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Integrating genomics into the care of people with palliative needs: A global scoping review of policy recommendations

Abstract

BACKGROUND: Genomics has growing relevance to palliative care, where testing largely benefits relatives. Integration of genomics into the care of patients with palliative care needs has not received the critical attention it requires, and health professionals report a lack of policy guidance to support them to overcome practice barriers. **SUMMARY:** To identify policy recommendations related to: (1) integrating genomics into the care of patients with palliative care needs and their families, and (2) care of the family unit, we performed a scoping review of palliative care and genomic policies. Two of 78 policies recommended integrating genomics into palliative care. Six palliative care policies mentioned genomics in background information but were without relevant recommendations. No genomics policies mentioned palliative care in the background information. Across all policies, guidance related to “Delivering Family-Centred Care” was the most frequent recommendation related to care of the family unit, (n=62/78, 79.5%). **KEY MESSAGES:** We identified a policy gap related to integrating genomics into palliative care. Without policy guidance, health services are less likely to commit funding towards supporting health professionals, reducing the personal and clinical benefits of genomics to patients and relatives. Framing genomic information as family-centred care enables policy makers to communicate the value of genomics to palliative care that will resonate with genomic and palliative care stakeholders. These findings increase awareness among policy makers of the benefits of genomic information to patients with palliative care needs and their families and call for incorporation of appropriate recommendations into palliative care and genomic policy.

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Integrating genomics into the care of people with palliative needs: A global scoping review of policy recommendations

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ABSTRACT

BACKGROUND: Genomics has growing relevance to palliative care, where testing largely benefits relatives. Integrating genomics into palliative care has not received the critical attention it requires. Health professionals report a lack of policy guidance to support them to overcome practice barriers to identify palliative patients who are eligible for genetic testing, provide genetic counselling and facilitate genetic testing or DNA storage.

SUMMARY: To identify policy recommendations related to: (1) integrating genomics into the care of patients with palliative care needs and their families, and (2) care of the family unit, we performed a scoping review of palliative care and genomic policies. Two of 78 policies recommended integrating genomics into palliative care. Six palliative care policies mentioned genomics in background information but were without relevant recommendations. No genomics policies mentioned palliative care in the background information. Across all policies, "Delivering Family-Centred Care" was the most frequent recommendation related to care of the family unit (n=62/78, 79.5%).

KEY MESSAGES: We identified a policy gap related to integrating genomics into palliative care. Without policy guidance, health services are less likely to commit funding towards supporting health professionals. Without funding, delivering the benefits of genomics to patients and relatives is more difficult for health professionals. Framing recommendations about genomics as family-centred care may resonate with genomic and palliative care stakeholders. These findings highlight an opportunity to improve the policy landscape and access to genomic information

for patients with palliative care needs. We call for incorporation of appropriate recommendations into palliative care and genomic policy.

INTRODUCTION

Genetics and genomics (herein referred to as 'genomics') has growing relevance to most areas of healthcare, including palliative care, as the genetic basis for disease increasingly influences treatments, risk management, reproductive options and social decisions.[1] The ability of health professionals to identify palliative patients who may have an inherited pathogenic variant, provide genetic counselling, facilitate genomic testing (or DNA storage for future testing) and support family communication has utility for both the individual and family. For the individual, genomic testing may help them access personalised therapies , while unaffected family members can have predictive testing to inform future disease risk and screening or risk-reducing options.[2, 3] Additionally, genomic testing has utility beyond medical decision-making (often termed 'personal utility').[4] Genomic information has the potential to yield psychological benefits for patients with palliative care needs; providing answers for the cause of an illness, a sense of control, and relief at knowing family members may be able to avoid the same disease.[5, 6] For the clinical and personal benefits of palliative-genomic testing to be realised, integrating genomics into the care of people with palliative care needs must be added to the palliative care agenda.[7]

Genetic and palliative care health professionals have identified a lack of guidance and organisational support to overcome barriers to integrating genomics into the care of people with palliative care needs and their families.[8, 9] In the palliative care context, heightened patient and family emotions, deteriorating patient health and cognition, and variable genomic attitudes and knowledge may influence a health professional's decision to initiate a discussion about genomic testing.[10]

