defined quality assessment tool, “QualSyst”, which allows simultaneous assessment of both

qualitative and quantitative study designs [23]. The quality appraisal was conducted by a single reviewer (AM) and approved by an additional reviewer (KT). Given the wide-reaching approach of this review, studies were not excluded on the basis of quality, but quality was taken into account if results conflicted.

Results

Study characteristics

Eight studies met the inclusion criteria and were selected for full review. Of these, two used quantitative methods, three used qualitative methods, one used mixed-methods and two were illustrative case studies. The study characteristics and quality scores are summarised in Table 1. Genetic practices in palliative care were explored using a number of approaches, including surveys of palliative care nurses ($n = 3$) and physicians ($n = 1$), patient survey ($n = 2$) and illustrative case studies ($n = 2$).

Main findings

The themes extracted from the qualitative data focused on three main areas: (1) practice barriers, (2) ethical and emotional barriers (as perceived by health care providers) and (3) patient perspectives. Each of these themes was further divided into categories, as summarised in Table 2.

Practice barriers

Two studies identified suboptimal genetic assessment practices [36, 37]. In one study, 21% (9/43) of palliative oncology patients were identified as having strong genetic risk according to published criteria [7, 33, 38] but none had undergone genetic counselling, genetic testing or DNA storage [36]. In a survey of 49 oncology and palliative physicians, none had arranged DNA storage for patients within the last year, and 20% (10/49) commented that they had never assessed a patient’s familial risk [37].

Lack of knowledge

Lack of knowledge amongst health care providers was cited in five studies as a barrier to discussing genetics with palliative care patients or their family members [19, 25, 26, 30, 37]. In a survey of palliative physicians, only 10% were aware of the availability of DNA storage for patients with a possible underlying genetic predisposition [37]. In the same study, only 18% (9/49) of physicians responded correctly to all knowledge-based questions about familial cancer. Responses were poorer for hereditary bowel cancer syndromes, with 29% (14/49) of physicians unaware of the availability of genetic

Table 1 Study characteristics

| Author | Aim(s) | Methods/ analysis | Participants | Findings and implications | Future directions | Quality score* |
|--|--|---|--|---|--|----------------|
| Quillin, Bodurtha and Smith (2008) | To illustrate the value of genetic assessment in palliative care | Case study | 1 palliative patient with gastrointestinal cancer and family history consistent with FAP | Genetic assessment aligned with “family-centred” palliative model and can provide clinically meaningful information for relatives | Need for (1) resource to educate palliative care health professionals and (2) development of more reliable triaging systems | N/A** |
| Lillie (2009) | To (1) describe the experience and needs of palliative patients with a family history of cancer and (2) assess nurses’ perceptions of the effect of family history on patient care | Qualitative study using exploratory interviews | Patients with advanced cancer and a family history of cancer ($n = 12$) and hospice nurses ($n = 10$) | Patients had pre-existing concerns about cancer risk for relatives. Genetic assessment provided reassurance for some participants. Nurses are reluctant to discuss genetics—concerned about provoking additional distress to patient and family | New model of care proposed to incorporate the patients experience and concerns about the family history of cancer | 0.95 |
| Metcalfe, Pumphrey and Clifford (2009) | To determine nurses’ perceived importance of genetics in the palliative care setting and their confidence carrying out genetic-related activities | Mixed methods: questionnaire and follow-up telephone interviews | 328 hospice nurses completed questionnaire, telephone interview with 8 nurse education leads | Hospice nurses felt that genetic assessment was important but the majority lacked confidence carrying out genetic activities | Need for genetic education amongst hospice nurses, with focus on psychosocial implications | 0.9 |
| Lillie, Clifford and Metcalfe (2010) | To assess how palliative care nurses perceive the needs of patients with a family history of cancer | Qualitative analysis of semi-structured interviews | 10 nurses working in specialist palliative care | Nurses lacked knowledge about genetics and were concerned about causing additional distress by raising these issues | Nurses require further education about genetics and insight into the potential benefits of addressing genetic issues during palliative care | 0.75 |
| Quillin et al. (2010) | To estimate proportion of palliative patients with hereditary cancer risk appropriate for genetic services, and assess their awareness of genetic testing/DNA banking | Quantitative analysis of 43 structured interviews, patient medical records reviewed | 34 palliative care patients answering for themselves ($n = 34$) and medical decision-making surrogates ($n = 9$) | 1 in 5 palliative patients had strong familial risk but none had undergone previous genetic counselling, testing or DNA banking | Genetic risk not being assessed in palliative setting, need for greater awareness and further research investigating barriers and facilitators of genetic assessment | 0.9 |
| Quillin et al. (2011) | Determine current practice of DNA banking for cancer susceptibility in palliative care | Quantitative study using online questionnaire | 49 palliative care physicians | Only 5% of palliative care physicians felt “somewhat qualified” to order DNA banking. None had requested testing in the prior year | Need for clinician education and guidelines and genetic assessment tools | 0.85 |
| Daniels et al. (2011) | To highlight the importance of genetics in end of life care for women with terminal ovarian cancer | Illustrative case studies | Case studies of 2 patients with terminal ovarian cancer | Genetic counselling can address pre-existing concerns and provide hope for a better outcome for the patients’ relatives | Need for (1) greater awareness amongst health care providers and (2) further research to identify more effective referral pathways | N/A** |
| Ingleby (2015) | To understand barriers/facilitators of staff discussions regarding familial risk with patients during palliative care | Qualitative study using exploratory interviews | 13 palliative care workers: clinicians ($n = 4$), nurses ($n = 9$) | Many participants believed palliative care was an inappropriate setting to raise genetics and lacked confidence discussing genetic issues | Integration of genetics in palliative care requires staff education, improved awareness and a multidisciplinary approach | 0.9 |

