

Critical Review

Assessing and Providing Culturally Competent Care in Radiation Oncology for Deaf Cancer Patients



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Abstract

Purpose: Recognition of disparities for vulnerable populations in the field of oncology is increasing, but little attention has been paid to deaf patients. At least a million Americans are culturally deaf and use American Sign Language. Poor linguistic and cultural competency among physicians is a barrier to care delivery for these patients, placing them at risk for treatment disparities. To better educate oncology practitioners, including radiation oncologists, regarding the unique needs of this cohort, we performed an evidence-based literature review of culturally competent care for deaf patients to improve patient care and delivery.

Methods and Materials: PubMed was systematically reviewed for publications reporting on deaf patients for articles regarding (1) survivorship, patterns of failure, or toxicity in treating malignancies or (2) cultural and linguistic barriers to delivery of oncological care. Publications were excluded if deafness was a side effect of treatment or barriers and outcomes were reported on nonmalignant conditions.

Results: Barriers to care were poor health literacy, accessibility to providers or resources in preferred language (ie, American Sign Language), and limited cultural and linguistic proficiency of providers. Deaf patients may have a delay in cancer diagnosis, but no articles reported on treatment outcomes for malignancies in deaf patients. Currently, no oncology-specific guidelines exist on care delivery for deaf patients with cancer. We propose the need for a care model that provides guidelines on creating effective and total communication accessibility for deaf patients and improves cultural and linguistic competency among providers. Guidance should be provided on implementation of resources and training for oncology practitioners and how their respective institutions and staff can help create inclusive care environments.

Conclusions: Clinical outcomes of deaf patients with cancer remain poorly characterized, highlighting the need for a care model to promote provision of linguistically and culturally competent oncological care for deaf patients.

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Introduction

Although recognition of disparities in outcomes for many vulnerable populations in the field of oncology is increasing, little attention has been paid to the outcomes

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of deaf patients with cancer. Of the subset of Americans who have at least moderately to severely profound hearing loss, at least a million of these Americans identify as culturally deaf and use American Sign Language (ASL),¹ which may be an underestimate given the difficulty of performing an accurate census of this group. ASL users and culturally deaf people have unique linguistic and cultural needs that distinguish them from others with hearing loss as a result of aging, traumatic damage to the hearing apparatus at an advanced age, and those who develop hearing loss as a result of medical treatment. Moreover, within this group, one finds a diverse amalgam of immutable factors including peoples of multiple races, ethnicities, ages, and a wide continuum of demographic characteristics such as language preferences, education, socioeconomic status, and health literacy. There have been an increasing number of public health initiatives among hospitals and medical education programs in recent years²⁻⁴ to educate and increase awareness among physicians and other health care providers. Despite that, the vast majority of physicians have very limited training that teaches them how to deliver health care to these patients at a linguistically and culturally competent level.

The minimum requirement was defined in 1990 by the Americans with Disabilities Act (ADA), which states health care systems and providers are required to ensure effective communication with patients through reasonable accommodations.⁵ The term *effective communication* can be very vague and does not clearly delineate the needs to someone not well versed with this group. This is highlighted by the fact that there have been multiple studies identifying poor linguistic and cultural competency among physicians as a significant barrier to care delivery for these patients, placing them at risk for treatment-related disparities. For example, Iezzoni et al⁶ performed focused group interviews on the experience of deaf adults with the general health care system and found that physicians frequently required them to use inadequate modes of communication, did not understand their responsibility to ensure effective communication, and often complained about the difficulties of hiring interpreters or providing special equipment. Another study on deaf women in the United Kingdom found that fewer than 1 in 10 deaf women said they fully understood what their physician said to them when they came in for a clinic visit on their own.⁷ To better educate oncology practitioners, including radiation oncologists (ROs), regarding the unique needs of this cohort in the oncology setting, we performed an evidence-based literature review of culturally competent care for deaf patients with the goal of identifying potential barriers to care and providing some considerations for a future

care model to improve care and delivery for deaf patients.

