UNDERSTANDING OF TREATMENT-FOCUSED GENOMIC TESTING

Understanding and information needs of cancer patients regarding treatment-focused
genomic testing: A systematic review

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ABSTRACT

Objective: To systematically review literature exploring experiences of cancer patients regarding their understanding of treatment-focused genomic testing as well as their information needs and related themes.

Methods: Six databases were searched for the original studies published in English language that explored patients' understanding of the information related to the genomic testing and its implications for treatment of cancer. The Mixed-Method Assessment Tool was used to examine the methodological quality of selected articles.

Results: There were 14 studies (5 qualitative and 9 quantitative) that met inclusion and exclusion criteria. The majority of studies revealed that a considerable proportion of cancer patients lacked good understanding of treatment-focused genomic testing and wanted to be better informed. Some of the factors associated with poor knowledge about genomic testing were low education, older age, low income and unemployment.

The majority of people with cancer preferred face-to-face communication with their oncologists to discuss and ask questions about genomic testing and treatment. Most also wanted to receive simple, easy to understand written information about treatment-focused genomic testing.

Conclusions: Genomic testing and its implications for treatment emerge as an important aspect of health care across different types of cancer. The evidence indicates that cancer patients want to understand and be well informed about treatment-focused genomic testing in order to be part of decision-making process. Further studies addressing ways to improve cancer patients' understanding and knowledge of genomic testing are needed.

1.INTRODUCTION

In the last decade, there has been a rapid growth of personalized medicine due to advancements in genomic analyses used to individually tailor diagnostic and therapeutic approaches (1). Precision oncology, which is the fastest growing branch of personalized medicine, has been playing an instrumental role in assisting clinicians with the diagnosis, prognosis and treatment of tumours (1). Genomic analyses identify subtle alterations to the genes known as single nucleotide polymorphisms (SNP), which can inform the choice of treatment. This differs from genetic test results, which refer to inherited genetic mutations implicated in cancer susceptibility (1,2,3). Genomic analyses such as single-gene tests, multi-gene predictive arrays and next-generation sequencing (NGS) can guide therapeutic strategies (1). Routine tumour testing and targeting of various somatic mutations is now used in the treatment of certain cancer types e.g. lung or breast cancer (2,3). The Oncotype DX test is an example of an available genomic test currently used for early-stage breast cancer patients that analyses the activity of a number of genes affecting cancer growth and its response to treatment (4). It aids not only the clinical decisions regarding benefits of chemotherapy following breast cancer surgery but also the potential recurrence of cancer (4).

Currently, availability and reimbursement for the costs of these types of tests is not uniform across different countries and healthcare systems. However, it is likely that in the future more of this kind of testing will become routine in the treatment of many cancers. Ensuring that cancer patients have a good understanding of molecular profiling data is crucial for active participation in making illness-related decisions, developing self-efficacy and reducing psychological distress (5). Optimal patient understanding is important for

engagement in decision-making, especially if identified mutations could be targeted with selectively specific drugs that may be already available for patients or could be accessed via referral to clinical trials or other mechanisms (1).

To date, there have been only a handful of systematic reviews focusing on the experiences of cancer patients related to genomic testing and most of them focused on germline testing (6,7,8) rather than somatic testing and the implications on personalised therapies (9,10). While those systematic reviews explored important matters such as psychological distress, communication preferences and decision-making processes, none of them focused on the understanding of genomic testing and information needs of cancer patients. The present study provides a mixed-method systematic review of cancer patients' understanding and information needs regarding genomic testing and its impact on treatment. Related themes such as cancer patients' communication and decision-making preferences, perceived advantages and disadvantages of genomic testing, and factors associated with their understanding of genomic testing evident in the literature are also reviewed.

2. METHOD

The systematic review followed the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA-P) 2015 Guidelines (11). Inclusion criteria were: original publications in English language that explored patients' understanding of the information related to the genomic testing and its implications on treatment decision making. Exclusion criteria were: non-English articles, literature reviews, books, unpublished articles, commentaries, and abstracts of conferences. Studies focusing only on genetic tests assessing

familial risks of developing hereditary malignancies such as breast, ovarian and colon cancer were also excluded. Date of coverage was not restricted.

A literature search was performed in November 2018 and run in the following six databases: Ovid Medline, Ovid Embase, Ovid PsycINFO, EBSCOHost CINAHL, Cochrane (Wiley) and Scopus (Elsevier). An update literature search was performed in November 2019, but no new studies were identified.