Although some palliative care health professionals have concerns about initiating genomic discussions with patients who have palliative care needs and their families,[11] there is no evidence of psychological harm resulting from genomic discussions.[12] In fact, addressing existing concerns that patients with palliative care needs have about their relatives' future disease risk may yield positive psychological benefits.[13] In either case, offering genomic testing to a person at end-of-life

for the benefit of family members highlights the uncertain ethical and legal terrain of palliative care health professionals' duty to the family, particularly where there are complex family dynamics.[14] Furthermore, the absence of support from health services leaves health professionals alone to manage the complex ethical, legal and social implications of approaching discussions about genomics with people who are palliative (and their families), particularly as they near end-of-life.[11] When these barriers prevent patients with palliative care needs from accessing genomic testing before they die, their DNA and family history knowledge are irretrievably lost, which in turn, impacts the quality of information relatives are provided with about future disease risk and management.[15]

Positive public policy for genomics in palliative care will support health professionals to deliver the benefits of genomics to patients and families. Implementation science theories (such as Michie and colleagues' "Behaviour Change Wheel") highlight policy as an important influence upon health professionals' capability (e.g. having the knowledge to patients eligible for genomic testing), opportunity (e.g. processes in place to enable DNA storage at end-of-life) and motivation (e.g. belief they are acting in patients and families' best interests).[16] Other frameworks demonstrate the relationship between the macro- (policy environment), meso- (health services and professional organisations) and micro-level (patient-provider interactions) factors that affect the success of health intervention implementation.[17] For instance, policy recommendations ideally stimulate funding to overcome barriers and develop local guidelines to support health professionals integrate genomics into their practice. For families to benefit from the genomic testing of their dying affected relative, supportive policy at a government or organisational level is first needed to generate the flow-on effects to health services and professionals.[18] Governments and professional organisations are publishing policies that articulate the significance of genomics to routine medical care, but it is not known whether existing policies acknowledge the benefits of palliative-genomic testing or address the practical and ethical challenges health professionals face in the palliative care context.

To investigate the policy support available for palliative and genetic health professionals, we performed a scoping review to identify and map current policy recommendations about the integration of genomics into the care of people with palliative care needs, including recommendations related to care of the family unit. We sought to answer the following questions:

1. What global policy guidance is available that describes the integration of clinical genetic and genomic health information into the care of people with palliative needs and their families?
2. What recommendations in palliative care and genetic/genomic policies regarding care of the family unit are relevant to the integration of clinical genetic and genomic health information into the care of people with palliative needs and their families?

METHODS

DESIGN

A scoping review, using the methodology described by the Joanna Briggs Institute, was selected to map and describe global policy recommendations related to genomics in palliative care, rather than evaluate impact or effectiveness of recommendations.[19] We used the World Health Organization Innovative Care for Chronic Conditions framework as an initial conceptual framework, which guided us to explore the ‘macro’ policy environment.[17] Reporting items aligned with the PRISMA-ScR extension.[20] An a-priori review protocol was published on Open Science Framework (<https://osf.io/5eumn/>) and updated in January 2022 when the second review question was added. The review team (consisting of palliative care and genetic counselling experts with experience in systematic and scoping reviews) developed the second review question following initial exploration of the extracted recommendations about care of the family unit. We identified an opportunity to determine whether recommendations about care of the family unit could reveal common policy ground between palliative care and genomics.

ELIGIBILITY CRITERIA

Eligibility criteria were developed using the Population, Concept and Context framework.[19] For the purpose of this review, we used the term ‘policy’, but sought to include a range of governance documents, including ‘frameworks’, ‘strategies’, ‘standards’ or similar. Policies were required to focus on the provision of palliative care or clinical genetic and genomic services (including genetic counselling). We did not include clinical practice guidelines for singular conditions as we aimed to examine the broader policy environment (for example, service development frameworks were included, while care guidelines for terminal breast cancer were excluded). Eligible policies were published in English between 2010 – 2022 and authored by national or state (or equivalent) governments or their agencies, or international, national or state-based professional palliative care, clinical genetics/genomics or genetic counselling organisations. To retrieve policies from countries with the infrastructure to integrate genomics into palliative care, we included policies from the top 20 countries ranked by the Economic Intelligence Unit Quality of Death Index, for the quality of their palliative care provision.[21] The full eligibility criteria is available in the supplementary material.