*Based on standard quality assessment criteria for evaluating primary research papers (Kmet et al. 2004)

**Quality not assessable as not containing primary research findings (illustrative case studies)

Table 2 Themes and categories identified through thematic analysis

| Theme | Category |
|----------------------------|---------------------------------------|
| Practice barriers | Lack of knowledge |
| | Low confidence |
| | Provider assumptions |
| | Perceived clinical utility |
| Ethical/emotional barriers | Timing/patient trajectory |
| | Additional distress |
| | Facilitating a good death as priority |
| Patient perspectives | Predetermined fate |
| | Awareness of heritable cancer risk |
| | Worry for future generations |
| | Altruism and emotional benefits |

testing for Lynch syndrome and familial adenomatous polyposis (compared to 2% for *BRCA1* and *BRCA2*) [37].

Lack of knowledge also emerged in each of the three qualitative studies exploring nurse perspectives.

Participant G: “it’s definitely the lack of knowledge that stops you...talking about it...I wouldn’t even think about it” (Ingleby, 2015, p. 70)

Participant A: “we’re lacking in education...who should we be referring? When should we be referring? Have they been referred?” (Ingleby, 2015, p. 70)

Low confidence

Both palliative care nurses and physicians had low self-confidence about discussing genetics with their patients. Of palliative care physicians, nearly 40% (19/49) felt “not qualified at all” to recommend DNA storage [37]. In a mixed-methods study of hospice nurses, 75% (248/328) reported feeling “not at all confident” about integrating genetics into everyday clinical practice [30], with 54% (177/328) lacking the confidence to refer and 74% (241/328) being unaware of how to refer patients to genetic services [30]. Low confidence was also reflected in a qualitative study, with one hospice nurse suggesting development of guidelines for referral and ways to broach the subject [19].

In the survey of hospice nurses, seniority was a predictor of confidence in the ability to assess genetic risk and refer to genetic service [30]. Although nurses with previous education in genetics were more confident than those without, the majority in both groups still had poor self-efficacy scores overall [30]. In a qualitative study of palliative nurses, four participants cited poor confidence as a result of lack of knowledge [19]. In contrast, however, genetic knowledge did not predict confidence for palliative oncology physicians when requesting DNA storage [37].

