



The views of cancer patients of Turkish, Moroccan, Surinamese, and Dutch-Caribbean descent on diagnosis, treatment and prognosis: A systematic literature review

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ABSTRACT

Background: The number of international migrants is increasing worldwide. The four major non-western ethnic groups in the Netherlands are Turkish, Moroccan, Surinamese, and Dutch-Caribbean. This review examined the scientific literature on the views of cancer patients from these four ethnic groups on cancer diagnosis, treatment, and prognosis.

Methods: A systematic literature review was conducted using the databases EMBASE, Medline Web of Science, and Cochrane Central Register. Studies with patients who were of Turkish, Moroccan, Surinamese, and Dutch-Caribbean descent were included. Both qualitative and quantitative studies were included, and thematic analysis was performed. The methodological quality was assessed using the Mixed Methods Appraisal Tool.

Results: Thirteen studies were conducted in Turkey on Turkish cancer patients, while three were conducted in the Netherlands on Turkish and Moroccan cancer patients. Four themes emerged from the included studies: disclosure of diagnosis, communication, information provision, and decision-making. The majority of cancer patients in Turkey wanted information regarding their diagnosis and treatment. However, disclosure of a cancer diagnosis was rarely discussed with cancer patients in Turkey, whereas in the Netherlands it was provided directly. Family members in both the host and native countries had a strong influence on communication and decision-making. No literature on this topic for Surinamese or Dutch-Caribbean cancer patients was found.

Conclusion: Although major ethnic groups live in host countries, there is a lack of knowledge on optimal communication and information disclosure on cancer to patients and their families.

Policy summary: Further research into the views of ethnic groups on how to communicate about cancer is essential to ensuring that every patient receives optimal care and treatment.

1. Introduction

The number of international migrants worldwide increased to 281 million in 2020, corresponding to 3.6% of the world's population. The greatest growth is found in Europe and Asia, which account for 61% of the global international migrant population [1]. An international migrant is defined by the United Nations as "someone who changes his or her country of usual residence, regardless of the reason for migration

or legal status" [2]. In this article, "migrants" refers to both those who migrate internationally and those who stay longer or permanently. This definition is useful for examining the diversity of the migrant population and their experiences upon arrival in the host country.

Many migrants will remain in their host country for extended periods and, as such, become an integral part of the community and are dependent on the local healthcare system of their "new" home country. However, the local healthcare system is frequently unprepared for these

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migrants with their own language, cultural values, and ideas about health. According to some studies, non-Western migrants (i.e., those with backgrounds from Turkey, Africa, Latin America, or Asia) have worse physical and mental health as they age and have more chronic diseases than the older host population [3,4]. Additionally, linguistic barriers and culturally based health attitudes may make it more difficult for migrants to access medical care, which is a major risk factor for poorer health outcomes [5–8]. For example, migrants' inability to communicate their difficulties due to language barriers can lead to the risk of being misunderstood and eventually misdiagnosed [7,9]. To overcome these challenges, healthcare systems need to develop culturally competent services that are tailored to the needs of migrant populations.

Migrants have distinct health care needs, beliefs, expectations, and communication styles compared to native populations. These distinctions can already come into play when telling the patient the truth about a cancer diagnosis, which is common practice in countries like the Netherlands and many other Western European countries. Full information provision and truth telling, however, are sensitive subjects in other parts of the world due to differences in religion, culture, and social aspects [10,11]. Therefore, it is essential for healthcare providers (HCPs) to understand the views of these migrants when discussing topics such as diagnosis, treatment, and prognosis.

Migrants who arrived in Western Europe in the decades following World War II and have remained since then form the longest staying majority of ethnic minority groups in the countries. In the Netherlands, the four major non-western ethnic groups consisted of Turkish, Moroccan, Surinamese, or Dutch-Caribbean [12–14]. These ethnic groups differ from the average Dutch person in education, health care, and socioeconomic status [15].