INFORMATION SOURCES & SEARCH

The search strategy was co-designed with an information scientist (S.S) and peer-reviewed at a genetic counselling research seminar. The strategy consisted of three approaches: (1) database search, (2) web-search (3) emailing key informants. The database and web-search strategies are available in the supplementary material. We repeated the database and web-search twice: once for palliative care policies and once for genetic and genomic policies. The search was run on the 1st June 2020 and repeated on the 21st February 2022.

1. Database search: Three databases (Medline, EMBASE and CINAHL) were interrogated using nesting and Boolean operators to combine relevant terms, such as ‘Guideline’ and ‘Health Policy’ with ‘Genetic Counseling’, ‘Genetic Testing’, or with ‘Palliative Care’. The database search was supplemented by hand-searching the Canadian Agency for Drugs and

Technologies in Health grey literature tool.[22] Database records were exported to, and deduplicated in EndNote.[23]

2. Web-search: We designed a systematic web-search to retrieve non-commercially published documents.[24] Using Google, we constructed a single-line search using nesting and Boolean operators based on the Medline strategy. To reduce the potential bias of geo-locating algorithms, we used incognito mode and cleared caches and cookies prior to running the search.[24] Based on the number of retrieved pages identified on a test run, we made a pragmatic decision to limit the search to the first ten pages of returned results.[25] The results were captured by copying the web-site name and URL into a Microsoft Excel spreadsheet so the same results could be screened by more than one reviewer.[26] On advice from the information scientist, we ran two additional searches with the “type:PDF” function (one for palliative care and one for genetic/genomic policies), to increase the sensitivity of the search towards retrieving policy documents.
3. Emails to key informants: To capture any missed policies, we emailed key informants to cite their local and/or national palliative care or genetics/genomics policy. Palliative care key informants were identified in the contact list in the Economist Intelligence Unit Quality of Death Index.[21] Genetic and genomic key informants were identified via the Transnational Alliance of Genetic Counseling, consultation with experts, authors identified in this review and targeted, country-specific web searching.[27]

Forward-searching (using Web of Science database) and backward-searching (reviewing reference lists) was conducted on all policies meeting inclusion criteria.

SELECTION OF SOURCES OF EVIDENCE

S.W. & C.J. piloted the eligibility criteria by independently screening 25 randomly selected policies. Changes to criteria included specifying that at least 50% of the policy must be relevant to palliative care or genetic/genomic service provision. S.W. & G.M. then independently screened 20% of the records at title and abstract, and full text screening using Covidence and Microsoft Excel.[26, 28] For

records arising from the web-search, title and abstract screening involved reviewing the web-page, and full text screening involved reviewing the web-site in full. We also followed any potentially relevant internal or external web-links (snowballing). With biostatistician consultation (K.R), we used a Prevalence-Adjusted Bias-Adjusted Kappa statistic and achieved substantial inter-rater agreement (>0.7) before S.W. screened the remainder of the records independently.[29, 30]

DATA ITEMS & CHARTING

We used a modified Joanna Briggs Institute data extraction instrument with pre-determined data items (see supplementary material). In addition to policy characteristics (e.g., author, year, country), we extracted verbatim recommendations with their relevant heading and page number. Ten policies were randomly selected for S.W., G.M. & C.J. to independently pilot the extraction tool. Changes included adding extraction fields, including organisation's jurisdiction (e.g. state, national, international) and population age group (e.g. paediatric, adult, all ages). S.W. independently extracted recommendations about genetics and genomics from palliative care policies, recommendations about palliative care from genetic and genomic policies and recommendations about care of the family unit from both palliative care and genetic and genomic policies. G.M. reviewed extracted data from 20% of the included policies and verified accuracy.