Provider assumptions

In a survey of 328 hospice nurses, a fifth of the sample had assumed that genetic issues would already have been addressed prior to commencing palliative treatment [30]. This assumption was also reflected in one of the qualitative studies [19], where one participant stated:

Participant N: “people assume it will have been done previously by the surgeon or the oncologist” (Ingleby, 2015, p. 66)

Perceived clinical utility

In the three exploratory interviews of hospice nurses, there were conflicting perspectives on the clinical utility of raising genetics in the palliative setting. Some nurses recognised the potential value for cancer prevention in subsequent generations.

Participant B: “they can feed the knowledge into us that it makes a difference and...you can stop people getting it...and that’s a huge revelation!...You’ll save lives really” (Ingleby, 2015, p. 83)

Others, however, were focused more on the lack of clinical benefit for the patient.

Participant NP1: “I think it should be done long before palliative care personally ... Because it is really too late, isn’t it” (Lillie et al., 2010, p. 119)

Ethical and emotional barriers

Timing in patient trajectory

Palliative care workers had moral objections to genetic issues being raised during end-of-life and concern about causing additional psychological distress [19, 26, 30]. The theme of “too much too late” emerged in each of the three qualitative studies assessing health care providers’ attitudes and practices [19, 26, 30].

Participant NP3: “...a palliative care hospice is not the right situation. No: because we are at the other end of the journey” (Lillie et al. 2010, p. 119)

Additional distress

Three studies identified concerns that raising genetics would intensify, rather than ease, the emotional distress of the patient

and their family [19, 26, 30]. In the qualitative study of nurse participants, all expressed concern that discussing genetics would undermine the central ethos of palliative care in providing comfort and support during an emotionally vulnerable time [19].

Participant N: "... particularly at the end of life, we feel we're there to...give comfort and ease distress, so it does feel like you're adding distress...[and that's] contradictive to what you aim at" (Ingleby 2015, p. 64)

In another of the qualitative studies (2010), two nurse participants recalled separate cases in which there was a family history of cancer suspicious for an underlying genetic predisposition, but deliberately avoided discussing this due to other emotional stressors.

Participant NP3: "I can remember a lady who had bowel cancer and she had other members of the family who had died of bowel cancer... because she had a son and a daughter... but we didn't discuss, it wasn't appropriate ... She struggled with emotional issues, which were more important at the time than that" (Lillie 2010, p. 216)

Facilitating a "good death" as priority

In all three qualitative studies, nurse participants voiced concern that discussing genetics would deflect the focus of care away from the dying patient [19, 25, 26]. Nurses felt that the process of dying should be prioritised, with emphasis on facilitating a "good death" through symptom control and alleviation of distress. Genetics was seen to be peripheral to these issues.

Participant C: "I think if somebody's dying they've got enough on their plate with dying" (Ingleby, 2015, p. 65)

Participant NP7: "I think it would distract from what we are trying to do to some extent. ..., you can imagine someone on a ward bringing all this up ... and trying to sort all that out and not concentrating on the patient who is actually dying" (Lillie, 2015, p. 205)

Predetermined fate

In two of the qualitative studies, two nurses raised concerns that by discussing genetics during palliative care, family members may identify more closely with their dying relative and envisage the same fate [19, 25].

Participant B: "it can become a huge component for the family if they've never considered it before...you're

kind of watching how you might die in a very much more focussed way" (Ingleby, 2015, p. 55)

Participant NP8: "...They wouldn't have hope: they would come to see death as the end, as opposed to getting wrapped in screening and treatment ... It could really depress their whole life" (Lillie 2009, p. 205)

Patient perspectives

Awareness of cancer predisposition

Only one study explored patient perspectives on genetic issues in palliative care [25]. Exploratory interviews amongst palliative oncology patients with a family history of cancer identified an awareness of underlying hereditary predisposition [25]. When asked about previous cancer diagnoses in the family, numerous participants alluded to there being a possible underlying genetic component.

Iain: "...I'm just thinking out of the eleven of us there are four left. So I'm wondering if it is inherited." (Lillie, 2009, p. 171)

Beth: "I think it's hereditary, because I had it, and my father had it." (Lillie 2009, p. 167)

Concerns for future generations

There was widespread concern amongst patients about cancer risk for their relatives—particularly their offspring.