Two previously conducted systematic literature reviews have focused on the information preferences and needs of non-Western cancer patients. One focused on the palliative care needs of Turkish and Moroccan cancer patients [16], while the other one included a wider range of non-Western cancer patients in Western countries, also including survivors [17]. Within this latter review, only one study discussed the information needs of Turkish and Moroccan cancer patients. Therefore, it remains crucial to gain insight into the views of Turkish, Moroccan, Surinamese, and Dutch-Caribbean cancer patients on discussing diagnosis, treatment, and prognosis, regardless of their geographical location. Our aim with this systematic review is to bridge this knowledge gap and provide insights for HCPs by addressing the question: What are the views of Turkish, Moroccan, Surinamese, and Dutch-Caribbean cancer patients regarding discussions of diagnosis, treatment, and prognosis?

2. Methods

2.1. Selection criteria

Included were studies that fulfilled the following criteria: (i) if they focused on views, needs, and preferences, referring to all the information patients would like to receive regarding their illness; (ii) if the publication was an original study; (iii) if the full report was published in a peer-reviewed journal; and (iv) if it was published in English. The study population of all studies had to be Turkish, Moroccan, Surinamese, and Dutch-Caribbean cancer patients living in their country of birth or residence. In this review, qualitative and quantitative empirical studies were included.

Studies were excluded for the following reasons: (i) if the study focused on patients' ethnic backgrounds: African Americans, Asian Americans, Hispanic Americans, American Indians, and Mexican Americans; (ii) if the study focused on the economic burden of cancer; (iii) if the study focused on cancer and COVID-19 or Sars-COV-2; (iv) if the study focused on screening or mammography; and (v) if the study only focused on hematologic malignancies.

After removing duplicates, the inclusion and exclusion criteria were used on our first 2019 hits. Two independent reviewers (A.G. and M.R., individually) screened all hits based on title and abstract, and finally, 28 full papers were selected. After careful review by both reviewers, 16 articles met our selection criteria and were included in this review. Any discrepancies were resolved by a third reviewer (O.H.). A PRISMA checklist is presented in [Supplementary Table 2](#), and the flow chart of this selection procedure can be found in [Supplementary Figure 1](#). This review was not registered in a publicly accessible registry. We conducted the study systematically and followed established research procedures to ensure the reliability of our findings.

2.2. Literature search

Literature was retrieved on September 25, 2023 from the most commonly used search engines: EMBASE, Medline Web of Science, and Cochrane Central Register. Search strings were assembled with an experienced librarian. [Supplementary Table 1](#) gives the details of the search strings. The reference lists of all identified publications were searched for additional relevant publications. There were no restrictions with regard to the year of publication. A bibliographic management software program, EndNote, was used to keep track of the selected literature and to remove duplicates.

2.3. Quality assessment

The quality of the selected papers was measured according to the Mixed Method Appraisal Tool (MMAT) 2018 version [18]. MMAT is a comprehensive tool designed to evaluate the quality of the articles across a range of research designs. It categorizes studies into five types: (a) qualitative, (b) randomized controlled, (c) nonrandomized, (d) quantitative descriptive, or (e) mixed methods. For each included study, one category of criteria was selected and rated. Each item scored 0 or 1 and yielded a maximum of 5 points (100%). A higher score indicated a higher quality of paper. Studies scoring 3 points (60%) or more were considered "high quality", while those scoring less than 2 points were classified as "low quality". The assessment of study quality was independently conducted by two investigators (A.G. and M.R.), and any discrepancies were resolved through discussion between the authors. Importantly, none of the articles were excluded based on the quality assessment. Further details can be found in [Supplementary Table 3](#).

2.4. Data extraction and analysis

The data retrieved included the first author, year of publication, study design, setting, number of patients, most common diagnosis and stage of cancer, treatments, and results. As high heterogeneity between individual studies was expected, the main themes of the included studies were identified through thematic coding [19]. An inductive approach was chosen to be open to research findings. The first author became familiar with the data by continuously reading and rereading. The first codes were identified in the studies through a systematic process that extracted relevant and interesting parts of the research findings. Each stage of the coding process was monitored. In the last step, the codes were compiled into themes and sub-themes. The authors gave feedback at different stages of the analysis, and consensus was reached after discussion.

