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Exploring Literacy and Knowledge Gaps and Disparities in Genetics and Oncogenomics Among Cancer Patients and the General Population: A Scoping Review

Katerina Nikitara [1,*], Maria Luis Cardoso [2,3], Astrid Vicente [2,3], Célia Maria Batalha Silva Rasga [2,3], Roberta De Angelis [4], Zeina Chamoun Morel [5], Arcangela De Nicolo [6], Maria Nomikou [1], Christina Karamanidou [7] and Christina Kakalou [7]

1 Hellenic Cancer Federation, Athens, Greece
2 Instituto Nacional de Saúde Doutor Ricardo Jorge, Avenida Padre Cruz, 1649-016, Lisboa, Portugal.
3 BioISI—Biosystems & Integrative Sciences Institute, University of Lisboa, Faculty of Sciences, Campo Grande, C8, 1749-016, Lisboa, Portugal
4 Department of Oncology and Molecula Medicine, Istituto Superiore di Sanità, Viale Regina Elena 299, 00161, Rome, Italy
5 Advanced Training Office, Institut Curie, 26 rue d'Ulm, Paris Cedex 05, France
6 Center for Omics Sciences, IRCCS San Raffaele Scientific Institute, via Olgettina 60, 20132 Milan, Italy
7 Centre for Research and Technology Hellas, Institute of Applied Biosciences, Thessaloniki, Greece
* Correspondence: euprograms@ellok.org

Abstract: BACKGROUND: Genetic and genomic literacy is pivotal in empowering cancer patients and citizens to navigate the complexities of omics sciences, resolve misconceptions surrounding clinical research and genetic/genomic testing, and make informed decisions about their health. In a fast-evolving scenario where routine testing has become widespread in healthcare, this scoping review aimed to identify current literacy and knowledge gaps among cancer patients and citizens on matters related to genetics and genomics. **METHODS:** Adhering to the PRISMA framework, the review included 43 studies published between January 2018 and June 2024, which evaluated the understanding of genetics and genomics among cancer patients, caregivers, and citizens. **RESULTS:** Although the selected studies had significant heterogeneity in populations and evaluation tools, our findings indicate inadequate literacy levels, with citizens displaying lower proficiency than cancer patients and caregivers. The review highlighted consistent knowledge gaps in understanding the genetic and genomic underpinnings of diseases, encompassing misconceptions about mutation types and inheritance patterns, limited awareness of available genetic testing options, and difficulties in interpreting test results. Ethical and privacy concerns and the psychological impact of genetic testing were also common, highlighting the imperative need for effective communication between healthcare providers and patients. **CONCLUSIONS:** Given the dynamic nature of genomic science, the review underscores the need for continuously evolving educational programs tailored to diverse populations. Our findings could guide the development of educational resources addressed explicitly to cancer patients, caregivers, and the lay public.

Keywords: literacy; knowledge; cancer patients; citizens; caregivers; genetics; oncogenomics; genetic testing

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Background

Significant strides have been achieved over the past 20 years in genetics and oncogenomics, the former focusing on individual genes and their inheritance and the latter on the whole gene pool and environmental interactions [1]. Genomic variants play a relevant role in driving cancer. Comprehensive analysis of genomic modifications via new technological approaches has become vital to early diagnosis, prognosis, and personalised treatments within precision medicine [2]. However, to ensure the successful implementation and sustainability of technological advances in healthcare, it is essential to educate all stakeholders, including cancer patients and citizens [3].

Genetic and genomic literacy is linked to the broader concept of health literacy [4]. It is crucial for empowering cancer patients, caregivers, and citizens to understand omics sciences, enabling them to make informed decisions about their health and dispelling misconceptions about clinical research and genetic/genomic testing. Genomic literacy could also support an efficient and harmonised integration of omics data into healthcare [5,6]. However, cancer patients' literacy in precision medicine, including genetic and genomics technologies, is reportedly low [7]. This knowledge gap will likely widen as new technologies and personalised treatment options emerge. Without proper education and understanding, patients may struggle to fully benefit from these innovations, potentially hindering the effectiveness of early diagnosis methods and cutting-edge treatments. In addition, several crucial related aspects raise concerns about the storage and management of genomic information, privacy and confidentiality of personal data, accessibility and affordability of testing, and the potential issues associated with insurance and employment discrimination [8]. The genomic literacy of cancer patients and citizens is still poorly documented. Most research has focused on healthcare professionals [9,10] without delving into the needs and knowledge of patients. Furthermore, minorities and underserved communities are often underrepresented in these types of studies, highlighting the need for more inclusive research [11]. Addressing these shortfalls would ensure that all patients can access (and benefit from) the latest advancements in precision medicine.