Methods and Materials

Literature review

A systemic literature search was conducted using PubMed for publications with the search terms “Deaf AND Cancer.” Then, “Deaf” was interchanged with keywords such as “Hard of Hearing,” “Hearing Loss,” “Hearing Impaired,” “ASL,” and “Deaf Culture.” The following filters were applied: publications after 1990; English; and human species. Studies were then screened by title and abstract to determine eligible articles for review. Articles were included for analysis if they reported on deaf patients with a malignancy; their knowledge, experiences, or perspectives in regards to cancer; survivorship, patterns of failure, and toxicity with various treatment modalities for these patients; or cultural or linguistic barriers to delivery of optimal oncological care. Publications were excluded if they reported on deafness or hearing loss as a side effect of treatment, or if they reported on outcomes or barriers in deaf patients with nonmalignant conditions. Eligible articles were then reviewed in entirety with an emphasis on identifying treatment outcomes or barriers to care for the patient cohort of interest. The references for selected articles were also reviewed for additional articles not identified using the search terms but that met inclusion criteria. To maintain a broad scope but to also limit the search to publications with data more relevant to the modern era, we did not include publications before 1990.

Literature analysis and data extraction

For the qualified studies, the articles were categorized by the methodology and purpose of the study. For each study reporting on barriers in health care for deaf patients, descriptive information was collected on the type of barriers or disparities identified in the study and at what level these barriers or disparities existed in the current health care system. Because reported barriers to care across different articles were often multifaceted views of a similar theme, unifying themes were created to account for the heterogeneity of patient groups, methodology, intent of the study, and malignancies of interest. To ensure such themes were relevant to this patient population as a whole, themes were created if relevant theme-related barriers were not limited to gender or type of malignancy and if supporting data could be identified in at least 5 different studies. If a study reported on oncology treatment outcomes for deaf patients, qualitative and quantitative variables were collected including, but not

limited to, age, sex, race, cancer histology, type of treatment, treatment outcomes (including local failure, distant failure, overall survival, and treatment toxicity), and length of follow-up time.

Results

Descriptive characteristics

The literature search yielded 1105 potential articles, which were then screened by title and abstract. After the initial screening, 37 articles were subjected to further review with 3 being ultimately excluded for analysis in this study, leaving 34 articles^{3,4,7-38} that were qualified for analysis and inclusion in this study. Of the excluded articles, 1 reported on the validation and evaluation of an online module for cancer genetics for deaf adults; another reported on the utilization of deaf-friendly ministries to promote general, including cancer-related health care information; and a third reported an educational initiative by a cancer center for medical students but did not have an oncological focus (Fig 1). Qualified studies were categorized by methodology and health care barriers/disparities are summarized in Table 1. Multiple studies (16) conducted survey-based assessments or focus group interviews of deaf patients with or without a control cohort to identify disparities in health care and overall knowledge of cancer and specific types with the majority focusing on the attitudes, practices, and perceptions of deaf adults regarding screening guidelines for certain cancers. Of note, in 1 of these 16 studies, the study cohort was composed of ASL interpreters working in the health care system instead of deaf adults.⁸ One study was a multi-institutional retrospective review of the diagnostic stages of deaf adults at time of diagnosis.⁹ Another study conducted a review of major research databases for literature on the quality and outcomes of health initiatives tailored to improving the knowledge of deaf adults while adhering to national guidelines on cancer treatment and prevention.¹⁰ The rest, 16 in total, were interventional studies designed to assess various educational initiatives in the form of programs, videos, or online modules, and so forth, which were tailored to be accessible to deaf participants. Four interventional studies were randomized, and 4 did not have any control arms.