CRITICAL APPRAISAL

In line with scoping review guidance, we did not perform critical appraisal assessments on individual policy documents because (a) policies are not primary research articles and (b) to our knowledge, a validated critical appraisal tool for policy documents does not exist.[25] However, to embed a quality check into our eligibility criteria, we required policies to be evidence-based and include a description of the method by which the policy was developed (informed by the AGREE-tool).[31]

MAPPING & SYNTHESIS

To determine what global policy guidance was available for the integration of genomics into the care of people with palliative needs, policies were grouped by region, policy focus (palliative care or

clinical genetics and genomics), jurisdiction (state or equivalent, national or international) and population age group (paediatric, adult or all ages). The presence or absence of recommendations related to integration of genomics into palliative care was tabulated and narratively summarised.

To determine which recommendations regarding care of the family unit were relevant to the integration of genomics into the care of people with palliative needs, S.W. and C.V. independently grouped recommendations about care of the family unit into one of three categories: (a) Relevant to palliative care only, (b) Relevant to genetics and genomics only, or (c) Relevant to both palliative care and genetics and genomics. Initial agreement was 67.44%. S.W. and C.V. then collaboratively assessed and sorted each recommendation into the appropriate category using a broad approach. For example, we broadly interpreted the recommendation “If services cannot meet the family’s needs, appropriate referrals are made” as referring to any need (e.g. physical, psychological or social) and could therefore apply to both palliative care and genetic and genomic services. S.W. further sorted the recommendations relevant to both palliative care and genetics and genomics into descriptive categories. C.V. reviewed the descriptive categories and provided feedback, including the suggestion to collapse and rename some of the categories. Once categories were finalised, we calculated the percentage of each category as a proportion of the total number of policies. Initially, a granular-level matrix with all recommendations relevant to both palliative care and genetics and genomics were cross-tabulated with each policy. Individual recommendations were grouped into categories to demonstrate which policies included recommendations from each category (note: this did not represent how frequently the category showed up in each policy). We used descriptive statistics to calculate the presence of each category across all policies, using proportions (n) and percentage (%) of the total number of policies (N). We additionally stratified by policy focus (palliative care or genetics and genomics) and region. To visually represent the proportion of each category across policies (stratified by region), the biostatistician (K.R.) generated a “heat map” using ‘R’ software.[32, 33] A narrative synthesis accompanies the visual results.[34]

ETHICS

The University of Technology Sydney Research Ethics Office waived the requirement of ethics approval for this study. However, the reviewers were mindful of contacting key informants as part of this project. A maximum of three email attempts were made to each person and no direct quotes are included.

RESULTS

In total, 78 global policies were included (see PRISMA-flow diagram in Fig. 1). The majority were palliative care policies (n=61, 78.21%) with a country-level focus (n=41, 52.56%) and relevant to all ages (n=58, 74.36%). Australian policy accounted for one-quarter (n = 20, 25.64%) of the included policies. Table 1 provides a detailed summary.

INTEGRATION OF GENOMICS INTO PALLIATIVE CARE

Of the 78 policies, only two (2.56%) included recommendations about integrating genomics into palliative care (Fig. 2).[35, 36]. The first, an international genomics policy, recommended palliative care involvement when planning care for people with mitochondrial disease.[35] The second, an English palliative care policy for patients with neurological disease, recommended being aware of the psychological impact of a positive family history on the patient, including fear of the disorder and of their children developing the same disease.[36]

Of the 61 palliative care policies, only six (9.84%) mentioned genomics in the background information, and none of these incorporated genomics into their recommendations.[37-42] The background information in these six policies illustrated the increased likelihood of a genetic cause in palliative children and examples of genetic conditions.[37-42] One policy described the impact of life-limiting, congenital anomalies, including pain, social isolation, stigmatisation and a lack of resources to provide long-term palliative care.[40] In three of the six policies that mentioned genomics in the background, genomic information was referred to in policies, or sections of the

policy, about paediatric palliative care.[37, 40, 42] Excerpts of the background information are in the supplementary material. None of the genomic policies mentioned palliative care in their background information.