With constant advancements in the fast-paced field of genomic science and the increasing adoption of routine testing in healthcare (for diagnosis, prevention, and treatment), we aim to uncover the literacy and knowledge gaps related to the concepts of genetics and genomics of cancer patients, caregivers and citizens. This scoping review was undertaken in the context of the European Union-funded project "Can.Heal—Building the EU Cancer and Public Health Genomics Platform", with the ultimate goal of informing and developing future educational initiatives for cancer patients and citizens.

Methods

This scoping review was conducted and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [12]. Two electronic databases (Medline and Scopus) were searched for peer-reviewed articles published between January 1, 2018, and June 18, 2024. The details of the literature search strategy are outlined in **Tables S1 and S2**. The inclusion criteria were developed based on the PCC (P-Population, C-Concept, C-Context) framework, according to which the eligible studies should be in English, have a qualitative or quantitative study design and explore knowledge and understanding of genetics and oncogenomics concepts among cancer patients and/or survivors, caregivers, and families, as well as citizens of any age and sex.

Study Selection

Studies retrieved through the above-mentioned electronic searches were entered into Endnote, and duplications were systematically removed. The collected studies were then imported into the Rayyan software (https://www.rayyan.ai/) and screened based on the predefined inclusion criteria. As a first step, all studies were assessed based on their title and abstract. To test the robustness of the screening process, a pilot title/abstract screening was run by two reviewers independently, covering 10% of the hits. Any discrepancies were resolved through discussion. The level of agreement between

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the reviewers was assessed using Cohen's Kappa coefficient, and the result was adequate (Cohen's Kappa = 0.72). A single reviewer carried out the remaining screening. The studies selected from the title/abstract screening underwent further assessment of their full texts by a single reviewer.

Data Extraction and Presentation

Details about the study type and setting, the characteristics of the analysed populations, and the outcomes of interest were rigorously extracted via a standardised process. For qualitative analyses, the retrieved data included information about the methodology of each study. To test the reliability and consistency of the data extraction, two reviewers independently conducted a pilot in 10% of the studies. Once consensus was achieved between the reviewers, one reviewer extracted data from the remaining studies. The results are presented in a tabulated format and synthesised as a narrative.

Results

Study Characteristics

A total of 12,993 studies were initially identified through the Medline and Scopus databases using the developed search strategy (**Tables S1 and S2**). After removing duplicate entries, 12,977 studies underwent title/abstract screening. Of these, 99 studies were eligible based on the predefined selection criteria and underwent full-text assessment. Sixty-one studies were excluded because of (i) limited data (n=19), (ii) insufficient outcomes of interest (n=38), (iii) ineligible study type (n=3), and (iv) ineligible population (n=1). As a result, 38 studies were included in the scoping review after successfully passing the rigorous screening process. Five studies were identified from the references of the selected studies and added to the list, thus leading to a total number of 43 eligible papers included in this scoping review. A flow chart summarising the study selection steps is presented in **Figure 1**.

