J Community Genet (2018) 9:243–256
https://doi.org/10.1007/s12687-017-0345-1

ORIGINAL ARTICLE

Mainstreaming genetics in palliative care: barriers and suggestions for clinical genetic services

A. Dearing[1,2] · **N. Taverner**[2]

Received: 4 January 2017 / Accepted: 7 November 2017 / Published online: 20 November 2017

Abstract Palliative healthcare professionals (PHCPs) frequently do not refer their eligible patients for genetic testing. After the death of the affected individual, clinically relevant information for family members is lost. In previous research, PHCPs stated that the end-of-life setting is not appropriate to discuss genetic issues. It is unclear if this has changed due to increasing awareness of genetics in the media and efforts to mainstream genetic testing. Semi-structured interviews of PHCPs were analysed by thematic analysis. Seven PHCPs (four nurses, two consultants, and one clinical psychologist) were interviewed. Participants reported feeling unfamiliar with the role of clinical genetics services, and did not feel confident in addressing genetic issues with their patients. A lack of scientific knowledge and unawareness of existing infrastructure to support their patients were cited. Many stated that palliative patients are interested in exploring a potential hereditary component to their disease, and acknowledged the potential for psychological benefit for their patients and their families. Most stated that addressing genetics fits within their skill set, but expressed concern about issues of consent, logistical difficulties, and ethical dilemmas. These perceptions differ considerably from those reported in existing literature. Importantly, each participant stated that the potential benefits of addressing genetic issues outweighed the potential for harm in most cases. These results suggest a need for clinical genetics staff to develop closer links with their local PHCPs and to provide education. Clinical psychologists may also be a helpful resource to address PHCPs' concerns.

✉ A. Dearing
Audrey.dearing@stgeorges.nhs.uk

[1] Clinical Genetics, St. George's University London, Blackshaw Road, Tooting, London SW17 0QT, UK

[2] Institute of Medical Genetics, University Hospital of Wales, Heath Park, Cardiff CF14 4XN, UK

Introduction

Palliative patients remain an underserved cohort by clinical genetics in the UK as well as internationally (Daniels et al. 2011; Lillie et al. 2011; Quillin et al. 2011b), although many may be eligible for referral. Genetic counselling and testing is recommended by the National Institute for Health and Care Excellence (NICE), a UK-based health authority which publishes guidelines for treatment provided by the National Health Service (NHS). NICE has recommended evaluation by a genetic professional in patients with a personal family history of cancer, in order to enable access to appropriate screening and preventative treatment for both the affected individual (proband) and extended family (NICE Guidelines 2010). Improving access to genetic testing is also of focus internationally, including by the European Society for Medical Oncology (ESMO) and the USA-based National Comprehensive Cancer Network (NCCN) (Paluch-Shimon et al. 2016; NCCN 2016).

Wherever possible, it is desirable to test someone who is affected by cancer rather than an unaffected relative to maximise the chances of identifying a gene alteration. As a result, it may happen that an older generation meets testing criterion (whether by private insurance or through the NHS), while their children do not. When no gene alteration is identified in a family, cancer screening (such as mammograms, colonoscopy) may still be offered to a younger generation, but often not as frequently or from as young an age as when a genetic alteration is identified. Similarly, preventative surgery is less likely to be funded by insurance companies or the NHS.

If no one affected by cancer is living, a family may be told that testing can only be funded upon a subsequent diagnosis of cancer in the younger generation. As one goal of genetic testing is to identify who would benefit from risk reducing action, it is hardly ideal to "wait and see" if another person develops cancer before action can be offered. Lakhani et al. (2013) performed a retrospective analysis of referrals to one British clinical genetics department which found that a significant proportion (22%) of referrals were received after the death of all living affected relatives, with a quarter of these deceased within the year. This suggests that the opportunity was tantalisingly recent, but unfortunately was not exploited. Palliative care teams are therefore uniquely positioned to take advantage of the last opportunity to collect a genetic sample for future generations as the speciality providing end-of-life care for these patients. This is particularly urgent as there is a limited amount of time during which genetic material can be collected from the affected relative before death.

Even in the absence of genetic testing, genetic counselling still has value as a therapeutic intervention. Through exploration of the patient's perceptions of disease aetiology and non-directive shared decision-making, the process of genetic counselling has been demonstrated to facilitate autonomy and to engender the patient with a sense of control (Kessler, 1997; McConkie-Rosell and Sullivan 1999). Not only does this patient empowerment apply to perceived personal control, but also to the patient's sense of "future orientation," also described as hope for future generations and family members (McAllister et al. 2008). In this way, genetic counselling has the potential to be psychologically beneficial even in the case when a genetic diagnosis would not be of immediate medical benefit to the proband: for example, when the proband is receiving palliative treatment for cancer.

Genetics teams in the UK are not commonly involved in the care of those affected by cancer. Therefore, the onus is on oncology or palliative teams to identify those who would benefit from genetic risk assessment. It is unclear if palliative patients are aware of the possibility of exploring a familial link to their cancers. Limited empirical studies have suggested that palliative patients knew little or nothing about genetics (Quillin et al. 2008). However, anecdotal evidence suggests that palliative patients have deep concerns for the welfare of their families, including the worry that family members will also be affected by disease (Daniels et al. 2011; Lillie 2006). This is similar to empirical evidence which examines the perceptions and opinions of non-terminal patients for whom a genetic link to disease would have no direct medical benefit. These participants expressed that they had a desire to find a genetic aetiology to the cancer in the family for altruistic reasons, including concerns for unaffected family members as well as the greater good (Vadaparampil et al. 2011; Novetsky et al. 2013; Skirton et al. 2006).

However, despite approximately 1 in 5 palliative patients meeting the criteria for referral to the local clinical genetics department in one American centre, palliative healthcare professionals (PHCPs) are thought to be amongst the professionals least likely to refer their patients for genetic evaluation (Quillin et al. 2010; Lakhani et al. 2013). Multiple barriers to accurately and appropriately identifying patients that would benefit from genetic evaluation have been previously identified by a limited number of studies. For example, both British nurses and American physicians have reported feeling as though they did not have sufficient education or resources to appropriately identify at-risk patients (Lillie et al. 2011; Quillin et al. 2011b). UK nurses have also stated that they were concerned about raising anxiety or feelings of grief with their patients, questioning whether it was appropriate to discuss genetic issues at the end of life (Lillie et al. 2011; Metcalfe et al. 2010).

However, these studies were limited in number and scope, suffering from poor response rates (between 29 and 37%) and limited generalisability. None of these studies contacted multiple professional types within the palliative department, resulting in a narrow view of patient care which exists in practice as a multi-disciplinary team. The quantitative methodology used in two of these empirical studies does not lend itself to capturing deeper information on the perceptions and motivations of PHCPs, particularly in an area in which little empirical work has been published (Pope et al. 2002).