CARE OF THE FAMILY UNIT

Almost all policies (n=72/78, 92.31%) had recommendations about care of the palliative patient's family. We identified 168 unique recommendations, 55 of which were relevant to palliative care only, five relevant to genetics and genomics only and 108 recommendations relevant to both palliative care and genetics and genomics. Recommendations relevant to both palliative care and genetics and genomics were grouped into 11 descriptive categories (Table 2).

The most frequent category overall (n=62/78, 79.5%), including by region (n=10/18, 55.56%) was "Delivering Family-Centred Care", although only 29.41% (n=5/17) of genomic policies included this category compared to 93.44% (n=57/61) of palliative care policies. This category described the importance of attending to family members' psychological, social and spiritual needs. The second most prevalent category overall was "Governance & Policy" (n=53/78, 67.9%), which recommended care for families be enshrined in policy and enacted by health services. The least mentioned category overall (n=5/78, 6.4%) and by region (n=4/18, 22.22%) was "Physical & Symptom Care", which related to assessing and managing family members' physical health (Fig. 3)

In addition to "Delivering Family-Centred Care", genomic policies gave equal attention to "Ethical Care" (n=5/17, 29.41%) and "Governance & Policy" (n=5/17, 29.41%). "Ethical Care" recommendations described the ethical obligations health professionals have towards family members. For example, that discussions surrounding consent for genomic testing must include implications for family members. As for the palliative care policies, their other focus was upon recommendations related to "Governance & Policy" (n=48/61, 78.69%) and "Informational Needs" (n=43/61, 70.49%). "Informational Needs" recommendations described health professionals' duty to

respond to each family's unique informational needs by assessing family members' information requirements and provide information in an accessible way.

DISCUSSION

This global scoping review of policy recommendations complements the evolving dialogue about patients', [12, 43] families' [44] and health professionals' [8, 11, 45] experiences and views of the barriers and facilitators affecting integration of genomics into palliative care by examining the policy environment. We have identified and mapped recommendations related to the integration of genomics into the care of people with palliative care needs. A policy gap was evident, with only two of 78 policies explicitly including recommendations to integrate genomics into the care of patients with palliative care needs and their families. We also mapped recommendations about care of the family unit, finding that "Delivering Family-Centred Care" was a key recommendation across both palliative care and genomic policies.

Implementing genomics into the palliative care setting requires policy action from the meso- (i.e. health services and professional organisations) and macro-level (i.e. government). [17] Our review suggests the palliative care profession is falling behind other medical specialties, such as oncology, [46] neurology, [47] and cardiology, [48] which have published documents highlighting the importance of genomics to their patient groups. Despite this, translation of genomics into routine care is slow and there are numerous reasons why health professionals across specialties do not broach genomics with their patients. [49] If genomics is not addressed by treating specialists, palliative care becomes the final point to collect DNA from the affected person for the family's benefit before the patient dies and the opportunity is lost. [15] Palliative care and genomic organisations need to communicate this duty to their health professionals, as guiding relatives to engage in appropriate levels of screening or risk-reduction is a key clinical and economic benefit offered by genomics. [50, 51] Palliative care and genomic health professionals have called for organisational support, including initial tertiary genomic education, continuing professional

development, co-locating palliative care and genetic teams within health services and developing point-of-care guidelines to identify high-risk patients.[8, 45] Resources and funding are essential to the success of these strategies but health services are unlikely to commit these without a positive policy environment.[18] We have demonstrated a need for policy that articulates the importance of a genomics discussion before the palliative person dies, acknowledges the complexities and challenges, and delivers potential solutions to support health professionals.

One reason policy guidance may be lacking is that demonstrating the economic value of genomics in palliative care is challenging. Traditionally, research assessing the economic value of genomics to the family unit is measured through rates of predictive testing and changes in an individual's health behaviour.[3] To generate economic evidence in the palliative care context, researchers must overcome difficulties related to ethical concerns (e.g. satisfying institutional review boards that their research will not unduly harm vulnerable people) and logistical hurdles (e.g. patients dying prior to research participation).[52] To holistically assess the value of genomics to families and fill this important gap, health economists have suggested enriching economic evaluations with ethical, legal and social implication (ELSI) research.[53] As genomics continues to revolutionise healthcare, we see a need for palliative care implementation research to demonstrate the economic value of genomic testing to families, alongside the clinical, psychological and social benefits.