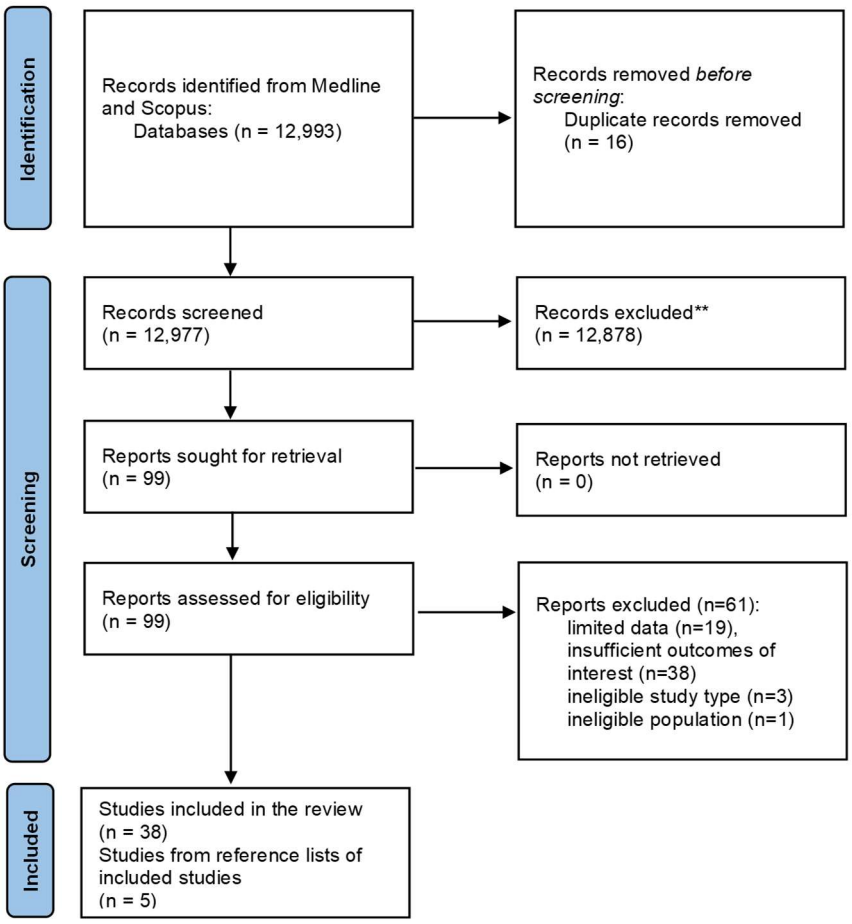

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Figure 1. PRISMA flowchart of study selection.

Of the 43 studies included in the review, a total of 29 reported data on adult cancer patients and/or survivors with sample sizes ranging from 11 to 1139 participants (total N=6358) [13–41]. Additionally, six studies reported data on caregivers/family members with participants varying from 29 to 213 (total N=617) [13,29,33,42–44]. Nine studies presented data on citizens with cohorts ranging from 32 individuals to a maximum of 2895 (total N = 6102) [13,45–52], and three studies presented mixed results for cancer patients and caregivers with cohorts ranging from 15 to 111 participants (total N=152) [53–55]. With regards to the geographic location, 25 studies were conducted in the United States [15–20,22,23,25,30,33,34,36,38–40,42,45,46,48,50–53,55], seven studies in Australia [14,28,29,31,32,47,49], three in Canada [26,27,54], two in South Korea [24,35], one in Malaysia [13], one in India [41] and one in China [44]. Only two studies were carried out in Europe, one in the Netherlands [43] and one in Ireland [21]. Finally, one study included individuals from several countries [37]. Considering the study design, 14 articles were associated with umbrella clinical studies; thus, only baseline data were retrieved and presented in this scoping review [15,17–20,22,27–29,31–33,42,50]. Sixteen studies used a cross-sectional approach [13,16,21,23–26,30,35,40,41,44,46,48,52,53], five studies had a cohort design [14,37,38,43,47], four studies applied a qualitative methodology [36,39,49,54], and four studies used a mixed methods analysis [34,45,51,55]. A detailed overview of the published studies included in the scoping review is provided in **Table S3**.

Results on Genetic and Oncogenomic Literacy

For structured data reporting, the population was divided into four groups: (A) cancer patients and/or survivors, (B) cancer patients and caregivers (mixed results), (C) caregivers and family members, and (D) citizens. For each group, knowledge of genetics and oncogenomics concepts was categorised as follows: (i) knowledge of general genetic and genomic concepts, (ii) knowledge of genetic and genomic concepts related to general health and cancer, and (iii) knowledge of genetic and genomic testing.

A—Cancer Patients and/or Survivors

Twenty-nine studies [13–41] assessed the overall level of knowledge of cancer patients and/or survivors on genetic and oncogenomic concepts (**Table 1**). In 23 out of the 29 studies, objective knowledge was evaluated [13–20,22–27,29–31,33–35,38,40,41], self-perceived knowledge was reported in two studies [21,39]. In the remaining four studies, either qualitative methods or unspecified methods were used. Approximately half of the studies recruited individuals who participated in clinical studies [15,17–20,22,27–29,31–33] and either were in the process of receiving or had already undergone genetic or genomic testing. Prior experience with genetic or genomic testing was also a prerequisite for inclusion in most observational studies [16,23–26,30,34,35,38]. Overall, except for three studies [13,21,41], most participants had undergone genetic or genomic testing.

Table 1. Results for cancer patients' and/or survivors' knowledge of genetics and oncogenomics.