In Medline, the search strategy consisted of a combination of subject headings (MESH) and various text words to identify the literature. Subject headings used in Ovid Medline included: 'Comprehension', 'Genetic testing', 'Neoplasms'. These were combined with keywords such as 'patient knowledge', 'pharmacogenetic testing', 'Cancer' using the "OR" Boolean operator. The "AND" Boolean operator was applied to link the concepts. All word variations were searched, and adjacency searching was applied in some instances. The "NOT" command was used to exclude results corresponding to the criteria. Searches in EMBASE, PsycINFO and CINAHL followed a similar format to the Medline search with variations according to each database's subject thesaurus. In Cochrane and Scopus, keyword combinations were used. Complete search strategies for each database are outlined in Appendices (see Supplementary Information). Following the removal of duplicates, abstracts were independently assessed for eligibility by three reviewers (K.W, J.S and P.S). Disagreements between reviewers were discussed and resolved by consensus.

The Mixed Method Appraisal Bias Tool (12) was employed to evaluate the methodological quality of selected publications. The MMAT provides tools for simultaneous

assessment of qualitative, quantitative and mixed method studies (12). Five assessment criteria were applied to each study, which produced a quality score ranging from 0 (no criteria met) to 5 (all criteria met). Where scores differed between reviewers, discrepancies were addressed through discussion.

The first author identified and synthesised themes that emerged from the studies relevant to the understanding and information needs of cancer patients regarding treatment-focused genomic testing. The review strategy was approved and registered with PROSPERO.

3. RESULTS

3.1. Description of the selected studies

The screening of the six databases identified 538 results (Medline=122; Embase=336; PsycINFO=18; CINAHL=52, Cochrane=0 and Scopus=10). Following the removal of duplicates there were 437 references, of which 404 were identified as non-relevant and were excluded. From the remaining 33 references, 19 were excluded on the basis of not meeting the eligibility criteria. A total of 14 articles were included for the analysis (three qualitative, ten quantitative and one mixed-method). The PRISMA flowchart is shown in Figure 1.

3.2. Quality of the articles

Quality scores were assigned to each publication according to MMAT criteria (12). Scores ranged from four to five, suggesting that the selected studies were of high quality. A score of five was allocated to all of the qualitative studies and two quantitative studies. Agreement between two authors (K.W. and J.S.) who independently assessed and rated the studies was reached on nearly all (>90%) of the appraisal items.

3.3. Description of Qualitative studies

The qualitative studies were published between 2011 and 2017 from Australia (n=2), USA (n=2) and France (n=1). Four out of five qualitative studies (13,14,15,16) explored information and communication needs regarding treatment-focused genomic testing of patients diagnosed with various types of cancer such as ovarian, gastrointestinal, breast, lung as well as melanoma. Three studies examined patients' knowledge and understanding of genomic testing and its implication on cancer treatment (14,15,16). One study focused specifically on the understanding and helpfulness of metaphors used by oncologists to explain genomic testing to cancer patients (17). A detailed description of all the studies is provided in Supplementary Table 1. The number of individuals participating in the qualitative studies ranged from 22 to 66. All the qualitative studies were cross-sectional in nature and adopted either thematic content analyses (13,14,15,17) or grounded theory to analyse the data (16).

In this review, thematic analysis was employed to reveal recurrent themes expressed by cancer patients in the selected five qualitative studies. The following four themes were identified: understanding and knowledge of genomic testing; information needs regarding genomic testing; communication preferences regarding genomic testing; and perceived advantages and disadvantages of genomic testing.

3.3.1. Theme 1: Understanding and knowledge of cancer patients about genomic testing

Although most cancer patients had heard about genomic testing and its implication for precision oncology (14,15,16), in some studies less than half of them were able to provide

accurate and comprehensive definitions by linking genomic testing with the analysis of mutations in DNA, which could be targeted by drugs (14,15). In two studies, most patients associated genomic testing exclusively with cancer susceptibility and familial risk without acknowledging its impact on informing cancer treatment (14,16). One in five patients in a single-study understood genomic testing as a biopsy that could identify type of cancer and cancer-specific treatment, while 38% of patients loosely associated genomic testing with accessibility of targeted therapies (15). Interestingly, one study found that nearly all patients reported understanding the explanation about somatic and germline testing provided to them by their doctors, however we appreciate that this may not be representative of the general experience (14). In one study of 66 patients diagnosed with melanoma, breast or gastrointestinal cancer as many as 85% of cancer patients found various metaphors (see Supplementary Table 1) helpful when receiving explanation of genomic testing results from their oncologists and demonstrated good understanding of the meaning conveyed by those metaphors (17). Nevertheless, in another study of 37 breast cancer patients it was found that patients had limited understanding regarding non-interpretable genomic results and incorrectly associated these results with poor prognosis, which impacted their psychological distress (16).