As these results were limited in scope and not generalisable, it was unclear whether other centres also did not appropriately identify palliative cancer patients in line with local guidelines. As a result, the literature gives little to no information about whether these issues continue to be relevant as genetics expands into other areas of medicine. Additionally, it is not clear if these views continue to persist as genetic testing is performed with more frequency by non-genetic HCPs as a result of "mainstreaming" efforts, as genetic test results become more likely to affect treatment (George et al. 2016; Kentwell et al. 2017), as little work has been done in this area in recent years.

The aim of this work is to explore the perceptions PHCPs have regarding providing genetics services to palliative patients, and to discuss their level of comfort with discussing these issues with their patients. Additionally, the aim will be to determine what resources or educational training programmes may be welcomed by PHCPs, and whether the local Clinical Genetics Service is familiar to this cohort.

Methods

Data collection

Data was collected by individual interviews which were between 20 and 40 min in duration. Interviews are a commonly

used method for data collection in qualitative analysis, and have been demonstrated to be effective for gathering qualitative data concerning healthcare professional perceptions and experiences (Ash et al. 2003; Nordgren and Olsson 2004). The interviews were guided by a semi-structured, qualitative interview guide, which can be found in Appendix A. A semi-structured approach was chosen in order to ensure that the topics of interest were addressed without the constraints of a fully structured approach. All interviews were conducted in person by the primary investigator: a female MSc student, in the workplace of the participant. Interviews were digitally audio recorded with consent, and transcribed by the investigator as soon as possible. Participant identifiers were removed at the point of transcription, and the anonymised transcripts were seen exclusively by the investigation team. The digital, anonymised transcripts of the interviews will be retained for no less than 5 years after the study concludes or 2 years post-publication (if applicable), then will be destroyed. This is based on guidelines published by Cardiff University and is current at time of writing (Cardiff University 2015).

Participants were informed that they had the right to decline to answer any question, or to conclude the interview without explanation. Definitions of key concepts (ex: genetic testing) were provided upon request. As the subject is related to their professional practice, it was unlikely that the interview would cause emotional distress to the participants.

Data analysis

As the aim of this study was to identify and synthesise reoccurring or unique themes in participant experience, thematic analysis was used as an approach for analysis. In thematic analysis, identification and exploration of themes take priority over the quantification of their occurrences, and makes no attempt to explain the root of these themes (Braun and Clarke 2006). Reoccurring or significant codes were informally identified and roughly defined as interviews are conducted. These initial "proto-codes" were refined and rigorously defined as more interviews were conducted. Although other researchers have identified themes in health care professional perceptions regarding this topic (Lillie et al. 2011), re-emergence of these themes were not given preference in coding. Use of more inductive, data-driven analysis allowed for flexibility and emergence of new themes which may be unique to this cohort (Braun and Clarke 2006). The codes were discussed with the academic supervisor who reviewed the transcripts to ensure appropriateness and accuracy with the goal of maximising validity.

Interviews were concluded as new themes ceased to emerge. Following conclusion of interviews, formal coding of the proto-codes occurred with the entire dataset in mind. Codes were then organised into higher themes. All codes were retained, even in the event of no higher theme organisation. To fully capture the breadth of experience, no attempt was made to resolve contradictory or discrepant themes (Braun and Clarke 2006).

Table 1 Demographic information of participants

Professional title (terminology self-reported)	Gender	Experience in palliative care	Other previous experience
Palliative care clinical nurse specialist	Female	4 months	General surgery for 10 years
Palliative care clinical nurse specialist	Female	4 months	Ward nurse for 16 years
Clinical psychologist	Female	3 years	19 years total in NHS, unspecified previous experience in paediatrics
Advanced nurse practitioner in palliative care	Female	5 years in oncology palliative care, 7 years in hospice	
Palliative care nurse	Female	10 years	Senior staff nurse on colorectal ward
Palliative care consultant	Male	10 years	Previously in different unspecified specialities
Consultant in palliative medicine	Female	22–23 years	

Note that this table is ordered by years' experience in palliative care, and as such does not indicate which participants expressed which views in the following sections

Results

Participants

Eight PHCPs responded to the recruitment email, and seven completed interviews. The final participant was ultimately unable to participate due to a time conflict between the participant's annual leave and the researcher's timetable. This gives a response rate of 58%, as 12 PHCPs were eligible for participation, although it is unclear if all were made aware of this study. Of the seven participants, six (86%) were female and one (14%) was male. There were four nurses, two consultants, and one psychologist. Years of experience in palliative care ranged from 4 months to 23 years. The demographics of this cohort are further detailed in Table 1.

Overview of results

Each of the participants ($n = 7$) stated that providing genetic services to patients in their department was happening

neither consistently nor effectively. Several barriers to appropriate identification and management of eligible patients were described by the cohort, described as subthemes under the general theme "There are Barriers to Addressing Genetics in Palliative Care." However, each participant also described genetics services as important for their patients, as described under the theme of "Genetics is Relevant to Palliative Care." Several subthemes described situations and complications that straddled these two themes, and have been organised under the heading "Timing is Critical."

Main theme: there are barriers to addressing genetics in palliative care

Of the seven PHCPs interviewed, five mentioned that they had met with a palliative patient who had a family history or genetic link to their cancer. However, most of these participants ($n = 3$) were not able to give a detailed account of these experiences, and none of them were able to specifically detail whether any genetic investigations were conducted, or the outcome. The lack of knowledge which acted as a barrier to improving quality of care is further detailed by the following subthemes.

Subtheme: lack of information

Of the seven participants interviewed, all stated that that they were interested in receiving additional information about the relationship between cancer and genes. Many participants explicitly stated that they did not feel equipped to identify patients who may require specialist services. This perceived lack of sufficient knowledge was expressed in varying levels by the different participants; consultants were more likely than nurses to express some level of confidence or experience with dealing with genetic issues. Lack of sufficient knowledge was expressed as both a desire for more scientific information, as well as training on issues of consent and how the information is used.

Nearly all participants ($n = 6$) were able to list some features which suggested a genetic link to cancer, such as an unusually young age of onset, multiple family members with cancer, etc.. However, most of the participants stated that they did not have a sufficiently detailed amount of knowledge to consistently and accurately identify patients eligible for further discussion with genetic professionals. They stated that they would not feel confident in addressing genetics with their patients because they would not be able to accurately answer their questions and address their concerns.

None of the participants mentioned that they had formal training in genetics in the past, although several participants stated that they had learned about genetics from discussion with colleagues or reading literature. The science of genetics was described as not "straight forward" by one participant, and another described the field as "emerging." Similarly, one consultant acknowledged this "knowledge gap," and suggested that this was partially due to the relative rarity of patients with a known genetic link.