Author, Year	Knowledge of general genetic/genomic concepts	Knowledge of genetic/genomic concepts related to cancer	Knowledge of genetic/genomic testing
Aizuddin et al., 2021 [13]	N/A	High score: 41.4% (Score for high: 6-10)	50.6% scored high (Score for high: 6-10)
Butow et al., 2022 [14]	N/A	Mean score: 47.9 % (SD = 30.1 %, n = 261)	N/A
Makhnoon et al., 2021 [15]	N/A	N/A	Average score: 48.2% (10.6 of 22 total possible points)

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Wing et al., 2021 [16]	N/A	Average correct questions: 5 (SD = 2) out of 9	Average correct questions: 10 (SD = 5) out of 19
Anderson et al., 2021 [17]	N/A	N/A	48% correct answers (SD 31%)
Roth et al., 2021 [18]	N/A	N/A	The proportion providing correct answers to these questions was moderate
Roberts et al., 2019 [19]	N/A	N/A	Average score of 5.3 (SD = 0.99) out of 6 items (88% correct answers)
Adams et al., 2020 [20]	Mean score of 0.72 (range: 0–1)	N/A	N/A
Mullally et al., 2021 [21]	N/A	N/A	58% (n= 49) declared little or no knowledge
Gornick et al., 2018 [22]	N/A	Low level: 29.8% correct answers	High level: 72.49%-89.20% correct for each question
Pozzar et al. 2022 [23]	N/A	Mean score: 11.9 (SD = 3.5) out of 19	N/A
Shin et al., 2021 [24]	N/A	N/A	Mean score: 6 (range of 0–11)
Underhill-Blazey et al., 2021 [34]	N/A	Mean score: 12.3 (SD 3.4) out of 19 / on average participants answered 63% of questions correctly	N/A
Park et al., 2022 [35]	N/A	N/A	Mean score: 66.9 (SD 21.7) (range 0-100)
Marron et al., 2019 [33]	N/A	4 participants had high genetic knowledge and 5 had low	N/A
Underhill-Blazey et al., 2019 [25]	N/A	Mean knowledge score:10 (SD 3) (range 0–16)	N/A
Dehar et al., 2022 [26]	N/A	Moderate	Moderate to high
McCuaig et al., 2021 [27]	N/A	N/A	Mean score: 7.8 (SD 2.1) (range 0-10)
Bartley et al., 2020 [28]	N/A	N/A	85% of participants acknowledged that they did not fully understand or were uncertain about what genome sequencing is
Napier et al., 2022 [29]	N/A	N/A	Mean score: 45% (SD 25)
Liang et al., 2018 [30]	N/A	Moderate	High level of knowledge
Davies et al., 2020 [31]	N/A	N/A	Overall, poor to moderate knowledge with an average correct response score of 43% (SD 20%)
Best et al., 2019 [32]	N/A	N/A	Participants' understanding was generally poor

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Gómez-Trillos et al., 2020 [36]	N/A	N/A	Low level of knowledge of genetic services
Frost et al., 2019 [37]	N/A	High level of familiarity with/interest in genetic	N/A
Hamilton et al., 2019 [38]	Mean score: 0.84 (SD 0.16) (range 0 to 1)	N/A	N/A
Robles-Rodriguez et al., 2024 [39]	N/A	Confused about precision medicine, with 42% believing that genes have little effect on health	Participants understood the concept of genetic testing, but they had difficulties relating genomic testing to personalised medicine
Pramanik et al., 2024 [41]	N/A	Mean score: 5.11 (SD 2.54) (range: 0-13)	N/A
Wang et al., 2023 [40]	N/A	N/A	Mean score: 1.90 (SD = 1.48) (range 0–7)

i. Knowledge of general genetic and genomic concepts

Two studies evaluated the literacy related to general genetic and genomic concepts. A high level of knowledge was found by Hamilton et al. (2019) [38] in 57 individuals with a history of cancer, scoring a mean of 0.84 (SD 0.16), ranging from 0 to 1, while a slightly lower level was reported by Adams et al. (2020) [20], in 58 patients with metastatic breast cancer who scored 0.72 (score range: 0–1).

ii. Knowledge of genetic and genomic concepts related to general health and cancer

Thirteen studies assessed the knowledge of genetic/genomic concepts related to cancer, among which eleven consistently showed an overall moderate level of understanding, and two indicated poor knowledge. Specifically, Butow et al. (2022) [14] found a mean score of 47.9% (SD 30.1%, n=261) in a cohort of individuals with a personal history of cancer. Similarly, Pozzar et al. (2022) [23] estimated a mean score of 11.9 (SD 3.5, score range: 0-19) among 87 gynaecological/breast cancer patients. Two additional studies focusing on breast cancer patients, both conducted by Underhill-Blazey et al. [25,34], also indicated a moderate level of knowledge. In the most recent one [34], a mean genetic knowledge score of 12.3 (SD 3.4, n=602) (score range: 0-19) was observed, while in the earlier one [25], a mean knowledge score of 10 (SD 3, n=591) (score range: 0-16) was obtained. Likewise, participants (n=85) in a study by Wing et al. (2021) [16] answered correctly five out of nine questions on average, while 58.6% of the cancer patients in the study by Aizuddin et al. (2021) [13] obtained a moderate or low score regarding their knowledge of cancer genetic/genomic concepts. Similar findings were reported by Dehar et al. (2022) [26] in a cohort of 113 cancer patients, by Liang et al. (2018) [30] in 53 ovarian cancer patients, by Marron et al. (2019) [33] in 11 cancer patients, and by Gornick et al. (2018) [22] in a cohort of 537 newly diagnosed patients with early-stage breast cancer, where no detailed numerical data were provided. Finally, qualitative results from Frost et al. (2019) [37], reflecting 32 individuals with a history of cancer or increased cancer risk, showed a moderate level of understanding.