Health care barriers

Multiple health care barriers were identified at several different levels in the health care system, but 3 unifying themes were present: (1) poor health literacy among deaf adults; (2) accessibility to tailored health care resources for cancer-specific information; and (3) poor linguistic and cultural competency among physicians (Table 2). In every study, a common denominator was poor health

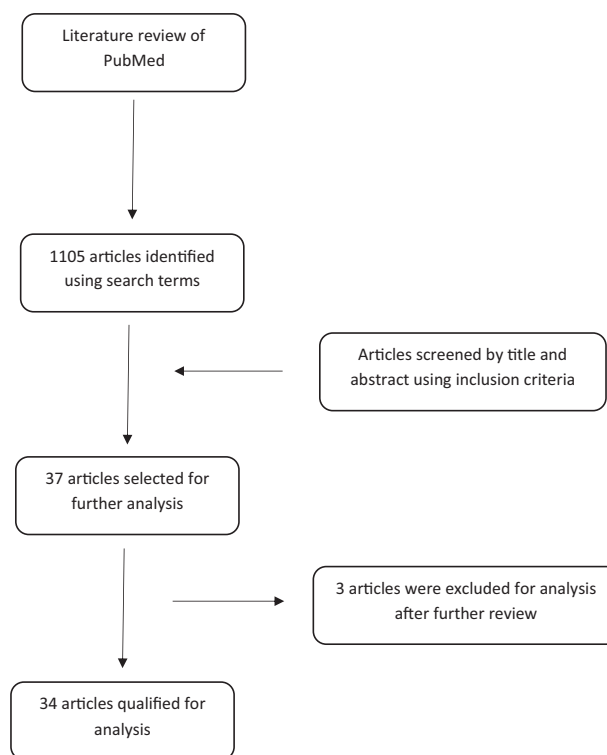


Figure 1 Flowchart: Systematic review of eligible articles from the PubMed database.

literacy of deaf youth or adults at baseline compared with average expected literacy levels for hearing peers. For example, multiple interventional studies in our series conducted preintervention surveys and found that deaf adults consistently had statistically significant lower baseline scores for cancer-specific knowledge and were more likely to not understand the value of or recognize cancer-specific screening tests.^{4,11-21} In the most extreme example, a focus group interview study reported that a breast cancer survivor stated she did not know what cancer was when asked, despite being a survivor.²¹ However, other variables, beyond deafness, may also be in play such as socioeconomic status, level of education, language preference, and so forth. Palmer et al⁴ reported that level of education was associated with participants' baseline level of knowledge and ability to improve post-intervention. Another study identified the level of reading comprehension to be significantly associated with the level of comfort deaf patients had discussing cancer with their physicians.⁷

A second barrier to care is poor health literacy or differences in cancer-specific attitudes and practices. However, this may be reflective of the limited amount of health care resources that are accessible and tailored to this population rather than the fact that patients are deaf. Multiple studies in our series reported on interventional programs designed to improve cancer-specific knowledge in deaf participants and overwhelmingly showed that the knowledge of deaf patients about specific cancers

Table 1 Summary series of qualified studies

Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
Cumberland et al ¹¹	Breast cancer	Randomized, interventional control trial	Assessment of whether participating in a culturally and linguistically tailored educational program improved the knowledge of deaf breast cancer patients with limited education	Desire to participate in regular mammography screenings increased in the interventional group and knowledge increased from baseline in the interventional group, demonstrating the benefit of accessible programs
Hickey et al ¹²	Breast cancer	Interventional study without a control cohort	Deaf women with a preference for ASL were exposed to a breast cancer education video in ASL	Disparities in knowledge about breast cancer were identified and deaf women demonstrated improved knowledge about breast cancer after utilization of an accessible resource
Berman et al ²²	Breast cancer	Focus group interviews and survey-based assessments	Deaf breast cancer survivors were interviewed in the first and surveyed in the second study	Women expressed that their physicians did not understand how to interact or did not want to interact with them because of their deafness; inadequate communication methods were used, and there were profound health literacy disparities (some women did not even know what procedures/medications they received)
Berman et al ²³	Breast cancer	Survey-based assessment	Survey of knowledge and health practices among deaf women with breast cancer	Disparities in knowledge about breast cancer were identified and deaf women demonstrated low compliance rates with screening guidelines for breast cancer
Sadler et al ²⁶	Breast cancer	Survey-based assessments	Pilot study of deaf women surveyed about breast cancer after participating in an intervention study	Similar findings to Berman et al, Cumberland et al, and Hickey et al
Steinberg et al ²⁴	Breast/gynecologic cancers	Focus group interviews	Deaf women were interviewed regarding health literacy, knowledge of health issues, accessibility issues, and general understanding of health issues	Many women did not understand the value of cancer screening, including mammograms or pap smears and recommended medical/surgical treatments and many reported negative experiences with the health care system due to a lack of a common language with providers that did not use interpreters or demonstrate a willingness to improve communication
Wollin et al ²⁸	Breast/gynecologic cancers	Focus group interviews	13 Australian deaf women were interviewed on their experiences with getting mammograms/pap smears	Disparities were identified in baseline knowledge about screening tests, compliance with recommended guidelines, and some perceived difficulties navigating the health care system