3.3.2. Theme 2: Information needs of cancer patients regarding genomic testing

There were three qualitative studies that explored information needs associated with genomic testing (13,14,15). On one hand, the majority of cancer patients wanted to be well informed about the impact of genomic testing results on their treatment and also wanted to know about

potential family implications of genomic result (13). On the other hand, a significant proportion of cancer patients expressed concerns about revealing information related to incidental findings of heritable mutations as well as potential information overload (14). Many patients diagnosed with advanced lung cancer and melanoma preferred not to be provided with technical information or any specific aspects of genomic testing because of their limited capacity for understanding (15). Some individuals expressed a need to receive more information about implications of genomic testing on the treatment of their cancer and potential risks associated with genomic testing (15).

3.3.3. Theme 3: Communication preferences of cancer patients regarding genomic testing

The majority of cancer patients preferred face-to-face verbal communication with their oncologist about treatment-focused genomic testing, which would allow them to discuss and ask questions (13,15). They also expressed a need to receive accompanying written summary of what they were told during the consultation (13,15). Most patients also wanted printed information such as a leaflet providing them with a sufficient explanation of key concepts associated with genomic testing, which would help them to make sense of the purpose and meaning behind this type of testing (13,15). In a study of 24 patients with lung cancer and melanoma who had undergone somatic genomic testing more than half expressed a preference to receive the explanation about genomic testing and cancer treatment in a way that is jargon and technical-terms free, simple and easy to understand, which would in turn help reduce their anxiety (15).

3.3.4. Theme 4: Perceived advantages and disadvantages of genomic testing

Among the main benefits of genomic testing mentioned by cancer patients was that it could be used to inform the most suitable treatments such as targeted therapies (14,15). Other advantages of genomic testing indicated by cancer patients included that it could be used to advance cancer research by learning about its causes, and improve diagnosis and prognosis as well as the effectiveness of treatment (14,15).

Interestingly, most of the patients in one study indicated no disadvantages associated with genomic testing, with only a few reporting pain, complications from biopsy and anxiety stemming from waiting for the results (15). In contrast, another study found 71% of cancer patients (n=49) linked genomic testing with various disadvantages such as its potential to disclose unwanted information and its negative impact on psychological wellbeing (14). In addition, some cancer patients in this study expressed concerns over the negative impact of genomic testing on their health insurance and employment discrimination.

3.4. Description of Quantitative studies

There were nine quantitative studies, published between 2007 and 2017, from Canada (n=2), USA (n=6) and France (n=1) (18,19,20,21,22,23,24,25,26). The majority of cancer patients in these studies were middle-class and well-educated Caucasian women. Six out of nine studies focused exclusively on women diagnosed with breast cancer who underwent Oncotype Dx genomic testing (20,21,24,25,26). The remaining three studies explored genomic testing experiences of people with various types of cancer such as gastrointestinal, lung, liver and

melanoma (18,19,22). The details of the selected studies are presented in Supplementary Table 1.

All of the quantitative studies were cross-sectional in nature. While four of the studies employed reliable and validated measures (18,19,20,24), in the five remaining studies the authors developed their own questionnaires, which were not pre-tested or validated (21,22,23, 25,26). Patients' understanding and knowledge about genomic testing was examined in most of the studies, and six of them investigated association between knowledge of genomic testing and socio-demographic factors such as age, income and level of education (18,20,21,23,24,25). Most studies also explored cancer patients' information needs and the experiences of decision-making process regarding genomic testing.

3.4.1. Understanding and knowledge of genomic testing

There was variability in the use of measures assessing patients' knowledge about genomic testing. Two of the studies adopted measures that were reviewed for validity and further evaluated by pilot testing prior to performing the study (18,24). Authors of each study generally developed their own measures, most of which were statements with true or false answers (18,21,20,21,24,23). Cuffe et al., (2014) (19) used Likert-scales eliciting cancer patients' level of agreement with series of statements about genomic testing, whereas Seror et al., (2013) (25) and Tzeng et al., (2009) (26) used open ended-questions to investigate patients' understanding of genomic testing results.