A low level of understanding was reported in two studies [39,41]. The survey of Pramanik et al. (2024) [41] in 84 women with breast or ovarian cancer revealed a mean knowledge score of 5.11 (SD 2.54), with a range of 0-13, amounting to 39.3 ± 19.5%. Also, the qualitative findings of Robles-Rodriguez et al. (2024) [39] showed that women with breast cancer (n=29) were unfamiliar with precision medicine, with 42% believing that genes have little effect on health.

iii. Knowledge of genetic and genomic testing

Twenty studies assessed comprehension of genetic and genomic testing by cancer patients or survivors. Of these, five studies reported a high level of knowledge [19,22,26,27,30], seven

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documented a moderate level [13,15,16,18,24,29,35], and the remaining eight studies identified either a low to moderate [17,21,31] or a low level of understanding [28,32,36,39,40].

Roberts et al. (2019) [19] revealed a high level of understanding of genetic/genomic testing in 217 patients with treatment-resistant, metastatic cancer, achieving an average score of 5.3 (SD 0.99) out of 6. Likewise, McCuaig et al. (2021) [27] reported a mean knowledge score of 7.8 (SD 2.1) (score range: 0-10) among 120 patients with breast and ovarian cancer, while Dehar et al. (2022) [26] observed that over 80.5% of the 113 adult cancer patients in their study comprehended the purposes of genetic testing. Similarly, a high level of knowledge concerning the benefits and purposes of genetic testing was reported by Gornick et al. (2018) [22] among 537 newly diagnosed patients with early-stage breast cancer and by Liang et al. (2018) [30] in 53 patients diagnosed with epithelial ovarian cancer.

A moderate level of knowledge of genetic and genomic testing was found by Makhnoon et al. (2021) [15], obtaining a mean score of 10.6 (score range: 0-22) from 18 colon cancer patients, whereas Shin et al. (2021) found a score of 6 (score range: 0-11) among 103 ovarian cancer patients. Similarly, Park et al. (2022) [35] estimated a mean knowledge score of 66.9% (SD 21.7%) from a cohort of 700 BRCA1/2 mutation-negative breast cancer patients, while Napier et al. (2022) [29] indicated a relative score of 45% (SD 25%) in a population of 348 patients diagnosed with a likely hereditary form of cancer. Likewise, in the study by Wing et al. (2021) [16], the average number of correct answers given by 85 cancer patients was 10 (SD 5) out of 19, while Roth et al. (2021) [18] reported a moderate proportion of correct answers on genetic testing among 207 participants with advanced non-small-cell lung cancer. Finally, Aizuddin et al. (2021) [13] found a moderate level of knowledge in more than half of the 86 participating cancer patients.

A low to moderate level of knowledge was observed in three studies. The research by Anderson et al. (2021) [17] included 1139 cancer patients, a percentage of 48% provided correct answers with a standard deviation of 31%, evidencing a notable heterogeneity in the level of knowledge. In a study by Mullally et al. (2021) [21], 58% (n=49) of cancer patients had little or no knowledge about genetic testing. Additionally, according to Davies et al. (2020) [31], adult patients with confirmed advanced or metastatic solid cancers (n=777) displayed poor to moderate knowledge about molecular tumour profiling, scoring an average of 43% (SD 20%) incorrect responses. Finally, a low level of knowledge regarding genetic and genomic testing was identified in five studies. The survey by Wang et al. (2023) [40] resulted in an average genetic testing knowledge score of 1.90 (SD = 1.48; range 0–7), suggesting a low level of genetic knowledge, while the qualitative studies by Bartley et al. (2020) [28], Best et al. (2019) [32], Gómez-Trillos et al. (2020) [36], and Robles-Rodriguez et al. (2024) [39] showed that although participants understood the concept of genetic testing they had difficulties in relating genomic testing to personalised medicine.