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Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
Shabaik et al ¹³	Gastrointestinal: colorectal cancer	Interventional study	Deaf adults watched an accessible video in ASL about CRC	Deaf adults who watched the ASL video improved their CRC knowledge, and data also supported sustained retention in the crossover cohort
Farber et al ³	General oncology	Interventional study without a control cohort	Medical students participated in a deaf culture education and ASL immersion program with an oncological focus	Medical students demonstrated improvements in ASL proficiency, deaf cultural competency, and were more competent in medical interactions with deaf patients. Deaf patients qualitatively reported overwhelming positive experiences with participants in the program
Palmer et al ⁴	General oncology	Parallel, 2:1 randomized prepost interventional study	Does the provision of bilingual educational modalities improve knowledge of cancer genetics compared with monolingual modalities?	Bilingual modalities improved the cancer genetic knowledge of patients with low education, and these patients were more likely to see a genetic counselor or have cancer genetic testing based on a physician's recommendation
Zazove et al ⁷	General oncology	Survey-based assessment	Deaf adults took a reading comprehension test	Higher scores were associated with greater comfort in discussing cancer with physicians and lower scores were associated with ASL use with providers and deaf community membership, suggesting that adults preferentially using ASL with limited access to English proficiency may be experiencing disparities in understanding and acquiring relevant health care information
Hommes et al ⁸	General oncology	Survey-based assessment of ASL interpreters	Investigational study on the perception of interpreters on barriers for effective communication for deaf patients in health care	Health care providers were perceived as not understanding how to adequately meet communication needs for deaf patients with limited understanding by deaf patients of their diagnosis; overreliance on video-based interpreting and lack of empowerment among deaf patients to advocate for their preferences
Druel et al ⁹	General oncology	Multi-institutional chart review	Deaf patients with cancer treated in 5 French hospitals were identified and their diagnostic stages were compared with hearing peers	Deaf patients may present with more advanced stages of prostate, melanoma, and colorectal cancer than hearing peers, raising concern for limitations in access to public

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Table 1 (continued)

Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
NaseriBooriAbadi et al ¹⁰	General oncology	Systematic literature review	Research databases were searched for articles on educational programs with the aim of improving knowledge and attitudes of deaf patients toward cancer	health campaigns and screening programs Health literacy of deaf patients is poor, and educational interventions tailored for deaf people have shown the ability to improve literacy in this cohort
Berman et al ¹⁴	General oncology	Survey-based assessment	Faculty at 4 schools for the deaf were surveyed regarding tobacco use in young deaf adults	Limitation of accessible curriculum and materials were barriers to educate young deaf adults on healthy practices and attitudes on tobacco use
Orsi et al ²⁵	General oncology	Survey-based assessment	Deaf adults were surveyed on knowledge, attitudes, and behaviors toward cancer screening tests and compliance rates	Females who reported using an interpreter primarily to communicate with their physician were more likely to have a pap smear compared with their deaf peers and only 48% of females could correctly identify a pap smear. Despite undergoing screening for various cancers, many participants could not clearly define the screening tests despite placing a high importance on screening in general. A higher than normal number of patients had access to interpreters and physicians using ASL in this study, suggesting that there are still linguistic and cultural disparities at play that remain to be fully addressed
Zazove et al ²⁷	General oncology	Cross-sectional survey-based assessment	Deaf adults were given 4 ways to complete a questionnaire including knowledge of cancer prevention recommendations by way of voice, an ASL video, captions, or printed English	Lower scores occurred when participants used ASL or another language at home, wrote notes to communicate with physicians/nurses, or used an interpreter or ASL with physicians/nurses, suggesting that effective communication needs were not being met for ASL users
Berman et al ²⁹	General oncology	Survey-based assessment	Deaf college students were surveyed on tobacco attitudes and practices	Although deaf adults had lower smoking rates than the general population at the time of the study, they were more likely to try smoking and also try multiple types of tobacco. Only 20% reported ever seeing an antitobacco advertisement geared toward deaf people