Diane: "I've got five kids and my sister ... and I'll be very upset if anything happens to them ... I would be very distraught, if anything happened to them" (Lillie, 2009, p. 159)

This was also illustrated in one of the two cases described by Daniels et al. (2010), where the husband of a patient with ovarian cancer and a strong family history requested a genetic assessment during the terminal stage of her illness, out of concern for their teenage daughter. Fortunately, blood was drawn shortly before death and a *BRCA1* mutation identified, though this opportunity would have been lost had the family not acted on their concerns.

Altruism

Patient participants alluded to a sense of duty to prevent future cancer occurrences within the family and many had urged

their relatives to be aware of their cancer risk, and engage in proactive screening behaviours.

Jenny: “If it is on the cards that one of my nephews and nieces, or one of my great nephews and nieces are going to have cancer, then I want to do everything possible to help the future. I will do anything; I will talk to anybody” (Lillie, 2009, p. 166).

Diane: “I say look after yourself, keep on feeling around (demonstrated breast examination), if you feel anything, there, tell someone.” (Lillie, 2009, p. 170).

Emotional benefits

Given her family history of breast cancer, one patient participant had previously requested a genetic referral out of concern for her daughters [25]. The genetic assessment provided the patient with reassurance that her daughters’ cancer risks were not as high as she had previously believed.

Diane: “They spoke to the doctor and got all the information, and they said it was just unfortunate, and that it mightn't happen to the girls at all: which is a relief” (Lillie, 2009, p. 159)

Discussion

This literature review revealed suboptimal genetic practices within the palliative care setting. Reasons for this included (1) the assumption that genetics would have been addressed earlier in the disease trajectory, (2) concerns amongst providers that initiating a discussion about genetics would cause patient distress and (3) lack of knowledge and poor confidence addressing genetic issues. Failure to address the family history of cancer in this setting signifies lost opportunities for mutation detection, genetic counselling and appropriate risk management for surviving relatives.

Despite care of the family being central to the values and ethos underpinning palliative care [34], genetics appeared to be missing from the palliative agenda due to assumptions amongst providers that genetic issues will have already been addressed earlier in the disease trajectory. This assumption is flawed, given that numerous studies have identified suboptimal genetic referral rates within the oncology setting, with genetic issues often being overlooked at the time of initial diagnosis [6, 8]. Furthermore, patients with particularly aggressive cancers may not present until the advanced stages of their disease [8], and concerns about the family history may only surface as the affected individual becomes

increasingly unwell [21]. It is therefore inevitable that for some patients, the option of genetic testing or DNA storage may only become available in the palliative setting.

Nurses and physicians both lacked the knowledge and confidence required to initiate discussion of genetics with patients and their families. Given the complexity of genetic information, most of the health care providers surveyed felt that it was beyond the scope of their practice and required specialist referral [25]. However, as the window of opportunity is often limited, intervention by genetic services may not always be feasible. As such, it is necessary for palliative care nurses and doctors to acquire the knowledge, skills and confidence to ensure that eligible patients have access to genetic testing or DNA storage. Palliative care nurses are well-equipped with the necessary skills and experience to initiate difficult discussions in such a setting [19]. Genetics services need to be proactive in ensuring palliative care nurses have the skills, knowledge and confidence to discuss genetic issues and know how to assess genetic risk and make a referral.

Numerous studies have identified deficits in the genetic skills and knowledge base amongst nurses in a variety of settings [4, 27], despite the development of guidelines and efforts to integrate genetics into the nurse educational curriculum [13, 22, 29]. The ability to identify patients who may benefit from genetic assessment has been described as a key nursing competency, and in the palliative setting, one that may determine whether or not this limited opportunity is seized [22]. Although nurses in one study described routinely taking a family history, this was used as a tool to gauge the family support network, rather than to identify a genetic risk [19]. Using this opportunity to ask about other cancer occurrences may help to identify patients who may benefit from genetic assessment.