B—Cancer Patients and Caregivers (mixed results)

Three studies (**Table 2**) presented mixed results for cancer patients and caregivers [53–55]. Oberg et al. (2018) [53], who analysed 111 parents of pediatric cancer patients and young adult cancer survivors, found (i) a mean score of 4.11 (SD 1.41) (score range: 1-7) for general genetic concepts, (ii) a mean score of 8.07 (SD 2.37) (score range: 1-12) for genetic concepts related to general health and cancer, and (iii) a mean score of 6.18 (SD 4.44) (score range: 0-16) for sequencing-related concepts. The study by Hill et al. (2018) [54], focusing on 15 parents of children with retinoblastoma and adult retinoblastoma survivors, showed that although the participants generally understood that retinoblastoma is a genetic disease, concepts related to retinoblastoma genetics were often misunderstood. Finally, Stallings et al. (2023) [55], who performed a mixed-methods analysis, concluded that the 26 enrolled individuals with personal cancer experience (patients or caregivers) were not familiar with precision medicine concepts.

Table 2. Results for cancer patients and caregivers' knowledge of genetics and oncogenomics.

Author, Year	Knowledge of general genetic/genomic concepts	Knowledge of genetic/genomic concepts related to cancer	Knowledge of genetic/genomic testing

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Oberg et al., 2018 [53]	Mean score: 4.11 (SD 1.41) (range 0-7)	Mean score: 8.0 (SD 2.37) (range 0-12)	Mean score: 6.0 (SD 4.44) (range 0-16)
Hill et al., 2018 [54]	N/A	Variable (often limited) knowledge of retinoblastoma genetics	N/A
Stallings et al., 2023 [55]	N/A	Low familiarity ratings for precision medicine-related terms	N/A

C—Caregivers and Family Members

Six studies [13,29,33,42–44] (**Table 3**) recruited caregivers and family members, hereinafter mentioned as caregivers. The identified studies evaluated two of the three domains of knowledge considered in this review.

Table 3. Results for caregivers' knowledge of genetics and oncogenomics.

Author, Year	Knowledge of genetic/genomic concepts related to cancer	Knowledge of genetic/genomic testing
Aizuddin et al., 2021 [13]	High: 39.4% (Score for high: 6-10)	High: 33.8% (Score for high: 6-10)
Johnson et al., 2019 [42]	Median percentage of total correct answers: 77.8% / 54% of the participants had 75%-100% correct answers	N/A
Bon et al., 2022 [43]	Parents faced difficulties grasping genetic concepts	N/A
Xiao et al., 2020 [44]	N/A	Median total score: 5 (range: −2–7) / Less than one-third parents (n = 37, 29.4%) correctly answered all 7 questions
Marron et al., 2019 [33]	24 participants had high genetic knowledge and 8 had low	N/A
Napier et al., 2022 [29]	N/A	Mean knowledge score: 43% (25%)

ii. Knowledge of genetic and genomic concepts related to general health and cancer

A moderate to high level of knowledge was identified in two studies. According to Johnson et al. (2019) [42], a median percentage of 77.8% correct answers were obtained from 158 parents of children with cancer. Marron et al. (2019) [33] reported a high level of genetic knowledge in 24 participants and a low level in eight. A lower level of knowledge was demonstrated by Aizuddin et al. (2019) [13], who found that only 39.4% of 57 caregivers had adequate knowledge, and Bon et al. (2022) [43], who highlighted difficulties in understanding genetic concepts by 29 parents of cancer patients.

iii. Knowledge of genetic and genomic testing

Regarding genetic and genomic testing, one study [44] reported a high level of knowledge, while the remaining two [13,29] agreed on a low to moderate level. Specifically, a high level of knowledge was demonstrated by Xiao et al. (2020) [44], with a median total knowledge score of 5 (range: 2–7) obtained from 126 parents of children with retinoblastoma. In contrast, in the study by Aizuddin et al. (2019) [13] involving 57 caregivers, only 33.8% scored high based on the tool measuring genetics and genomics knowledge, while in the study by Napier et al. (2022) [29], the median score of 213 caregivers was 43% (SD 25%), implying a low to moderate level of knowledge.

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D—Citizens

Nine studies [13,45–52] (**Table 4**) focused on citizens. One presented qualitative data [49], and the remaining eight reported quantitative findings. Objective knowledge was evaluated in six out of the eight quantitative studies [13,45–48,50], while subjective knowledge was measured only in two studies [51,52].

Table 4. Results for citizens' knowledge of genetics and oncogenomics.