A desire to know more about the consenting process in genetic testing was mentioned by three participants. One participant, a nurse, explained what she would expect to know about the genetic testing process in order to feel comfortable in obtaining informed consent from a patient:

> "I would need to know, you know, what it's likely to be used for, who can access it, the safety of the storage, how long it's kept for. You know, the kind of questions the patient's likely to ask really… because you can't consent someone until you have the full information and be able to answer their questions."
> - Participant 2

In essence, the participants' unfamiliarity with the process of genetic testing was preventing them from being able to address the concerns of their patients, and so was preventing them from mentioning it in general.

Subtheme: lack of links with genetics services

Only one participant stated that he or she knew how to get in contact with a specialist in cancer genetics, due to a professional relationship with several colleagues in the Cancer Genetics Service for Wales (CGSW). Other participants ($n = 5$) stated that they would attempt to find contact information for these colleagues using the hospital intranet, while one stated that he or she would not know where to begin to look for specialist advice. None knew where to find referral guidelines, although one participant stated that he or she thought they were readily available.

Despite most of the participants being uncertain how to contact the CGSW, the participant (participant 4) who had a personal contact in the genetics department felt as though his or her colleagues would be aware: "Uh, yeah I think they would know you could ring across."

Interestingly, genetic HCPs were not always cited as the most likely person to contact in the first instance. Breast nurse specialists were cited as a knowledgeable and accessible group by one participant. Two participants stated that they would likely go to a more senior member of staff within their own department for further advice.

Overall, many participants expressed that they were not familiar with the pathway available to refer eligible patients to the CGSW, nor what constitutes an eligible patient. Furthermore, many did not feel comfortable addressing

genetic issues as a result of this lack of information, in addition to concerns about how genetic information was used and stored. The participants who did feel more confident in these arenas had mixed opinions whether their colleagues were similarly positioned to enable access to genetics services for their patients.

Main theme: timing is critical

Time constraints were mentioned in several different contexts by this cohort. For example, several participants explained the important distinction between the terms "palliative" and "end of life," as illustrated in the below quote from consultant:

> "We've seen palliative care has sort of expanded over the last few years so we're no longer last few weeks of life. We cover the last few years of life quite frequently and we've had patients that have been with me for seven, eight years and are still going quite strong. So our specialty has certainly expanded… you find that patients sometimes come quite close to death but they recuperate and they have a course where they live a bit longer. Yes, life limiting conditions, yes, but sometimes they live longer than they would have maybe twenty years ago."
> -Participant 1

These participants described palliative care as having a role in these patients' lives over a longer period of time than in the past. However, these and other participants described time as an important factor to consider for their patients. Issues of timing illustrate the conflict between several professional responsibilities and fundamental principles, from "just distribution of finite resources" to "patient autonomy" and "primacy of patient welfare."

Subtheme: needs to be quick

Despite the extended role of PHCPs, several participants (n = 2) explicitly stated that palliative patients needed quick attention from the genetics services. One nurse explained that she felt as though the palliative care team had an "obligation" to indicate that the patient needed urgent contact with the genetics department.

> "No, I think it's our obligation to flag it up, because we have people in here whose prognosis is months, so it's our obligation to identify… So um, no I think it would be on the obligation of the referrer to identify how urgent it needed to be done"
> -Participant 6

Prioritisation of a quick intervention for imminently terminal patients was another important factor for the level of responsibility this participant was comfortable in assuming. In the below quotation, the same participant describes her willingness to take a sample of blood for DNA storage in any of her palliative patients, or whether she would prefer to have a specialist (ex: genetic counsellor) assume that role.

> "I think it's again about time really. I think if you've got the luxury of time then I think it's important to make sure that yeah, you've got the right person there who can give them the right information, but if you haven't got that luxury of time, and that's really important to them, and if I felt equipped to give sufficient, or answer sufficiently their questions, then yes, I would do it."
> - Participant 6

Similarly, one clinician, a clinical psychologist, discussed that expectations needed to be managed for patients at the end of life:

> "The process of genetic testing is quite slow I think, and you might have died before the answer comes out so you're still not knowing. And that's hard thing, so I think you have to be responsible when you do genetic testing towards the end of anybody's life that they've very aware of the time parameters, and that they need that information and unanswered questions from the time they're dying, which potentially could disrupt the grieving process for the other people in the family."
> - Participant 7

The pressure of time in this way acted as both a barrier to providing genetics services, and also a motivator for one participant to be open to taking on more responsibility. Participants stated that they felt as though these time pressures could probably be appropriately managed if PHCPs were clear with their patients and willing to accept responsibilities regarding requesting services from other departments or assuming some tasks themselves.

One more thing to worry about

About half (n = 4) of the participants mentioned that introducing the possibility of an inheritable component to their cancer may cause negative emotions (such as anxiety, concern, worry, etc.) in the patients or their families. In the below quote, one participant expressed her concern of what may happen if a PHCP talked about a genetic link to the patient's cancer:

> "Don't forget that for my role, a lot of my patients are towards the terminal stages of their disease anyway, so they've got lots of worries and lots of concerns about the family. So if we were suggesting to them this might be a genetic cancer, I wouldn't want them to be worrying

what they've done to the family when they're already worrying about their families, you know?"
- Participant 5

This participant and others described their patients as particularly vulnerable, due to pre-existing anxiety over death and dying, financial concerns, and the families which they are leaving behind. They also mentioned that family members may not wish to know if they are also at risk of developing cancer, and so that it may not always be in the best interest of the patient to address genetic concerns. These participants had mixed opinions whether patients had pre-existing concerns that their family members would also develop cancer ($n = 2$) or if PHCPs would simply be introducing new concerns ($n = 1$). One participant did not comment on this distinction.

Subtheme: duty to warn

About half of the participants ($n = 3$), including two of the participants who said that genetics was "one more thing to worry about," stated that PHCPs had an obligation to disclose to their patients if they thought a genetic link to cancer was possible in their family. Even when directly in conflict with the prior subtheme, these participants all agreed that they had a wider obligation to both the patient and the family. This internal conflict is illustrated in the below quote:

"I suppose because it might open a can of worms, people getting anxious about themselves and they're thinking about the relative, but sometimes... maybe if it's not addressed they'd be worried about afterwards and maybe you'd have to feel your way through a family to see who you'd address it with and who you wouldn't address it with. I think you need, if you had a strong suspicion, then you would really need to address it, cause it's unethical really not to, isn't it?"
- Participant 2

When asked to expand, the same participant continued to express concern for unaffected family members:

"If you knew something that was going to harm them, then shouldn't you do something about it? I suppose you're withholding information about them that I feel possibly should be shared with them."
- Participant 2

This participant and others stated that they felt as though the family members should be informed if the PHCPs suspected that they too could be at risk of developing cancer. Another participant also included the caveat that she would need to feel confident in her knowledge of cancer genetics before she felt comfortable making such an assessment.