3. Results

This review has included sixteen articles published between January 2002 and July 2021 from the 2320 abstracts retrieved by our search strategy. The flowchart of the study selection process is depicted in [Supplementary Figure 1](#). Characteristics of the included study populations are presented in [Supplementary Table 4](#). Most of the studies were performed in Turkey (n = 13), and the remaining studies were

performed in the Netherlands ($n = 3$). The total study population consisted of Turkish cancer patients receiving care in their own country, Turkish or Moroccan cancer patients receiving care in the Netherlands, and one study included both Turkish people in Turkey and Palestinian people living in the occupied Palestinian territory. In this latter article, we only used the results of the Turkish patients for this review. There were no studies on cancer patients from the Republic of Suriname or the Dutch Caribbean. The results revealed four distinct themes emerging from the collected data. The studies were organized according to their themes. Still, an overlap in themes exists for some studies, as themes partly overlap.

3.1. Methodological quality

Two reviewers' evaluations of the quality of the methodology differed on a number of topics, mainly due to differences in interpretation. The differences were resolved through discussion by the same two reviewers in a consensus meeting. Quality scores ranged from one to five points. Most of the studies were judged to be of high quality, whereas only two studies [20,21] were judged to be of low quality (Supplementary Table 3). In the included studies, lack of data on patient sampling, lack of data on non-responders, and unclear suitability of questionnaires were common shortcomings.

3.2. Theme 1: disclosure of diagnosis

Six studies mainly examined the disclosure of the cancer diagnosis to patients [22–27]. Three different subthemes about disclosure of diagnosis in Turkish and Moroccan cancer patients were identified: unawareness of diagnosis, coping with diagnosis (relying on cultural/religious beliefs), and the role of family.

3.3. Unawareness of the diagnosis

Three Turkish studies showed that 37.1–54.7% of patients were unaware of their cancer diagnosis [23,24,26]. Most of these patients had a low educational level. In one study, among patients with solid or hematologic malignancies, both higher age and illiteracy were significantly associated with not knowing the diagnosis [26]. Another Turkish study found that the majority (67.9%) of cancer patients had guessed the diagnosis from their treatment or adverse effects related to the prescribed drugs. The cancer histology can also make a difference with the vast majority of breast cancer patients (in total 92.3%), who were aware of their diagnosis [23]. A higher percentage of awareness of the diagnosis (78.8%) was also found in another study, of which 37.5% consisted of patients with breast cancer [20].

3.4. Coping with the diagnosis

Two qualitative studies with semi-structured in-depth interviews described the emotional reactions to discussing the diagnosis. According to one Dutch study, Turkish and Moroccan cancer patients and their families had distinct perspectives from Dutch HCPs on "good care" in the palliative setting. This was particularly the case on whether or not to inform the patient of the diagnosis to respect patient's wish to maintain hope [25]. In another study conducted in Turkey, women coping with a breast cancer diagnosis experienced a traumatic event that affected their emotional well-being, as the cancer diagnosis often symbolized death, leading to feelings of fear, sadness, anxiety, and despair. Furthermore, the women tried to cope with the diagnosis through religious activities and also pointed out that social support was very important [27].

3.5. Role of family

One qualitative Turkish study focused mostly on the relatives of 150 patients with recently diagnosed cancer. The majority of the relatives

(66%) in this study did not want the diagnosis to be disclosed to the patients for several reasons (Supplementary Table 4). In a multivariate analysis, relatives' "do not tell" attitudes were significantly related to the diagnosis of a non-breast cancer malignancy and their lack of general cancer knowledge [22]. As previously described, relatives of Turkish (and Moroccan) patients would prefer to maintain hope instead of discussing the cancer diagnosis and poor prognosis [25].