Author, Year	Knowledge of general genetic/genomic concepts	Knowledge of genetic/genomic concepts related to cancer	Knowledge of genetic/genomic testing
Aizuddin et al., 2021 [13]	N/A	High: 19.2% (Score for high: 6-10)	High: 15.6% (Score for high: 6-10)
Puryear et al., 2017 [45]	Mean score: 6.6 ± 3.6/12 (Score range −5 to 12)	N/A	N/A
Guo et al., 2022 [46]	N/A	Low	N/A
Saya et al., 2022 [47]	N/A	N/A	73% (95% CI: 65–80%) had adequate knowledge
Krakow et al., 2018 [48]	N/A	N/A	Moderate
Metcalfe et al., 2018 [49]	Low to moderate	N/A	Low
Horrow et al., 2019 [50]	N/A	N/A	Mean score: 8.1 (2.5), 0.0-11.0
Alvord et al., 2020 [51]	N/A	N/A	Mean score: 1.90 (SD = 0.7), 0-4
Fogleman et al., 2019 [52]	N/A	N/A	69.0% were aware of genetic screening modalities for cancer

i. Knowledge of general genetic and genomic concepts

The level of knowledge of general genetic and genomic concepts was estimated and found to be moderate in two studies [45,49]. In the survey conducted by Puryear et al. (2017) [45], involving 97 primary care adult patients, the mean knowledge score was 6.6 (SD 3.6) (score range: 5-12). Also, in the qualitative study by Metcalfe et al. (2018) [49], which included 56 non-expert members of the public, varying levels of awareness and understanding of genetic concepts were observed, overall classified as fairly limited.

ii. Knowledge of genetic and genomic concepts related to general health and cancer

Two studies consistently reported low knowledge of cancer-related genetic and genomic concepts in citizens. According to Aizuddin et al. (2021) [13], only 19.2% of the 32 participating community members had an adequate level of knowledge. Further, findings by Guo et al. (2022) [46], based on the responses of 677 adult women from low-income areas, revealed an overall low knowledge of genes and cancer risk.

iii. Knowledge of genetic and genomic testing

Overall, seven studies assessed citizens' level of knowledge about genetic and/or genomic testing. Four studies specifically addressed cancer [13,47,51,52], while the remaining three did not

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provide specific references to cancer [48–50]. A moderate to high level of knowledge was identified in four studies [47,50–52]. Horrow et al. (2019) [50] reported a mean knowledge score of 8.1 (SD 2.5) (score range: 0-11) in a cohort of 2895 adults. Similarly, Alvord et al. (2020) [51] found a mean level of knowledge of 1.90 (SD 0.7) (score range: 0-4) among 203 participants, and Fogleman et al. (2019) [52] suggested that more than two-thirds of the 114 participants in the survey (69.0%) were aware of genetic screening modalities for cancer. Finally, among the 150 general practice patients included in the study by Saya et al. (2022) [47], 73% (95% CI: 65–80%) had a knowledge score of 8 about genetic testing (score range: 0-11). The remaining three studies reported lower levels of knowledge of genetic testing. According to Krakow et al. (2018) [48], only 57.08% of 1878 adults were aware of genetic health tests. Similarly, in the study by Aizuddin et al. (2021) [13], only 19.2% of the community members had an adequate level of knowledge about genetic and genomic testing. A low level of knowledge was also reported in the qualitative study by Metcalfe et al. (2018) [49], with very few participants having heard about "direct-to-consumer" testing and only 7 out of 56 reporting having undergone genetic testing.

Factors Influencing the Level of Genetics/Genomics Knowledge

Fourteen out of 43 studies [14,15,20,22–24,28,29,31,33,34,44,47,48] included in the present scoping review explored the relationship between the level of genetics/genomics knowledge and various socio-demographic factors. Education was the most frequently examined factor, displaying a positive association with knowledge levels in nine studies [14,15,22,29,31,33,34,44,47]. Conversely, age exhibited a negative correlation with knowledge levels in five studies [15,22,23,34,48]. Also, race/ethnicity played a role, whereby being white/non-Hispanic and not belonging to a minority group was linked to higher knowledge levels in five studies [20,22,23,40,48]. Higher-income demonstrated a positive relationship with knowledge levels in three studies [20,23,48], as did, not surprisingly, having a medical background [14,28,29]. A familial history of cancer in a first or second-degree relative was associated with greater knowledge in two studies [24,29], along with prior personal or familial experience with genetic testing [28,34] and the use of English as the primary language at home [31,47]. Furthermore, individuals with higher health literacy exhibited greater knowledge in one study [14]. Women displayed a significantly higher level of knowledge compared to men in one study [47], as did individuals with a personal history of cancer [23].