There was a wide range of understanding of different questions asked across various questionnaires that measured the understanding of genomic testing (18,21,23,24). Cuffe et al.,

(2014) (19) reported that 22% of cancer patients lacked basic understanding of genomic testing, whereas Seror et al., (2013) (25) revealed that 63% of patients misunderstood their genomic testing results. Tzeng et al., (2009) (26) showed that 67% of women with breast cancer reported they understood large amounts of the explanation provided to them about genomic testing results, however there was no objective measure used in the study to confirm that these subjective claims corresponded to actual true knowledge. Lillie et al., (2007) (20) found that retention of educational information provided to cancer patients about genomic testing was higher for those with higher literacy compared to those with lower literacy (90% vs 76% of correct answers). One study investigated patients' understanding of somatic and germline mutations and its impact on genomic testing (24). Importantly, it was found that only 13% of breast cancer patients (n=13) were aware of the differences between somatic and germline mutations and its influence on genomic testing.

Together, these studies demonstrated a wide range of correct understanding (37% to 91%) regarding the impact of genomic testing on the choice of cancer treatment (18,21,23,24,25). The majority of cancer patients had good understanding about implications of genomic testing on making decisions about chemotherapy (18,21,23) and the fact that not everyone responds to targeted therapy (24). Many cancer patients had poor understanding about a potential limitation of genomic testing to identify therapeutic targets (24) and prognostic relevance of genomic testing (25).

3.4.2. Factors associated with patients' knowledge about genomic testing

A statistically significant positive association between levels of education and knowledge about genomic testing was consistently found across the studies (18,20,21,23,24,25).

Similarly, it was found that cancer patients who had higher incomes had significantly higher knowledge about genomic testing (18,21,23,24). Knowledge about genomic testing was also positively associated with young age, Caucasian ethnicity, being married, and having full time employment (19,23).

3.4.3. Information needs of cancer patients pertaining genomic testing

Most cancer patients, irrespective of their degree of literacy, wanted sufficient information about what genomic testing is. They wanted to know its benefits, the accuracy of testing, and the impact of genomic testing results on the selection of treatment, as well as the strengths and limitations of genomic testing (21,22,23). In addition, many patients expressed the need to receive information about potential heritable implications of testing for their family and its potential to predict recurrence of cancer (21,22). Some were interested in receiving information about incidental findings, testing procedure and any risks associated with genomic testing (22).

As far as information seeking by cancer patients was concerned, 27-62% of patients reported they sought information about genomic testing and treatment on the Internet (21, 24). Notably, 42% of patients expressed they would have liked to receive more information about genomic testing from their doctors (25). Most patients reported receiving verbal and printed information about genomic testing (23), which was in agreement with the Pinheiro et

al., (2017) (22) study showing patients' main preferences for receiving information were discussion with their clinician and written materials.

3.4.4. Decision-making process concerning genomic testing

The majority of cancer patients studied (49-77%) wanted to be involved in the shared decision making about treatment recommendations arising from the genomic testing (19,20,23,25,26). Interestingly, individuals with lower literacy were significantly less likely to be inclined to actively participate in decisions about genomic testing and subsequent treatment (20). In one study it was reported that nearly a third of cancer patients didn't achieve their preferred approach to sharing roles in making decisions about genomic testing and treatment implications (26).

4. DISCUSSION

The purpose of this review was to explore and integrate findings from quantitative and qualitative studies that investigated key aspects of cancer patients' experiences regarding their understanding and information needs about treatment-focused genomic testing. We also examined patients' communication and decision-making preferences, their perceived advantages and disadvantages of genomic testing, and socio-demographic factors linked to patients' knowledge about genomic testing. Overall, the findings from quantitative and qualitative studies consistently revealed that at least one third of patients diagnosed with different types of cancers showed low understanding and limited knowledge of the information about genomic testing. More than half of patients misunderstood their genomic

test results (25) and failed to recognize the importance of this type of testing on the decisions regarding the selection of the most effective treatment for their cancer (14,16). This finding is concerning given that the majority of cancer patients expressed a preference to be involved in making shared decisions about treatment of their illness (19,20,23,25,26), which is consistent with the findings from other systematic reviews (28,29,30). In all the quantitative studies analysed in this review, high education and higher socioeconomic status were associated with better knowledge about genomic testing and its role in directing cancer treatment. This is not surprising given a well-established link between general level of education and health literacy (31).