3.6. Theme 2: communication

Two qualitative studies focused on communication between patients and HCPs [28,29]. The first, a Dutch study, focused on how Turkish and Moroccan patients and HCPs communicated about care and treatment during the palliative phase. Most of the difficulties in communicating were due to language and cultural differences (Supplementary Table 4). Just seven of the 33 patients had sufficient Dutch language skills to communicate directly with the HCPs [25]. Communication was mostly triangular between the HCPs, the patient, and their relatives. Relatives frequently acted as participants and interpreters in the conversation, which might have impeded communication with HCPs owing to variations in expectations. For example, the relatives preferred that HCPs interact with them first rather than directly with the patient [28]. Another study discovered that poor communication about the disease within families might lead to conflicts. In cases where more HCPs were involved, communication also became more difficult which was also the case for decision-making [30].

The second qualitative study conducted in Turkey focused on the experiences of Turkish women with gynecologic cancer and their partners. In this study, there was no language barrier between the patient and HCPs. Nine of the nineteen patients and five of the twelve partners used the term "a bad result" instead of "cancer disease". Both the patients and their partners experienced strong emotions and thoughts of "death" when they first heard about a cancer diagnosis. Some of them attributed the illness to fate and used religion to cope [29].

3.7. Theme 3: information provision

Six studies from Turkey, one qualitative and five quantitative, focused on obtaining information about both diagnosis and treatment [20,21,31–34]. Notable subthemes were medical terminology, patient wishes, and information content.

First, a qualitative study conducted in Turkey showed that differences in socioeconomic and cultural contexts could lead to differences in the usage and understanding of medical language both within and across countries. For example, Turkish women in Aydin with less formal education and more traditional backgrounds avoided using the word "cancer" in interviews, instead referring to it as "that disease" or "the evil disease". In contrast, the majority of women in Istanbul adapted to the language of medicine and were more familiar with the various phases of cancer due to their greater exposure to diverse information sources [31, 32].

Second, all five [20,21,32–34] quantitative studies in Turkey found that most cancer patients wanted complete information about their diagnosis and treatment (Supplementary Table 4). The majority of cancer patients saw this as the HCPs' responsibility [21]. While the vast majority of patients were informed by HCPs, 4.8% were informed by their families, and 12.5% were not informed at all [20]. One of the studies showed that 29.8% of cancer patients strongly agreed, and 40.5% agreed that they needed to know the survival rate [32]. The studies did not discuss the prognosis. More than one third of the cancer patients had a low level of education [20,21,33,34], but in two studies [31,32] no education level was mentioned. All studies encompassed at least 20% of breast cancer patients, with the exception of one study, for which data on tumor type was not available [32]. Patients had more information-seeking behavior than their relatives [34].

Lastly, one study found that the majority of patients receiving

treatment were provided with information regarding the course of treatment and side effects; however, 7.3% had not been told about the treatments at all. In comparison to uninformed patients, informed patients reported higher levels of satisfaction and asked more questions about their diseases [20]. A quantitative study conducted in 2021 with 84 patients showed that patients were concerned about inadequate information from HCPs, a lack of understanding of medical terminology, and a lack of help in explaining information from HCPs [32]. Patients with higher levels of education were significantly more likely to question their HCPs [20]. Another study also found that well-educated patients had more information-seeking behavior [34] were more satisfied with the information they received, and had a better understanding of the information provided by the HCPs [33].

3.8. Theme 4: decision making

One study examined the challenges faced by Turkish and Moroccan patients in the Netherlands when making decisions, while another study focused on Turkish patients in Turkey [30,35]. Based on a Dutch study conducted in 2012, it was found that decision-making challenges in palliative care extended beyond ethnic-cultural differences between Turkish or Moroccan patients and Dutch HCPs. The study revealed that Turkish and Moroccan families often insist on pursuing a cure, while Dutch HCPs tend to prioritize quality of life. Moreover, the family's insistence on seeking a cure often leads to the involvement of additional HCPs, thereby further complicating the decision-making process. Internal conflict within families and professional teams was also identified as an additional factor that contributes to the complexity of these decision-making processes. It is important to note that the study did not provide specific information on the preferences of patients regarding treatment discussions [30]. According to a Turkish study, patients expressed uncertainty regarding their level of satisfaction with the treatment decision [35]. Another study conducted in Turkey revealed that 65.4% of Turkish patients when offered more treatment options, expressed a preference for shared decision-making with HCPs, while only 7.7% of patients allowed HCPs to make decisions on their behalf [21].