Discussion

Drawing on quantitative and qualitative data from 43 studies across seven countries, this scoping review evaluates the literacy levels and understanding of genetics and genomics among cancer patients, caregivers, and the public, focusing on implications for cancer prevention, diagnosis, and treatment. Despite the heterogeneity in the samples and methods of the included studies, our findings uncover inadequate knowledge levels among all studied populations, with lower levels in citizens compared to cancer patients and caregivers. This difference is likely ascribable to the limited exposure of the former category to these concepts and practices. Most cancer patients and caregivers in the selected studies of this review had been recruited in a clinical trial context, with genetic or genomic testing being part of the protocol. Hence, participants received basic genetic information as a prerequisite for informed consent. Consistent findings were reported in the systematic review by Botham et al. (2021), revealing that patients participating in clinical trials comprehended personalised medicine concepts (and terms) better than those undergoing testing with the only purpose of informing their treatment [1]. Providing educational support before enrollment in cancer clinical trials improves the probability of participants' acceptance [56]. This could explain the higher levels of knowledge shown by patients participating in clinical trials [57]. Nevertheless, though most participants had received genetic or genomic testing, there was still a significant lack of knowledge and misconceptions regarding interpreting the results. This stresses the importance of effective communication between cancer patients and their healthcare providers and the constant need for tailored and up-to-date education of all stakeholders [11].

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The knowledge gaps in this scoping review align with those reported in previously published reviews. The primary challenges cancer patients, caregivers, and the public face include comprehending genetics' role in cancer and other genetic diseases, distinguishing between germline and somatic sequence variants, understanding the inheritance patterns of specific cancer-related genetic mutations, and assessing familial cancer risk. Complexities in interpreting genetic test results also emerge, including the implications of specific genetic variants [1,58]. Ethical and privacy concerns are repeatedly raised since patients and citizens seem unfamiliar with the laws regulating the use of applied genetic information and preventing discrimination regarding eligibility for life insurance, disability insurance, and long-term care insurance. Finally, misconceptions about the practical processes of sample extraction, storage, and data protection have also been observed [52].

Another relevant finding of our work is that genetic literacy can be influenced by several factors, especially education and age. Education has been generally linked with higher health literacy, suggesting that individuals with higher education tend to more appropriately seek, interpret, understand, and apply health information to make informed decisions about their health and well-being [58]. In line with what was previously reported [11], younger individuals showed better genetic knowledge than older participants, possibly owing to their increased potential exposure to information through educational curricula and the Internet [59]. Lastly, another significant factor frequently related to higher genetic literacy is personal or family history of cancer, as individuals might have a greater interest in learning about the genetic aspects of the disease. Personal experience can motivate individuals to seek information, engage in discussions, and develop a better understanding of genetic factors contributing to cancer development [60]. It is important to note that genetic literacy is a complex and evolving field, and various other factors can influence an individual's understanding of genetic information.

Strengths and Limitations

This scoping review provides the most up-to-date evidence reflecting the knowledge of genetic and genomic concepts by cancer patients, caregivers, and citizens, synthesising the existing body of quantitative and qualitative data. We carried out a comprehensive literature search, adopting the best available standards to select and analyse the collected evidence—an approach that strengthens the methodology of this scoping review. However, the current scoping review was subject to some limitations due to the breadth of studies that were eligible for analysis. As mentioned earlier, most of the included studies were conducted in the United States, while only two were carried out in Europe, limiting the generalisability of our findings. In this regard, another factor that should be considered is the participation of a significant number of patients in clinical trials for which they were offered genetic or genomic testing, meaning that they had already been exposed to essential information for these concepts to be able to provide informed consent. Significant heterogeneity was noted regarding the type and the stage of cancer among cancer patients, whereas the cohorts of caregivers mainly encompassed parents acting as legal representatives of their underage children. Lastly, significant heterogeneity was identified in the knowledge assessment methods and tools, including variations in the type of acquired knowledge, difficulty levels, complexity, and the number of questions included.

Conclusions

In conclusion, the findings from this scoping review highlight variable levels of genetic and oncogenomic literacy among cancer patients, caregivers, and the public and identify significant gaps, which, if addressed, could markedly enhance patient engagement and health outcomes. Our results lay the groundwork for the development of targeted educational initiatives to address the specific needs of each group. By fostering a more knowledgeable population, these initiatives could, in turn, empower individuals to make more informed decisions about their health.

Authors' Contributions: KN, AV, MLC, and RdA designed the study. KN, MLC, and MN undertook the literature review and extracted the data. KN and MLC developed the search code, with inputs from AdN, ZCM,

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CKar and CKak. KN, AV, and MLC analysed and interpreted the data. RdA, CMBSR, and MN participated in data evaluation and interpretation. KN wrote the first draft of the manuscript with input from all authors. All authors reviewed and revised subsequent drafts.

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