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Table 1 (continued)

Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
Berman et al ³⁰	General oncology	Survey-based assessment	Deaf middle and high school students were surveyed on tobacco attitudes and practices	Smoking use was lower in deaf patients than in the average high school population and mainstreamed students were more likely to try tobacco than deaf school peers, suggesting that deaf patients undergo different health care pressures than hearing peers and that deaf patients are a heterogeneous group
Engelberg et al ³¹	General oncology	Survey-based assessment of deaf participants	Assessment of whether provision of accessible health information with ASL humor improved the health literacy and practices of participants	Participants' health literacy improved with accessible resources, and they were more likely to retain knowledge and share with others, showing the benefit of accessible resources in this population
Kushalnagar et al ³⁴	General oncology	Interventional study of deaf and hearing adults	Does simplifying health cancer text on the internet make information more accessible for deaf patient?	There may be a marginal benefit to simplifying text for deaf adults to improve accessibility to cancer-related resources
Tamaskar et al ³⁵	General oncology	Survey-based assessment	Deaf and hearing adults were surveyed on their attitudes about preventive medicine including cancer prevention	Deaf people may be more likely to receive cancer screening tests than hearing peers, but it is unclear whether they understood the rationale and value of these tests
Zazove et al ³⁶	General oncology	Interventional study	Deaf people watched a video on cancer with half receiving an accessible version with captions, ASL	Language utilization was not associated with improved knowledge scores, but on multivariate analysis, having a hearing spouse and a greater number of sources was associated with improved scores suggesting some patients are able to gain accessibility in more ways than others
Berman et al ³⁹	General oncology	Interventional study	Four schools for the deaf were provided with an accessible curriculum for educating young deaf adults on tobacco use	Accessible programming may lead to a decrease in tobacco use and increase in knowledge of the health consequences of tobacco use and antitobacco attitudes in young deaf adults
Folkins et al ¹⁵	Genitourinary: testicular cancer	Interventional study without control	Deaf men watched a prostate and testicular cancer video with ASL and captions to improve their knowledge about the mentioned cancer	General perception exists among deaf men that there are limited accessible resources providing health care information but when provided deaf men were able to benefit by demonstrating increased awareness of prostate/testicular cancer
Sacks et al ³⁷	Genitourinary: testicular cancer	Interventional study	Deaf and hearing men were exposed to a testicular cancer video (made accessible in ASL	Deaf men were at a disparity regarding baseline knowledge but demonstrated ability to

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Table 1 (continued)

Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
Kaskowitz et al ¹⁶	Genitourinary: prostate cancer	Interventional study without control	Prostate cancer educational program in ASL was developed for deaf men to improve knowledge of prostate cancer and adherence to screening recommendations	improve their knowledge when exposed to an accessible educational video Barriers listed among patients for obtaining health care information included communication with doctors (40%) and lack of resources including interpreters (26.1%), and at least 75% of patients reported at least 1 barrier. Participants' knowledge of prostate cancer improved after participating in the study, but it was higher in the subset with ASL as the preferred mode of communication
Kushalnagar et al ³³	Genitourinary: prostate cancer	Survey-based assessment of deaf and hearing males with prostate cancer	Public health study investigating the role of communication accessibility in SDM for prostate cancer screening	Deaf men were less likely to be engaged in SDM than hearing peers, possibly due to lack of accessible accommodations in preferred language (ie, ASL) and lack of a regular physician-patient relationship
Choe et al ¹⁷	Gynecologic: cervical cancer	Blinded, randomized trial	Deaf women participated in an accessible educational program about cervical cancer	Deaf patients were able to improve their cervical knowledge after watching an ASL video and were able to retain this knowledge at follow-up; they were also more likely to share or watch the video again than those who did not watch an ASL video
Jensen et al ¹⁸	Gynecologic: ovarian cancer	Interventional study	Deaf and hearing women were exposed to a video on ovarian cancer for the purposes of improving the general/ovarian cancer knowledge of participants	Deaf women were at a disparity regarding baseline knowledge but demonstrated ability to improve their knowledge when exposed to an accessible educational video
Yao et al ¹⁹	Gynecologic: cervical cancer	Interventional study	Deaf and hearing adult women were exposed to a cervical cancer education video to improve the cervical cancer knowledge of participants	Deaf women were at a disparity regarding baseline knowledge of cervical cancer but demonstrated ability to improve their knowledge when exposed to an accessible educational video
Wang et al ²¹	Gynecologic: cervical cancer	Blinded, randomized trial	Deaf women participated in an accessible educational program about cervical cancer	The internal health locus of control for deaf women did not predict for their baseline knowledge or ability to improve but women who watched the video in ASL did have improved knowledge scores over time suggesting

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Table 1 (continued)

Authors	Cancer	Methodology	Study description	Health care barriers or disparities for deaf adults
Spellun et al ³²	Gynecologic: cervical cancer	Survey-based assessment	Deaf and hearing adult males and females 18-26 years old were asked questions using a survey about HPV and cervical cancer	that accessibility was more important than self-directed behavior in improving outcomes Hearing participants were more likely to know that HPV can cause cervical cancer and that there is an HPV vaccine, identifying a disparity in health literacy and limited access to accessible informational health care resources
Kushalngar et al ³⁸	Lung cancer	Survey-based assessment	Deaf adults were surveyed about patient-centered communication, modes of communication, smoking status, and lung cancer screening in ASL	Deaf adults were more likely to be ask about a lung cancer screening test when they were provided with accessible options, such as an ASL interpreter
Harry et al ²⁰	Skin cancer	Interventional study	Deaf adults were exposed to a skin cancer education video to improve the skin cancer knowledge of participants	Deaf patients were able to improve their skin cancer knowledge after watching an ASL video and were able to retain this knowledge at follow-up

Abbreviations: ASL = American Sign Language; CRC = colorectal cancer; HPV = human papillomavirus; SDM = shared decision making.

improved after they had access to an accessible resource on the topic. Moreover, those same studies showed that accessible programs can lead to better adherence to cancer-specific screening recommendations or avoidance of carcinogens such as tobacco use in deaf youth.^{4,11-21} The third barrier was deaf patients' frustration with the health care system and the lack of linguistically and culturally competent health care providers. A survey of ASL interpreters showed that multiple providers did not understand what effective communication with deaf patients entailed and thought inferior methods such as lip-reading were acceptable forms of communication.⁸ Berman et al²² reported that several women stated that their doctors did not understand their deafness and failed to communicate with them about their cancer. Multiple studies showed that preference for ASL or ASL utilization at home or with health care providers was associated with detrimental experiences or outcomes, highlighting the poor level of linguistic competency among practitioners in general.^{7,8,22-26} Kaskowitz et al¹⁶ surveyed deaf patients in a prostate cancer education program and almost half reported that communication with physicians was a barrier to obtaining health care information. Another study investigated baseline knowledge of cancer prevention recommendations in deaf adults, and found that lower scores were associated with use of ASL at home or written notes with their providers, compared with those

patients who spoke English at home or with their physician.²⁷ Several educational initiatives have been developed to address this. For example, an ASL and deaf culture and cancer program was developed for medical students at the University of California San Diego School of Medicine to teach students about deaf culture and to help them gain proficiency in ASL. Deaf patients who worked with participating students reported overwhelming positive qualitative responses, and students were better equipped to interact with deaf patients, improving health care delivery.³

Oncological treatment outcomes

A multi-institutional retrospective series of 5 French hospitals identified 80 deaf patients diagnosed with and treated for cancer from 2005 to 2014. This study found that deaf patients may present at more advanced stages at time of diagnosis for certain cancers compared with their hearing peers, such as for prostate or colorectal cancer.⁹ This was only a small study of 80 patients and included a review of patients in a specific geographic subset, raising the issue of generalizability of these results. Our literature search revealed that there have not been any studies reporting on whether deaf patients are at a disparity in the type of medical or surgical treatment they receive in comparison with their hearing counterparts.