Subtheme: last chance to get DNA

Several participants mentioned that by the time that their participants had arrived in palliative care, a family history or genetic assessment "should have" taken place. Multiple participants explicitly stated that oncologists will likely have made, or should have made, such an assessment. However, each of these participants and two others stated that this likely is not always, or even frequently, the case. One participant explains why his or her colleagues should not always assume that their patients have been appropriately assessed before arriving in palliative care, or that conversations should still take place even if they have:

"I think we mustn't assume that all the discussions have already been held in an effective way. In fact I think sometimes when palliative care workers assume that this has already occurred and already happened it is now completely too late to have these conversations, I think they're wrong. I think discussions may have been held previously, with surgeons or oncologists and other professionals but I often find with many aspects of information, there's a need for a repetitive information giving with people until they understand something. That's quite a normal process I think, trying to cover all this in one busy oncology consultation with about twelve different subtopics is going to get forgotten quite, quite quickly."
- Participant 1

However, despite acknowledging that the palliative setting is a reasonable to address these issues, the same participant later stated that the patients who were unwell and potentially had the least amount of time left would not be ideal candidates for referral:

"I would choose patients appropriately, so only patients who would be able to make an outpatient appointment would I would refer. I probably wouldn't refer those who was too unwell for referral."
- Participant 1

For this participant, the lack of adequate time was not an overriding consideration spurring action.

Regarding discussing genetics in palliative care, several sometimes contradictory views were expressed, even by the same participant. Palliative care was described both as an inconvenient time to discuss genetics, but also as an important opportunity to address concerns and collect a sample. Despite

the conflicting views, all participants expressed both barriers and motivating factors to addressing genetics.

Main theme: genetics is relevant to palliative care

Every participant stated that genetics has a relevant role to play in palliative care, and that he or she was interested in further integration between the two departments (improved access to care). Several reasons were given, including facilitating cascade testing and preventative care for family members, the need to address patient concerns, and the potential for psychological benefit. Many of the participants discussed the following subthemes in the context of providing adequate care and addressing the needs and wishes of the patients (primacy of patient welfare and patient autonomy).

Subtheme: potential for psychological benefit

Six of the participants discussed that genetic testing for a predisposition to cancer had the potential to psychologically benefit the affected proband. The remaining participant stated that he or she thought the benefit was primarily of a medical nature for the surviving family. When discussing psychological benefit, the participants discussed the potential for feelings of closure, legacy creation, a sense of purpose or desire to help, comfort in prevention, and caring for one's family. One participant likened the storage of DNA to donating one's body for science:

> "I think this would be another way of feeling, 'I have done something useful with my remaining life that might be of benefit to my children, and their children in the future.' I think it would potentially give their children strong purpose and strong feeling of possibly satisfaction that they've left something that might be of use in this terrible situation of the cancer and the death and dying process. A bit of a legacy creation, something that others can find useful."
> - Participant 1

This participant and others described DNA storage or genetic testing as having the possibility to address some concerns and anxieties felt by the probands about their families. Another participant, a clinical psychologist, expressed a similar opinion about legacy creation, with the caveat that it would likely still be a difficult experience for a parent:

> "I'm not necessarily saying that it's a positive experience, I don't think it's every positive. If you have a BRCA gene it's rubbish, isn't it? It's rubbish. Um, but it's about why you're asking for it. If you're palliative it's about being able to protect your child..."
> - Participant 7

Participants acknowledged that the decision to have genetic testing would be difficult for probands, but has the potential to address the proband's psychological need to protect his or her family. In addition to the potential to address concerns for others, genetics was expressed by one participant as a way to help the patient deal with his or her emotions towards the diagnosis:

> "Often patients would come and ask me, 'What did I do wrong? When did I go wrong and, and what about my lifestyle made me have, have cancer?" And that's especially true for the people who didn't smoke. So younger patients, or even older patients who've not smoked at all and lived reasonably healthy lifestyles would often ask, 'What did I do wrong? What was wrong with my environment that I've developed this cancer?'… I think genetics can sometimes be an important way of explaining, if you do it sensitively and in the correct way of taking the guilt away from someone. And I think the guilt is a very strong factor with people sometimes in their lives."
> - Participant 1

In essence, genetics was a way for this PHCP to address negative emotions in his or her patients.

Patients are interested

Several participants ($n = 5$) stated that they had encountered patients or family members who expressed concern that the cancer ran within the family, or that they were interested in genetic testing. One participant stated that he or she felt as though younger generations are likely increasingly aware of genetics:

> "I think people are probably more aware of [a genetic relationship to cancer] now. I think there's probably so much more in the media, so much more screening programmes. So I think things are being picked up earlier as well, so they might be… this is a bit ageist I suppose, but I think they're a bit more aware, whereas we didn't really talk about genetics years ago, from a generational point of view, I think people are just more aware of it now, so they're more interested in it."
> - Participant 6

The relationship of media's effect of increasing awareness of hereditary cancer was mentioned by several participants ($n = 3$). This was expressed as both a positive thing:

> "These days with Angelina Jolie [laughs] she's got a lot of… she's probably helped a lot of people. So

> I suppose these days there are ways people can be proactive I suppose. But for me it would probably be the benefits of having that awareness and being closely monitored."
> - Participant 6

as well as a negative phenomenon:

> "There's a lot in the media, particularly with the Angelina Jolie stuff in the media, that they're much more aware that there is a gene, and also from my perception, for me, people over think it's them. They think the probability of having a cancer gene is higher than it is, so there's a lot more people who consider genetic testing who wouldn't necessarily meet the criteria, because there isn't the family history. There's some frustration and difficulty with that."
> - Participant 7

Although these participants had differing viewpoints as to whether this increased public awareness of hereditary cancer had a positive or negative effect on their patients, they seemed to agree that some of their patients are interested in exploring this link within the palliative setting.

Subtheme: fits well within our skill set

Every participant said that addressing genetic issues at the end of life fit well into the role of palliative care; one participant went as far to say that "the palliative setting lends itself to it." Participants also agreed that the goal of PHCPs should be to identify at-risk patients and signpost them quickly to genetics services, rather than provide the service itself:

> "I think as a nurse specialist, who is someone in the front line, a person that [the patient has] felt comfortable to be approached with, they have an obligation to have a basic knowledge… Palliative care is a little bit different where you're a jack of all trades… in palliative care, you cover everything… You can become very spread out thin with your knowledge, and I think… it's probably our role to have an insider identify it, and know where to signpost."
> - Participant 6

Nurses were more likely to feel comfortable taking blood to facilitate speedy DNA storage following consent training, while one consultant felt as though that should remain the responsibility of the genetics department.

Most participants were asked why their colleagues in previous studies did not think that genetics was relevant in palliative care. Reasons listed were a lack of scientific knowledge, fear of the unknown, and worry that it would be introducing a new concern into the patient. One participant from a psychology background described her perception on this topic:

> "Nurses like to protect patients… I don't agree. I think until you take your last breath you're an individual, and as long as you have the cognitive understandings of the implications of your decision, then you should allowed as a human being to make that decision about your life. That shouldn't be taken away from you by someone who wants to protect you and make it all okay."
> - Participant 7

For this participant, concern for the patient was perceived as overly paternalistic, and that the patient is entitled to receiving information if the PHCP thinks it is relevant to his or her situation.