Another key finding from the analysis of both quantitative and qualitative studies was that the majority of cancer patients wanted to be well informed about genomic testing and their treatment options, while also expressing concerns about incidental findings that may have implications for themselves and their family members (13,14,15,21,22,23). It is not uncommon for patients to worry about the consequences of incidental findings of genomic testing. For this reason, as genomic technologies became more commonly used in clinical settings, there has been a substantial increase in the number of published studies and recommendations for reporting, educating, and communication of incidental findings (32,33,34,35,36). It is also pivotal that clinicians dealing with genomic testing for cancer patients have access to and education about specific recommendations for dealing with incidental findings, that are unrelated to their cancer, but which may be uncovered during genomic analysis in order to reduce patients' concerns and anxiety. Some published guidelines recommend focusing on assessing small pool of genes that are highly likely to

benefit patients, being mindful about the quality of supporting evidence and potential limitations as well as considering patients' choices and preferences regarding genomic testing (32).

Importantly, it was consistently shown across the studies that patients wanted written material that is simple and free of technical terms, in addition to discussing genomic testing with their doctors (13,15,22). This is in agreement with other studies about cancer related materials and information needs (37,38). Many individuals diagnosed with cancer reported not receiving enough information about genomic testing from their healthcare professionals (25). It is therefore not surprising that a considerable percentage of patients report using the Internet to search for relevant information about genomic testing (21,24). This may be problematic given the variable accuracy of information available on the Internet. It is not uncommon for certain groups of cancer patients to feel inadequately informed, as in the case of people with cancer of unknown primary (39). Unfortunately, when cancer patients are forced to 'surf' the Internet to meet their need for more information, they are likely to encounter materials that are not accurate or peer reviewed, which can result in further confusion and distress (40).

4.1. Limitations

The publications analysed in this review had a number of limitations. Notably, the vast majority of studies employed convenience sampling. The data was usually derived only from a single hospital, and the patients were homogenous regarding race, ethnicity, education and socioeconomic status. As most of the participants in the selected studies were middle-aged,

Caucasian, well-educated and wealthy women, the generalizability of the findings may be limited. In addition, none of the studies looked at the understanding of test results by patient family members or indeed of their treating oncologists. Most of the quantitative studies focused on the one specific type of genomic testing called Oncotype Dx, which is used exclusively for breast cancer patients. Hence the data obtained from these studies may not be translatable to the experience of people diagnosed with other types of cancer undergoing genomic testing.

In addition, all of the studies reviewed were cross-sectional by design; hence it is impossible to make any causal inferences from these findings. It is important in the future to conduct longitudinal studies to elucidate the direction and mechanistic details between variables and account for multiple covariates that could affect cancer patients' understanding of genomic testing. For example the effect of chemotherapy or radiotherapy, co-morbidities, cognitive dysfunction, as well as psychological distress could have a major impact on cancer patients' attention and memory (41,42), as well as their capacity to comprehend and conceptualise information about genomic testing. In addition, while this review only looked at the perspectives of patients, it is important to consider the perspectives of oncologists and test providers who may feel ill-equipped to meet these needs due to insufficient understanding of the tests themselves, or lack of access to relevant written patient information materials.

4.2. Clinical implications of the systematic review

Given that precision oncology, with genomic approaches at its forefront, is the fastest growing field of medicine and has direct impact on the care and treatment of cancer patients, it is necessary to ensure the information and communication needs of cancer patients are met. While the approaches that could be used to facilitate patients' understanding remain to be investigated, a reasonable starting point could be to ensure that all cancer patients receive adequate information about the specific type of genomic testing they undergo that is personalised, clearly presented and easy to read. Finally, provision of communication skills training for oncologists to increase their ability to effectively educate cancer patients about genomic testing results and implications for treatment could be considered as a useful strategy for enhancing the quality of healthcare services (45,46).

5. CONCLUSION

This systematic review revealed that a substantial percentage of cancer patients demonstrated a limited understanding and knowledge of the treatment-focused genomic testing. They wanted to be well informed about genomic testing including its benefits, strengths and limitations, as well as its influence on the selection of cancer therapy. Importantly, most cancer patients wanted to receive written materials summarising their genomic results and relevant treatment implications in simple language, in addition to having the opportunity to discuss genomic results with their oncologists. This highlights the important responsibility for health professionals to take sufficient time to record main findings of genomic testing and its meaning regarding future decision making and ensuring that they use non-technical and jargon free language in their discussions with patients. Ideally test providers should also

produce written information materials for patients that could help oncologists to explain the nature of the tests being performed as well as the results. There could be a potential value in providing the patients with the audio-recordings of the oncological consultations in which genomic results are discussed (43,44).

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FIGURE LEGEND

Figure 1. Preferred reporting Items of Systematic Review and Meta-Analysis (PRISMA-P)
study selection flowchart

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