Table 2 Barriers to effective utilization of the health care system for deaf patients with cancer

Poor health literacy among deaf patients	Baseline health literacy and cancer-specific knowledge for deaf youth or adults was lower than average expected levels for hearing peers
Availability of tailored health care resources for cancer-specific information	Lack of educational resources, programs, and initiatives that are linguistically and culturally accessible
Poor linguistic and cultural competency among physicians	Limited training, experience, and bias prevents physicians from providing effective communication and practicing in a culturally sensitive manner

Data on whether deaf patients are getting treatment that adheres to national guidelines and whether their treatment outcomes are, at least, not inferior in terms of measurable variables such as survivorship or patterns of failure are not currently available in the literature.

Discussion

Our literature review identified 3 unifying health care barriers for deaf cancer patients, namely (1) poor health literacy among deaf adults; (2) accessibility to tailored health care resources for cancer-specific information; and (3) poor linguistic and cultural competency among physicians. These results are not necessarily uniformly generalizable. Deaf patients are not a homogenous group; they demonstrate remarkable geographic, racial, and socioeconomic diversity. The quality and level of communication accessibility at home can vary dramatically, with the majority of patients being shaped at a young age by birth into hearing families, most of whom having limited to no proficiency in ASL. Moreover, educational and literacy levels are also driven in large part by limiting factors outside of the health care system, which can prevent any attempts by the health care system to significantly improve the generally poor health literacy of these patients. Furthermore, there were no large-scale series in our study, and much heterogeneity in the demographics of patients participating in these studies. However, Pollard et al⁴⁰ showed that well-educated people with high school or college degrees in the United States still had lower than expected health literacy. This suggests that the barriers to health care are also due to inadequacies in the health care system and its lack of accessible resources. Our review identified multiple interventional programs designed to

educate deaf patients with the aim of improving the quality of accessible cancer-specific health care resources, which appear to be beneficial for deaf patients. Despite multiple studies reporting on frustration with the linguistic and cultural competency of providers, only 1 study in this series focused on addressing these deficiencies in health care practitioners, specifically medical students.³ Most physicians have not had access to similar educational initiatives about deaf culture and likely have limited to no training or knowledge of ASL. There are legal recommendations in the form of laws such as the ADA and national organizational guidelines to guide the provision of accessible healthcare delivery such as those from the National Association of the Deaf (NAD), but the significance of these resources are limited in practice.⁴¹ Again, the wording of the ADA regarding deaf patients is ambiguous and does not provide physicians with a clear definition of what is entailed in “effective” communication with a deaf patient. The National Association of the Deaf guidelines are very informative, but largely underused as they are a small body with a message that does not reach most physicians. Physicians are without any oncology-specific resource to guide them on how to optimize care delivery to deaf patients and compensate for their limited training and exposure to this population. We propose the need for a care model that provides guidelines on creating effective and total communication accessibility for deaf patients, and addresses the cultural and linguistic heterogeneity within this cohort, taking into account factors that can influence the physician-patient relationship including familial, cultural, health literacy, and socioeconomic dynamics.

Disparate outcomes experienced by deaf patients in other health care settings have also been documented in the literature. Physicians in the United States were surveyed and reported deaf patients were more likely than hearing patients to have greater difficulty in communicating with them, trusted them less, and were less likely to understand their diagnosis and treatment.⁴² Similar findings were documented in a large study by an organization in the United Kingdom, SignHealth.⁴³ In New Zealand, 40% of deaf patients do not feel there is adequate accessibility to interpreters in health care, and this was associated with a worse quality of life.⁴⁴ In the primary care setting, dedicated efforts have been made to develop care models for improving health care delivery to the deaf population. In Austria, a comprehensive program was developed that provides health centers for the deaf attached to general hospitals that are staffed by culturally and linguistically competent providers. This has become the de facto primary care facility for many deaf Austrians.⁴⁵ In France, dedicated outpatient primary care facilities have been beneficial for the deaf community.⁴⁶ Such examples serve to highlight the potential benefit of an oncological care model for the deaf-physician patient relationship.