In general, genetics was described as having the potential to benefit patients and their families, and that many of their patients are aware of or concerned about their possible genetic heritage. All participants stated that both consultants and nurses had the capability to discuss genetics with their patients in some basic capacity, although slightly different levels of involvement were discussed.

Discussion

The views and perceptions of these participants differ considerably from those reported in the existing literature in key areas. Perhaps most significantly, while each participant acknowledged that there may be additional psychosocial considerations when discussing genetic issues with those at the end of life, each participant also stated firmly that he or she believed that these barriers should not prevent conversations about genetics or inheritance of cancer susceptibility to be discussed with this cohort. In essence, every single participant emphatically stated that genetics has a key role in palliative care.

Interestingly, the psychological considerations which this cohort said must be addressed with patients at the end of life (complex grieving, feelings of guilt, worry for one's children) are extremely similar to those reported by PHCPs in other centres (Lillie et al. 2011; Metcalfe et al. 2010). This may indicate that these understandable concerns for patient care are deeply rooted in many HCPs across many centres. However, the important finding from these interviews is that these concerns may have the potential to be mitigated, and perhaps will act as thoughtful considerations to be made rather than acting as a barrier to providing vital services.

The role of clinical psychologists

There may be several ways for genetics professionals to address and minimise these reservations with their palliative colleagues. An intriguing novel possibility which arises from this evaluation is the potential for clinical psychologists to take an integral position in this process. The clinical psychologist who participated in this study was engaged in discussing genetic issues with her patients and had an impressive knowledge of ethical considerations. However, other clinical psychologists working in palliative medicine may not be so familiar with or open to discussing these issues. It is worth future investigation to assess if other psychologists would be comfortable with assuming this role, if they are not already, and whether other PHCPs would be confident in discussing genetic issues knowing that their colleagues were on hand. As this is the first time, to the author's knowledge, that a clinical psychologist working in palliative care has been asked about genetics issues, it remains an exciting possibility.

Clinical psychologists are relatively widely available in palliative and hospice settings, either employed directly as a core staff member or through charities. This availability means that they may be more widely accessible for patients and families for multiple, long-term discussions regarding the emotional impact of coping at the end of life, which may include fall out from genetic testing, than genetic counsellors. Psychologists are skilled at addressing complex issues of grief and loss, and contain specialist knowledge into the psychological process of dying. This skill set has the potential to provide support for families in these difficult situations. Clinical Genetics professionals may be able to tap into this this skill set by offering training/study days to their palliative HCP colleagues, including clinical psychologists, to discuss the psychological impact of receiving (or not receiving) a genetic diagnosis. Other possible topics suggested by this study may include the emotional impact of genetic information on the wider family, and issues related to confidentiality. With this additional training, psychologists may be more comfortable in offering psychological support to their patients who may be considering genetic testing or DNA storage.

The combination of a recognised expertise, and their potential familiarity to palliative HCPs working within the same centre may make clinical psychologists more palatable to their colleagues; in other words, a PHCP may feel more comfortable addressing the medical aspects of hereditary cancer knowing that a familiar and trusted professional is on hand to fully explore the psychosocial considerations, rather than an unfamiliar professional (genetic counsellor) whose role may be less widely understood by other practitioners. This could allow quick action following identification of a potentially eligible patient, as all required staff members would be present at the point of contact. Patients could also benefit from the continuity of contact with a professional who is able to meet with themselves and their families multiple times, which at the moment is not possible in many clinical genetics services due to resource limitations.

Once the patient receives enough medical information to give an informed consent to the storage of a DNA sample from a nurse or consultant, the DNA sample could be stored with confidence, ensuring that the genetic information is not lost to future generations. A clinical psychologist could be on hand to address any extreme objections or acute psychological concerns for the patients or families. After a DNA sample is safely secured, a genetic counsellor would be available to have in-depth conversations with the patient and the family regarding testing. In this way, the time pressure of quickly getting a sample would be somewhat assuaged.

However, in no way does this study suggest that a genetic counsellor's role would be entirely assumed by PHCPs. Rather, medical PHCP may introduce the concept of genetic testing to the patient and the family if they thought it was appropriate to do so. The psychologist would act in a supportive role for the medical PHCPs by addressing immediate psychological concerns for the patient and the family before a sample is collected, or maintaining contact with the families following testing. A genetic counsellor or geneticist would still be vital to discussions around what tests are most appropriate, and the psychological impact of genetic testing, but under this model, more time would be available to have these conversations at a more appropriate time. In essence, the PHCPs' roles in this process would be to help facilitate collection of genetic material in a safe and comfortable way for the patients and their families, allowing genetic testing following the death of the patient.

Implications for practice: a need for further training

The genomic revolution will likely continue to lead to an increase in professional knowledge, particularly for recent graduates, as genetics becomes integrated into medical training (Wilson et al. 2016). However, this study suggests a need for further training for working professionals. These participants together with other studies (Lillie et al. 2011; Metcalfe et al. 2010; Quillin et al. 2011a) all came to the consensus that the clinical genetics services and palliative care would benefit from a closer working relationship. Lack of knowledge was mentioned by many of the participants, and inspiringly, an openness to receive further education was indicated. Perhaps most urgently is the lack of knowledge about the availability of the services provided by Clinical Genetics, or indeed even simple information such as contact details and a list of the referral process and guidelines.

A Clinical Genetics Service offering continual professional development to their PHCP colleagues accomplish two goals. Firstly, it could foster a closer working relationship, as colleagues develop professional relationships between the two

services. Secondly, providing scientific and practical information about the benefits and limitations of genetic testing would be an excellent opportunity to address the barriers presented in this study, and to enable PHCPs to identify patients who may benefit from DNA storage or referral to clinical genetics.

Possible topics suggested by this study include DNA storage, an overview of cancer predisposition syndromes, "red flag" signs that a hereditary component may be in play, and the practical contact information and referral criteria to the local Genetics Service. It may also be a prime opportunity to discuss the role of other professionals who may access genetic testing. Similarly to the literature, the view that genetic conversations should have taken place with other HCP before the point of palliative treatment was raised by most of the participants (Lillie et al. 2011; Metcalfe et al. 2010). Unlike the literature, this was not necessarily cited as a reason to not have these discussions, as participants acknowledged that it should not be assumed that it had been previously addressed, such has been previously argued by genetics professionals (Daniels et al. 2011). Perhaps this healthy level of cynicism could be exploited by those providing training to this cohort.

Similarly, several participants mentioned awareness about oncologists providing genetic testing to their patients to inform their treatment, and used this as evidence that these conversations may have already taken place. Indeed, various genetic markers indicate which treatments would be likely to be more or less effective, and are tested by oncologists with increasing frequency. For example, poly ADP ribose polymerase (PARP) inhibitors have been shown to improve survival in women with *BRCA1/2*-deficient tumours of the ovary (Matulonis et al. 2016).