Our review corroborated the value of family-centred care to palliative care and clinical genetics, finding that recommendations related to "Delivering Family-Centred Care" were the most prevalent category of recommendations across both palliative care and genomic policies.[54, 55] These recommendations illustrate the importance of attending to family members' psychological, social and spiritual needs. Elements of family-centred care align with the personal utility of genomic information, such as satisfying altruistic motivations to protect their relatives from future disease, reducing the family's uncertainty of the future, providing a sense of control and making meaning through findings answers.[13, 56] Leveraging this common ground offers policy makers an avenue to

frame the benefits of genomics as family-centred care, so relevant recommendations resonate with both palliative care and clinical genetic and genomic stakeholders.

With accumulating evidence demonstrating the value of genomics in palliative care, it is timely for palliative care and genomic policy makers to develop policy recommendations about integrating genomics into palliative care, so the clinical and psychological benefits of genomics can be realised.

We call for a clear policy stance that communicates the importance of committing funding and resources towards supporting health professionals to address genomics with patients who have palliative care needs and their families.

STRENGTHS & LIMITATIONS

This review addresses a gap in our understanding of how genomics is conceived in the context of palliative care and is strengthened by adherence to established scoping review guidance. In addition, the multi-pronged search strategy (in particular, the web-search) identified relevant policies through commercial and non-commercial publishers, as opposed to relying solely upon academic databases. However, web-searching methods are described vaguely in scoping review guidelines, meaning we relied upon other researchers' published experiences to develop our own procedures. In addition, we took steps to reduce the web-searching "bubble-effect" (which is the tendency to retrieve web records within the searcher's location), but there appeared to be comparatively more web results from our home country (Australia).[11] Regarding eligibility criteria, our resources limited us to English-language policies, so we may have missed relevant recommendations from policies in other languages. Lastly, to maintain feasibility of the review, we focused upon palliative care and genomic policies; however, there may be related recommendations in policies in adjacent medical fields (such as oncology or obstetrics/gynaecology).

CONCLUSION

The dearth of policy recommendations related to the integration of genomics in the care of people with palliative care needs and their families is an identified gap. Without a clear policy stance, health services are unlikely to support health professionals to navigate the complexities of integrating genomics into routine palliative care. Delivering family-centred care was a prevalent existing recommendation across both palliative and genomic policies. Policy makers urgently need to harness this common ground to frame the benefits of genomics as family-centred care, to ensure recommendations resonate with both palliative care and genomic stakeholders. To realise the potential clinical, psychological, social and economic benefits of genomic medicine in palliative care, we call upon policy makers to incorporate recommendations about the integration of genomics in palliative care to communicate the importance of allocating resources and funding to health services.

STATEMENTS

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare

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AUTHOR CONTRIBUTIONS

Stephanie White, Chris Jacobs & Jane Phillips collaborated to conceive the review design. Stephanie White was responsible for managing the review, including operationalising the methods and management of review data. Stephanie White, Chris Jacobs, Gemma McErlean & Claudia Virdun were involved in conducting record screening and data extraction. Stephanie White, Chris Jacobs, Jane Phillips & Claudia Virdun conceptualised the results. Stephanie White wrote the initial manuscript. All authors provided feedback and approved the final manuscript version.

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FIGURE LEGENDS

Fig. 1. PRISMA-flow diagram demonstrating the number of retrieved records, inclusion and exclusion numbers and reasons for exclusion. From 4685 records, 78 policies were included in the final review. CINAHL: Cumulative Index to Nursing and Allied Health Literature; CADTH: Canadian Agency for Drugs and Technologies in Health

Fig. 2. Only two of 78 policies included in this review included recommendations about integrating genomics into the care of people with palliative care needs.

Fig. 3. The degree of shading in this heat map represents the proportion of policies (as a percentage of the total policies in that region) that included recommendations about care of the family unit. Policies are grouped by region on the x-axis, and the descriptive categories of recommendations related to care of the family unit are listed on the y-axis.