Given the current demand on genetic services and the growing availability of targeted therapies for mutation carriers, efforts have been made to facilitate the translation of genetics to mainstream clinical environments to ensure equitable access to genetic testing [20]. This often involves the provision of pre-test information and counselling by a non-genetic provider [20]. Although in its infancy, mainstreaming within the oncology setting provides a model by which genetics can be integrated within the palliative setting. In the UK, oncology health professionals (consultants, trainees and nurses) completed an educational training package, which enabled them to counsel and consent ovarian cancer patients for BRCA1 and BRCA2 genetic testing [35]. This has improved access to genetic testing and has been deemed by both patients and providers an acceptable alternative to traditional models of genetic service delivery [20, 35].

Lastly, there was widespread concern amongst palliative care nurses about the potential to cause additional emotional distress to the patient and their family by raising a potential inherited cancer susceptibility. Whilst studies have shown that

genetic testing for cancer susceptibility can cause distress in some individuals, this has been measured primarily in the setting of predictive genetic testing for a known mutation [17] [18, 28]. Further research is required to determine the validity of these concerns in the palliative setting, where the information and consent process is tailored to the needs of the family and often confined to DNA storage only (with referral to a genetic service at a later stage for consideration of mutation testing).

Only one study to date has explored patient experiences of genetics in the palliative setting [25]. The exploratory interviews in Lillie's study showed that patients with a family history are often already suspicious of a hereditary cancer predisposition and are fearful about cancer risk for subsequent generations [25]. In contrast to nurses' concerns about causing distress, there was a suggestion that a genetic evaluation may instead alleviate distress. The insight gained from a genetic assessment may provide reassurance about the likely level of cancer risk (which may be lower than what was expected), and the availability of risk management strategies [25].

Palliative patients may also perceive the provision of a DNA sample as a positive and altruistic experience, given the potential benefits for their family. When preparing for death, individuals often strive for spiritual closure and peace of mind [15]. This emerged in a study of women undergoing genetic testing for hereditary breast and ovarian cancer, where almost a quarter had been urged by a dying relative to seek advice about their risk in light of the family history [16]. Palliative patients may therefore be comforted to know that interventions are in place to manage or reduce cancer risk for subsequent generations.

Review limitations

Given the dearth of literature in this area, it was necessary to assess all available lines of evidence (regardless of quality) in order to explore emergent themes and highlight areas for future research. This is as a limitation, as the review contains studies of variable quality, participant groups, sizes and methodologies. Given that most studies had poor participation rates, the review may be biased towards individuals with an interest in genetics. The poor participation rates amongst palliative health care providers may also reflect attitudes towards genetics and its omission from the palliative agenda. However, if any bias does exist, the problem of poor engagement with genetics in palliative care is understated in this review.

Areas for future research

Further qualitative studies are needed to determine the genetic needs of palliative patients and their families. Whilst the qualitative study of the experiences and needs of palliative patients

with a cancer family history [25] highlighted some concerns, none had undergone a formal genetic assessment and information needs and preferences were not assessed. The lack of such literature may reflect the issues conducting research using this patient population, given their limited time, energy and emotional vulnerability [1]. However, given that such research is vital in improving patient care, strategies have been developed to conduct research in a way that addresses these sensitivities [5].

This review also highlighted the need for additional education and training for palliative care workers. The ability to (1) identify appropriate patients, (2) provide basic genetic information, (3) obtain informed consent and (4) initiate referral to genetic services should each be seen as key competencies amongst palliative care nurses. Current genetic referral pathways and practices should be reviewed within major tertiary centres and efforts made to improve these practices throughout both early and late stages of disease trajectory.

Conclusion

Ideally, patients should have the option of a genetic assessment, sooner rather than later, in the disease trajectory. However, given that current referral practices are suboptimal, further efforts are needed (guided by the above areas of future research) to ensure that opportunities are not missed in the palliative setting.

Compliance with ethical standards

Conflict of interest Author K. Tucker has affiliations (financial and advisory) with Astra Zeneca. The remaining authors declare no conflicts of interest.

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