However, presence of a *BRCA1/2* mutation within an ovarian tumour indicates a possibility of a relatively highly penetrant hereditary disposition to cancer, Hereditary Breast and Ovarian Cancer Syndrome (Weren et al. 2017). As oncologists are performing this tumour analysis to inform treatment, it does not automatically follow that they are acknowledging the potential for risks to other family members. Indeed, oncologists' knowledge of cancer predisposition syndromes has been described as low (Quillin et al. 2011a). Educating PHCPs on various ways oncologists and other HCPs earlier in the cancer journey could possibly miss the opportunity to discuss genetic issues with their patients may help PHCPs understand the need for a more proactive approach.

Interestingly, many participants mentioned that they would benefit from videos to pass on to their patients, as concentration and focus can be an issue for palliative patients. The website Cancer Genetics Story Bank (www.cancergeneticsstorybank.co.uk/) may be a useful resource, as it contains several educational videos aimed at discussing and explaining the process of genetic testing, decision making, completing a family history questionnaire, and psychological issues surrounding genetics and cancer. This website, which contains interviews of both patients and staff members of a Clinical Genetic Service, could easily be distributed to patients, families, and professionals to meet this need. It may be worth future consideration if a palliative-specific video would be beneficial to develop.

Evolving attitudes towards clinical genetics

Unlike participants in previous studies who reported that palliative care was an "inappropriate setting" to discuss genetic issues (Lillie et al. 2011), or of "little importance," (Metcalfe et al. 2010), this cohort agreed that the potential benefits of genetic risk assessment outweighed the potential for harm in most cases. However, confidence in addressing genetic issues was mixed, and experience with genetic risk assessment was low. This is similar to the experiences reported by both physicians and nurses in other cohorts (Metcalfe et al. 2010; Quillin et al. 2011b).

Even though genetic proficiency remained low within this cohort, their openness to become skilled in genetic risk assessment is notable. It may be that the perceptions of this cohort signal a wider shift in attitudes towards clinical genetic services. Since many of the previous work discussing genetics and palliative care have been published, technological advances have led to genetics and genomic medicine to become more integrated in other subspecialties. This may be leading to a greater understanding and appreciation for Clinical Genetics than existed previously, which may explain this cohort exhibiting increased interest in engaging with Genetics than in previous papers. As the only paper published (to the authors' knowledge) specifically regarding PHCPs' attitudes towards genetics in recent years, this study provides evidence that the attitude towards genetics is shifting within palliative medicine.

Similarly, it may be that the impact of an increased public awareness and acceptance of genetic issues within the media has diffused to healthcare professionals. To support this, three of the participants brought up Angelina Jolie's opinion articles or the family history of Kirstie Allsopp, a British TV presenter; one participant went as far as to say that she heard of genetics more in her private life than her professional life. The impact of the media on demand for cancer genetic testing has been well documented internationally, and is increasing (Evans et al. 2012; Desai and Jena 2016; Roberts and Dusetzina 2017). This receptiveness to engagement suggests that this could be a prudent moment for Genetic Professionals to take advantage of this interest to offer collaboration with their colleagues.

Thematic framework: a physician's charter

The themes which emerged by inductive analysis match closely to the framework proposed in the Physician's Charter by the

ABIM Foundation, ACP-ASIM Foundation, and European Federation of Internal Medicine (2002). This charter describes a set of ethical principles and professional commitments from HCPs to patients, from commitments to lifelong learning ("professional competence") to respecting patient confidentiality.

Some of the obligations listed in this charter could be fulfilled by addressing the barriers identified in this work. One obvious avenue is committing to gaining more knowledge of emerging fields such as genetics, particularly as genetic testing becomes mainstream in other clinical sub-specialities such as palliative care. Additionally, introducing genetic issues to the palliative agenda has the potential to address two further commitments: improving quality of care and improving access to care. As previously discussed, genetic issues can address the psychosocial concerns of the patient, ensuring more holistic, quality care. Additionally, by consistently considering genetic causes to disease, the PHCP is ensuring that they are providing an equitable service to their patients. As discussed in the charter, each healthcare system has a duty to provide "uniform" services. By assuming that discussions regarding genetics have already taken place, or that the patient would not want to consider a potential genetic link, one could argue that the PHCP is inequitably withholding information from certain patients based on perceptions of their treating team and the capacity of the patient. By setting a standard pathway of identification of patients and a system of onwards referral or DNA storage, PHCPs could ensure that they provide equitable care to all patients.

Strengths and limitations

While this study did have a relatively good response rate, the thoughts and perceptions of these PHCPs applied only directly to the participants interviewed, and do not represent the views of their colleagues or professionals in other centres who have not been interviewed. Additionally, there may be some other forms of bias in their responses. For example, several participants gave responses which insinuated that the interviewer was a part of the clinical genetics team. While the interviewer was a MSc student and not a clinical staff member, this perception may have unconsciously biased interviewees towards giving answers which were more open to and interested in genetics than was actually felt. To attempt to mitigate this, questions were framed in open, non-leading ways, but remains a potential source of bias.

Additionally, only one of the participants could recall a specific patient to whom he or she personally provided genetics services. As one of the aims of this study was to explore the experiences of PHCPs with genetics, this restricted the types of questions which could be usefully asked. To attempt to get meaningful information, the interviewer asked hypothetical questions about what the participant thought he or she might do. In order to minimise bias, participants were asked to think of a specific patient or several patients, and imagine how they would react and respond. By asking the interviewee to imagine a real person or family, it was hoped that they would be able to provide more realistic answers. However, this may or may not be representative of how a PHCP would actually react to a situation, particularly when under real-life pressures such as time and resource constrictions. Once training has been provided, it may be worthwhile re-contacting these PHCPs and attempting to assess if they have identified any eligible patients, and how they addressed the situation.

As this work has taken place in a national-based healthcare system, some of the insights may be specific to the UK. For example, there was little focus on financial implications such as insurance coverage for genetic assessment. However, many of the difficulties faced by this cohort (lack of specific training, lack of professional relationship with genetics specialists) are likely to be of international relevance.

However, despite these limitations, these interviews provide some novel insights into the workings of one multidisciplinary PHCP team. For example, not only did the interviews gather responses on how an individual would respond to a situation, but it was also possible to compare these answers to how another type of PHCP thought their colleagues would be able to handle the situation. This allows a fuller picture of how these different professionals operate as a team, not only in isolation, enabling accurate identification of whether this group of PHCPs would be interested in additional training, what they would like to learn, or clarifying expectations amongst staff members.

Additionally, it remains the only set of interviews to the author's knowledge regarding genetics and palliative care following the increased public interest in genetic susceptibilities towards cancer. Again, while these findings are not generalisable, it may indicate that other palliative centres are becoming more open to providing genetics services for their patients.