Considerations for a future RO care model

We envision the care model would allow physicians to create inclusive health environments by providing total communication accessibility within culturally appropriate framework. It would serve as a resource to navigate the cultural and linguistic nuances of interacting with deaf patients. This should be based on a robust understanding of the deaf identity, where deaf patients view themselves as more than just a disability group, but rather a linguistic and cultural minority. Physicians should be guided on the provision of individualized care, accounting for the fact that deaf patients are a very diverse group of people, a smorgasbord of racial and ethnic identities; can have multiple linguistic and cultural associations in addition to ASL and the deaf culture; and run the spectrum of socioeconomic status and educational backgrounds. It would clearly delineate what entails effective communication in the health care setting, clearly defining the ideal communication modalities, and how to provide this at various levels of the health care system. Significant weight should be given to how to develop optimal accessibility for varying services and resources in ASL, along with what entails effective procurement and utilization of qualified ASL interpreters. Opportunities to gain further exposure or the development of educational initiatives that allow physicians to gain cultural competency or ASL proficiency while in practice or training should be discussed. As this issue has remained largely unaddressed, oncology practitioners including ROs should set the standard for providing culturally sensitive and linguistically competent oncological care for deaf patients, and these guidelines should be made applicable to physicians and providers in the other fields of oncology, such as medical or surgical oncology. While in anticipation of such guidelines, physicians should focus their efforts on taking concrete steps to create total communication accessibility for their patients. This can be done by creating accessibility to ASL interpretation for all clinical encounters. ASL interpreters should be chosen based on their mastery of the language, cultural understanding, and adherence to ethics, and should have demonstrated competence with national or state interpreting certifications. Although in-person interpreting is preferred for such encounters, if that is not possible, physicians should consider providing alternatives such as video remote interpretation. Practices located in a large metropolitan area may have proximity to a large deaf community, representing a great opportunity to engage that community for advice on how to improve quality of interpretation and general guidelines about accessibility. Hospitals often have a patient and family advisory council, which members of the community can participate in to provide such community advice for a hospital. If a robust community is not present in the hospital location,

then simply asking a deaf patient about his or her opinion about language/communication accessibility is important in providing quality care.

Limitations of this study include those inherent to a retrospective literature review. Most of our studies contained a small cohort of patients, and the characteristics of the patients varied widely across series, making it difficult to control for other confounding variables that could have influenced outcomes. The majority of the studies had a narrow focus geared toward developing and implementing educational initiatives for preventive care or reporting on qualitative experiential outcomes, which can be very subjective and easily influenced by bias. Only 1 study attempted to collect quantitative data on current clinical or treatment outcomes for deaf cancer patients,⁹ limiting our ability to make meaningful large-scale analyses of oncological outcomes in this cohort.

We hope this review will lead to an increased emphasis among physicians in providing linguistically and culturally competent oncological care to deaf patients and a charge for the implementation of oncology-specific guidelines on specialty, regional, and national levels. Increasing awareness among physicians and creating acceptable standards should lead to improved health care delivery as has been noted for other diverse groups. Furthermore, there is a lack of literature on the treatment outcomes of deaf patients with cancer and whether disparities exist on rates of and adherence to national cancer-specific guidelines are not known. Future research should examine whether these patients have equivalent treatment outcomes, because data on patterns of failure and survivorship are not reported in this population in regards to treatment with different modalities, including radiation.

Conclusions

The clinical outcomes of deaf patients with cancer remain poorly characterized, highlighting the need for a care model for oncology practitioners to guide the provision of linguistically and culturally competent oncological care for deaf patients.

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