4. Discussion

To the best of our knowledge, this is the first systematic review of studies that has focused on the views of Turkish, Moroccan, Surinamese, and Dutch-Caribbean cancer patients when discussing cancer diagnosis, treatment, and prognosis. Since the results of the different themes (disclosure of diagnosis, communication, information provision, and decision making) are linked, we have decided not to discuss them separately.

4.1. Information needs of Turkish cancer patients

The results of our review on the information needs of Turkish cancer patients regarding diagnosis and treatment [20,21,32–34] were in line with those of systematic reviews of populations from North America and Europe [36–38]. However, in contrast to one of these systematic reviews that prioritizes prognosis as the first information need [38], we identified only one Turkish study with a focus on prognosis [32] which suggests that it is not common practice to discuss the prognosis with Turkish patients. Furthermore, our review showed that not all Turkish patients in Turkey were aware of their diagnosis, suggesting that factors may have affected the disclosure of the diagnosis [23,24,26].

4.2. Factors influencing diagnosis disclosure

Three factors contributing to the lack of sharing of a diagnosis among Turkish cancer patients in Turkey have been identified. Firstly, Turkish cancer patients wanted to know their diagnosis, but their relatives

declined to disclose it due to religious and cultural reasons [22]. This pattern of discrepancy between patients and their relatives is found in Asian [39,40] and southern European countries as well [41,42]. Secondly, Turkish cancer patients may have different preferences for the wording of their disease when HCPs inform them, but we could not find a specific study on this subject in Turkey to confirm this. However, Dutch studies included in our review found that the majority of the Turkish (as well as Moroccan) patients preferred to have the diagnosis discussed with them in veiled language [25,28] and, therefore, should use other words instead of "cancer" [31,43]. Lastly, the lack of awareness of a diagnosis may be due to the Turkish HCP's inclination to tell relatives first [44,45], while they may also be influenced by relatives not to inform the patient [46]. HCPs in Turkey who were trained and more experienced in delivering bad news were more likely to give the diagnosis [46].

4.3. Impact of factors on information provision

Our results also showed that age, education, and tumor type may affect information disclosure among Turkish patients. While one Turkish study among patients above 55 years of age found a significant association between not knowing the diagnosis and higher age and illiteracy [26], this association was not consistently observed in the other two studies within our review, which compared different age groups [20, 21]. Interestingly, one study in our review indicated that age did not seem to be a factor in the "do not tell" attitude held by relatives [22]. The majority of HCPs in Turkey did not disclose the diagnosis to the elderly patients in order to protect them from psychological distress. However, no association was found between knowing the cancer diagnosis and depression [26]. Another Turkish study found that psychological difficulties were more likely in Turkish cancer patients who were not directly informed of their diagnosis by their doctor and had to guess their diagnosis during the course of their disease [23]. Moreover, more than one-third of the patients in the included studies had a low level of education [20–23,26,33–35,47] which is associated with a lack of health literacy [48]. This may explain why patients in our studies had difficulty understanding and using medical terminology [49,50]. Tailoring information to the patient's needs is important for patient satisfaction [51]. The uncertainty expressed by Turkish patients in Turkey regarding their satisfaction with treatment decisions for their cancer underscores the importance of addressing their doubts and actively involving them in the decision-making process [35]. This is crucial to enhance their satisfaction and confidence in the chosen treatment plans. The type of tumor may also have an impact on the disclosure of the diagnosis, as was exemplified by the fact that breast cancer patients were generally more aware of the malignant character of their disease than patients with other diseases [21,22]. In the quantitative study, with the largest group being breast cancer patients, 78.8% of all participants were aware of their diagnosis [20]. However, the study had a low methodological score due to poor participant selection, measurement, and risk of bias (Supplementary Table 3), so the results of the study should be interpreted with caution, and further research is needed to confirm the findings. More research is required to determine the impact that these factors have on the information provided to Turkish patients so that this may be taken into account in practice.