Future studies

A significant barrier to providing genetics services for palliative patients needs to be more fully addressed by research: specifically, the question of whether palliative patients directly get benefit from storing a sample of their DNA or receiving genetic counselling which would not directly affect their health. While work has been done regarding affected patients being tested for the benefit of their families, little to none has been done to examine whether this is compounded by the process of death and dying. Not only would this help address PHCP concerns about the potential for negative psychological effects of genetic counselling a palliative patient, but it also may help identify ways to minimise potential harm for this vulnerable cohort.

One possible method of assessing this is a combination of qualitative interviews (in order to capture rich data for a novel area), in addition to a quantitative assessment which can measure change over time. One such questionnaire, the *G*enetic *C*ounselling *O*utcome *S*cale 24 (GCOS-24) has been validated to assess whether patients have a measurable improvement in psychological wellbeing following contact with clinical genetics services (McAllister et al. 2011). As patients with cancer are now being treated palliatively for months to years, such a study may be possible from a practical point of view.

Implication for future practice

In conclusion, this work provides a strong basis for the development of training programmes regarding genetics for the benefit of PHCPs. The results argue that some PHCPs are open and interested to receive more information, and also provide an outline of potential topics worth discussion. This includes but is not limited to referral guidelines, issues of consent, the distinction between DNA storage and testing, the role of the genetics department, and practical considerations. It also suggests potential areas for future evaluation or research, such as the possible role of palliative clinical psychologists in genetics, whether a training programme for PHCPs results in a change of behaviour, and whether other palliative centres in the UK and internationally also have a changing attitude towards genetics.

Funding No funding was obtained for this study.

Compliance with ethical standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

Appendix A: Interview guide

- Thank the participant for agreeing to participate in the study.
- Review the aims of the study, and offer the participant an opportunity to ask questions regarding any aspects of the study.
- Remind the participant that this is not an audit of their practice, and to feel free to ask questions at any point of the interview.
- Throughout the interview, definitions will be provided at request, or if the participant's definition of a concept is different to what will be used in this study.

Review of demographic information: Ask participant to state professional title and number of years' experience

1. *Understanding of the genetics of cancer*

   - To the best of your knowledge, how strongly genetic is cancer?
   - Have you ever treated patients with a family history of cancer?
   - In your opinion, is it important to consider a genetic predisposition to cancer in your patients?

2. *Taking a family history*

   - Have you ever taken a family medical history?
   - What would be the types of questions you asked during this process?
   - In your opinion, is it important to consider the family history of cancer when treating your patients?
   - Would you feel confident in identifying a patient with a significant family history of cancer? In your opinion, what would this constitute?
   - If you identified a patient with a significant family history of cancer, what steps would you take? What information would you share with the patient?
   - Do you have any examples where taking a family history turned out to be significant?
   - How do patients react to taking a family history?

3. *Genetic testing*

   - What is your understanding of genetic testing for genetic predispositions to cancer?
   - To the best of your knowledge, are there genetic susceptibility tests available for your subspecialty?
   - Is genetic testing for a genetic susceptibility to cancer something that you have ever considered or discussed with your patients?
   - As a health care provider, do you think terminally ill patients would benefit from genetic testing for a genetic predisposition to cancer?
   - Do you think the families of terminal patients are interested in testing for a familial link to their cancer? Have you ever been asked about genetic testing by patients or families?
   - Is the terminal care setting an appropriate place to discuss a familial susceptibility to cancer? Why or why not?

4. *DNA banking*

   - What is your understanding of DNA storage?

- Have you ever discussed or offered DNA storage with your patients?
- Is your opinion, is DNA storage a good alternative to genetic testing in terminally ill patients? Why or why not?
- How do you think patients would respond to the offer of DNA storage? How do you think their families would react?
- At what point do you think addressing DNA storage is most appropriate?
- In your opinion, whose responsibility is it to initially broach the topic DNA testing or storage? Ex: Physician, nurse, genetics services, patients
- Is DNA storage something you will consider for your practice in the future? Why or why not?

Definitions

Family history: Oral or written questionnaire exploring the patient's family's medical history. Used to assess potential genetic risks in the family. Ideally multigenerational.

Genetic testing: Scientific investigation into the somatic DNA of the patient, or in some cases the DNA of their tumour. In this setting, used to detect high-risk genotypes that would indicate a high-risk of cancer, or a familial cancer syndrome.

DNA banking: Storing of a sample of DNA, commonly blood or more rarely saliva or tissue, for genetic testing at a later date. Allows genetic testing after the death of the patient.

References

ABIM Foundation, ACP-ASIM Foundation, European Federation of Internal Medicine (2002) Medical professionalism in the new millennium: a physician charter. Ann Intern Med 136:243–246

Ash JS, Gorman PN, Lavelle M, Stavri PZ, Lyman J, Fournier L, Carpenter J (2003) Perceptions of physician order entry: results of a cross-site qualitative study. Methods Inf Med 42(4):313–323

Braun V, Clarke V (2006) Using thematic analysis in psychology. Qual Res Psychol 3(2):77–101. https://doi.org/10.1191/1478088706qp063oa

Cardiff University (2015) Managing your data after your project has completed. Cardiff University Information Services. http://www.cardiff.ac.uk/insrv/researchdata/aftertheproject/index.html (accessed 9 Aug 2015)

Daniels MS, Burzawa JK, Brandt AC, Schmeler KM, Lu KH (2011) A clinical perspective on genetic counseling and testing during end of life care for women with recurrent progressive ovarian cancer: opportunities and challenges. Familial Cancer 10(2):193–197. https://doi.org/10.1007/s10689-011-9418-1

Desai S, Jena AB (2016) Do celebrity endorsements matter? Observational study of BRCA gene testing and mastectomy rates after Angelina Jolie's New York Times editorial. BMJ 355:i6357

Evans DGR, Barwell J, Eccles DM, Collins A, Izatt L, Jacobs C, Donaldson A, Brady AF, Cuthbert A, Harrison R, Thomas S, Howell A, The FH02 Study Group, RGC teams, Miedzybrodzka Z, Murray A (2012) The Angelina Jolie effect: how high celebrity profile can have a major impact on provision of cancer related services. Breast Cancer Res 19(5):442

George A, Kaye S, Banerjee S (2016) Delivering widespread *BRCA* testing and PARP inhibition to patients with ovarian cancer. Nat Rev Clin Oncol 14(5):284–296. https://doi.org/10.1038/nrclinonc.2016.191

Kentwell M, Dow E, Antill Y, Wrede CD, McNally O, Higgs E, Hamilton A, Ananda S, Lindeman GJ, Scott CL (2017) Mainstreaming cancer genetics: a model integrating germline *BRCA* testing into routine ovarian cancer clinics. Gynecol Oncol 145(1):130–136. https://doi.org/10.1016/j.ygyno.2017.01.030

Kessler S (1997) Psychological aspects of genetic counselling. Am J Med Genet 72(2):164–171. https://doi.org/10.1002/(SICI)1096-8628(19971017)72:2<164::AID-AJMG8>3.0.CO;2-V

Lakhani NS, Weir J, Allford A, Kai J, Barwell JG (2013) Could triaging family history of cancer during palliative care enable earlier genetic counseling intervention? J Palliat Med 16(11):1350–1355. https://doi.org/10.1089/jpm.2012.0583

Lillie A (2006) Exploring cancer genetics and care of the family: an evolving challenge for palliative care. Int J Palliat Nurs 12(4):70–74. 10.12968/ijpn.2006.12.2.20533

Lillie AK, Clifford C, Metcalfe A (2011) Caring for families with a family history of cancer: why concerns about genetic predisposition are missing from the palliative agenda. Palliat Med 25(2):117–124. https://doi.org/10.1177/0269216310383738

Matulonis UA, Wulf GM, Barry WT, Birrer M, Westin SN, Faroog S, Bell-McGuinn KM, Obermayer E, Whalen C, Spagnoletti T, Luo W, Liu H, Hok RC, Aghajanian C, Solit DB, Mills GB, Taylor BS, Won H, Berger MF, Palakurthi S, Liu J, Cantley LC, Winer E (2016) Phase I dose escalation study of the PI3kinase pathway inhibitor BKM120 and the oral poly (ADP ribose) polymerase (PARP) inhibitor olaparib for the treatment of high grade serous ovarian and breast cancer. Ann Oncol:mdw672. https://doi.org/10.1093/annonc/mdw672

McAllister M, Payne K, MacLeod R, Nicholls S, Donnai D, Davies L (2008) Patient empowerment in clinical genetics services. J Health Psychol 13(7):895–905. https://doi.org/10.1177/1359105308095063

McAllister M, Wood AM, Dunn G, Shiloh S, Todd C (2011) The genetic counselling outcome scale: a new patient-reported outcome measure for clinical genetics services. Clin Genet 79(5):413–424. https://doi.org/10.1111/j.1399-0004.2011.01636.x

McConkie-Rosell A, Sullivan JA (1999) Genetic counseling—stress, coping, and the empowerment perspective. J Genet Couns 8(6):345–357. https://doi.org/10.1023/A:1022919325772

Metcalfe A, Pumphrey R, Clifford C (2010) Hospice nurses and genetics: implications for end-of-life care. J Clin Nurs 19(1-2):192–207. https://doi.org/10.1111/j.1365-2702.2009.02935.x

NCCN (2016) Clinical practice guidelines in oncology: genetic/familial high risk assessment: breast & ovarian Version 2.2016 ed. www.nccn.org/professionals/physician_gls/pdg/genetics_screening.pdf (accessed on 1 Apr 2017)

NICE (2010) Familial breast cancer: Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer. https://www.nice.org.uk/guidance/cg164/ifp/chapter/genetic-counselling-and-genetic-testing (2010, accessed on 13 July 2015)

Nordgren L, Olsson H (2004) Palliative care in a coronary care unit: a qualitative study of physicians' and nurses' perceptions. J Clin Nurs 13(2):185–193. https://doi.org/10.1111/j.1365-2702.2004.00816.x

Novetsky AP, Smith K, Babb SA, Jeffe DB, Hagemann AR, Thaker PH, Powell MA, Mutch DG, Massad LS, Zighelboim I (2013) Timing of referral for genetic counseling and genetic testing in patients with ovarian, fallopian tube or primary peritoneal carcinoma. Int J Gynecol Cancer 23(6):1016–1021. https://doi.org/10.1097/IGC.0b013e3182994365

Paluch-Shimon S, Cardoso F, Sessa C, Balmana J, Cardoso MJ, Gilbert F, Senkus E (2016) Prevention and screening in BRCA mutation carriers and other breast/ovarian hereditary cancer syndromes: ESMO clinical practice guidelines for cancer prevention and screening. Ann Oncol 27(5):v103–v110. https://doi.org/10.1093/annonc/mdw327

Pope C, van Royen P, Baker R (2002) Qualitative methods in research on healthcare quality. Qual Saf Health Care 11(2):148–152. https://doi.org/10.1136/qhc.11.2.148

Quillin J, Bodurtha J, Smith T (2008) Genetics assessment at the end of life: suggestion for implementation in clinic and future research. J Palliat Med 11(3):451–458. https://doi.org/10.1089/jpm.2007.0150

Quillin J, Bodurtha J, Siminoff L, Smith T (2010) Exploring hereditary cancer among dying cancer patients—a cross-sectional study of hereditary risk and perceived awareness of DNA testing and banking. J Genet Couns 19(5):497–525. https://doi.org/10.1007/s10897-010-9308-y

Quillin J, Bodurtha J, Siminoff L, Smith T (2011a) Physicians' current practices and opportunities for DNA banking of dying patients with cancer. Journal of Oncology Practice 7(3):183–187. https://doi.org/10.1200/JOP.2010.000190

Quillin J, Bodurtha J, Smith T (2011b) Genetic screening and DNA banking at the end of life. J Palliat Med 14(5):656–657. https://doi.org/10.1089/jpm.2011.9695

Roberts MC, Dusetzina SB (2017) The effect of a celebrity health disclosure on demand for health care: trends in BRCA testing and subsequent health services use. J Community Genet 8(2):141–146. https://doi.org/10.1007/s12687-017-0295-7

Skirton H, Frazier L, Calvin A, Cohen M (2006) A legacy for the children—attitudes of older adults in the United Kingdom to genetic testing. Issues in Clinical Nursing 15(5):565–573. https://doi.org/10.1111/j.1365-2702.2006.01372.x

Vadaparampil S, Quinn GP, Dutil J, Puig M, Malo TL, McIntyre J, Perales R, August EM, Closser Z (2011) A pilot study of knowledge and interest of genetic counseling and testing for hereditary breast and ovarian cancer syndrome among Puerto Rican women. J Community Genet. 2(4):211–221. https://doi.org/10.1007/s12687-011-0058-9

Weren RD, Mensenkamp AR, Simons M, Eijkelenboom A, As S, Ouchene H, van Asseldonk M, Gomez-Garcia EB, Blok MJ, de Hullu JA, Nelen MR, Hoischen A, Bulten J, Tops BB, Hoogerbrugge N, Ligtenberg MJ (2017) Novel BRCA1 and BRCA2 tumor test as basis for treatment decisions and referral for genetic counselling of patients with ovarian carcinomas. Hum Mutat 38(2):226–235. https://doi.org/10.1002/humu.23137

Wilson DJ, Harris BHL, Hibbitts SJ, Riley S (2016) Medical students—how much science education is needed? Med Sci Educ 26(3):403–406. https://doi.org/10.1007/s40670-016-0246-7