4.4. Challenges in healthcare for Turkish and Moroccan patients

In the Netherlands, Turkish patients and their relatives faced obstacles in palliative care due to cultural differences, language barriers, and triangular communication styles [25,28,30]. These challenges can hinder effective communication. A study conducted in Belgium with mainly Turkish patients also identified the language barrier as an important obstacle [52]. Like in Turkey, relatives of patients were involved in the conversations between patients and Dutch HCPs [28]. However, this involvement introduced different expectations and ideas

about the roles of each person in the conversation [53]. An observational study highlighted the dominant role of informal interpreters in these conversations, sometimes resulting in incomplete information reaching the patient or HCPs [54]. According to our findings, relatives who acted as interpreters, especially in the host countries, were able to hide the patient's diagnosis. Therefore, it would be interesting to investigate whether the role of relatives is the same when there is no language barrier and thus no need for an interpreter. The Dutch study did not provide additional detail, although seven out of 33 patients did not require an interpreter [28]. In Turkey, where there is no language barrier, it is questionable whether relatives of patients play the same role in conversations with HCPs. However, no research has been conducted in the Netherlands or Turkey to determine how Turkish patients wish to discuss these topics or what they think about their relatives' roles in conversations. This could be attributed to the common cultural practice of family involvement in Turkish society.

4.5. The need for further research and culturally sensitive care

The absence of studies providing direct insight into how to discuss cancer diagnosis, treatment, and prognosis with Turkish, Moroccan, Surinamese, and Dutch-Caribbean patients emphasizes the need for further research. Specifically, no studies were identified on Surinamese and Dutch-Caribbean cancer patients, while the majority of studies focused on Turkish patients. To bridge this knowledge gap, future research should prioritize understanding the preferences and communication needs of these diverse populations. This research can provide valuable insights for the development of culturally sensitive care approaches and enable HCPs to effectively tailor their communication strategies to meet the unique needs of these ethnic groups.

4.6. Study limitations

This review has several limitations. Firstly, it focused only on four ethnic groups: Turkish, Moroccan, Surinamese, and Dutch-Caribbean. However, studies were identified only for Moroccan patients in the Netherlands and Turkish patients in the Netherlands and Turkey, making it challenging to draw conclusions about other ethnic groups and generalize the results to other countries. Secondly, the review was limited to studies in the English language. It is possible that other studies written in their native language or in other European languages exist. Thirdly, we aimed to focus on patients with solid cancers, which led us to include studies related to both oncology and hematology while excluding those with solely hematological malignancies. Lastly, the quality of the included studies was low, partly due to small sample sizes. Therefore, the findings of this review should be interpreted with caution, and further high-quality research with larger sample sizes is needed to assess the different topics raised.

5. Conclusions

Several overarching themes were presented to gain insights into the views of Turkish and Moroccan cancer patients on diagnosis, treatment, and prognosis, with no data available for Surinamese and Dutch-Caribbean cancer patients. However, the limited number of studies makes it challenging to draw general conclusions, especially regarding information provision in host countries with direct communication styles like the Netherlands. The discordance between patients and relatives, and other influencing factors, such as age, education, and tumor type, warrant further research. Family members in both the native and host countries had a strong influence on communication and decision-making. In the host country, there were additional challenges related to ethnic and cultural differences, language barriers, and other obstacles. Further research can provide valuable insights into how to effectively communicate on all relevant aspects of cancer with patients and their relatives from diverse backgrounds to ensure high quality of care

and patient and family satisfaction.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.jcpo.2023.100455.

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