Importance of Incorporating the Perspectives of People with Cancer into Oncology Education: A Scoping Review

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ABSTRACT

BACKGROUND: With the shift towards person-centered care (PCC) in oncology, there is a need for parallel evolution of oncology education programs to prepare the next generation of health professionals to deliver effective PCC. These programs should be designed utilizing perspectives from individuals who have lived experience with cancer to ensure that changes to education curricula translate to improved PCC in the clinic.

OBJECTIVES: Our goal was to identify existing literature describing such programs as well as identify gaps for further development.

METHODS: Keywords were agreed upon and searched across Ovid Medline, Ovid Embase, ERIC, Google Scholar, and MedEdPORTAL databases. Duplicates were removed, unique articles were screened for relevance by title and abstract, and a full text review of each article was completed for validation. Included articles describe methods for involving people with cancer in developing and/or delivering oncology-focused education programs.

RESULTS: In total, 15 articles describing 12 unique oncology education programs from 7 different countries were identified, reviewed, and summarized. These programs involved learners undertaking undergraduate medical education, postgraduate medical education, continuing medical education, or training as nurses or radiation therapists. Current literature indicates that classroom-based sessions, experiential or simulated learning modalities, and/or asynchronous online modules can all feasibly be created with the integration of perspectives/narratives of people with cancer. Furthermore, involving people with cancer directly in the design and/or delivery of these education programs may contribute to improved patient experiences.

CONCLUSIONS: Including the perspectives of people with cancer directly in oncology curriculum development and delivery can improve established pedagogical approaches and enhance learner confidence and competency in delivering PCC. We provide recommendations for stepwise implementation of patient perspectives into oncology education, with the hope that future programs will better prepare and motivate learners to provide PCC aimed at improving cancer care, quality of life, and disease outcomes.

KEYWORDS: Oncology education, person-centered care, patient perspectives, classroom-based learning, experiential learning, asynchronous online models, curriculum development

Introduction

It is now widely acknowledged that cancer is characterized by heterogeneity not only across different cancer types but also between people who have been diagnosed with the same cancer type.[1,2] This variability in cancer biology makes each individual situation unique. Beyond biological variability, people with cancer find themselves in unique lifestyle situations. Quantitative studies have defined the challenges in health-related quality-of-life faced by individuals living with cancer to be multifaceted, encompassing both the disease itself and the many lifestyle and personal changes stemming from the disease. Treatment for cancer may cause physical issues including pain, dysphagia, nausea, vomiting, fatigue, and oral intake difficulties that negatively affect their experiences beyond their clinic visits. Psychosocial concerns including anxiety, depression, decreased social interaction, and extended sick leave are commonly observed and may further diminish quality of life.[3] It is essential to consider these challenges in parallel with those posed by the disease itself to fully understand the unique circumstances faced by each person with cancer.

Research has shown the value of involving people with cancer in developing treatment plans tailored to their individual needs. This concept has now become an integral part of clinical decision-making, emphasizing the transition towards person-

centered care (PCC) in oncology.[4] The individual's narrative, created through dialogue between themselves and health professionals, reveals their personal experiences, interpretation of symptoms and impact on daily life. This can serve as the foundation for collaborative care planning between the person with cancer, their family and the care team.[5] The evolution towards PCC in oncology has been facilitated by the development of formal guidelines by government and research organizations. The perspectives of people with cancer have also been studied through the collection of patient-reported outcomes (PROs) in cancer clinical trials.[6] In Canada, government organizations such as Cancer Care Ontario have now developed a Patient-Reported Outcomes and Symptom Management Framework to integrate PROs more formally into clinical practice.[7]

The involvement of individuals who have lived experience with cancer and other diseases via active involvement in research design, execution, validation and dissemination is also becoming an integral aspect of medical research and is recommended by many international research guidelines.[8–11] Of particular relevance to this scoping review, there has been a growing emphasis on creating partnerships with people with cancer, aiming to involve them in the process of enhancing cancer research. These partnerships have proven beneficial in shaping clinical trial protocols, analyzing data, and sharing knowledge.[12] However, to truly incorporate these important perspectives into cancer care, it is essential to concurrently advance oncology education programs. This will allow future oncology practitioners and researchers to receive training that encompasses an understanding of the significance of the impact of cancer on individuals' lives beyond their illness.

Current education programs focus primarily on understanding the scientific concepts of the medical conditions associated with cancer diagnosis, often focussing less on the practical skills required to take a holistic view in assessing the needs of the person with the disease. The perspectives of people with cancer should therefore be utilized in designing education programs that are better aligned with PROs.[13,14] The objectives of this scoping review are to describe and evaluate current educational programs in oncology that have incorporated such perspectives, to identify methods that show positive learning experiences and transferable skills for providing high-quality

Table 1. Key search terms used for each database. Key terms were agreed upon by all researchers and used for literature searches for multiple databases (Ovid Medline, Ovid Embase, ERIC, MedEdPORTAL, and Google Scholar) based on their search capabilities including the use of Boolean operators, MeSH terms, and/or whole phrases.

DATABASE	SEARCH TERMS
Ovid Medline	(cancer.mp. or exp Neoplasms/ or exp Radiation Oncology/ or exp Medical Oncology/ or oncolog*.mp.) AND (exp curriculum/ or curriculum.mp. or education, premedical/ or premedical education.mp. or exp education, medical/ or medic* education.mp. or exp education, nursing/ or nurs* education.mp. or students, medical/ or medic* student*.mp. or students, nursing/ or nurs* student*.mp.) AND (Narrative Medicine/ or narrative medicine.mp. or patient* perspective*.mp. or patient* stor*.mp. or patient* narrative*.mp.)
Ovid EMBASE	(oncology.mp. or exp oncology/ or cancer*.mp. or exp neoplasm/) AND (medical education.mp. or exp medical education/ or nursing education.mp. or exp nursing education/ or exp curriculum/ or curriculum.mp. or health student.mp. or health student/ or nurs* student*.mp. or medic* student*.mp.) AND (patient perspective* or patient stor* or patient narrative* or narrative medicine.mp. or narrative medicine/)
ERIC	(oncology OR cancer OR neoplasm) AND ("medical education" OR "nursing education" OR "continued medical education" OR "graduate education" OR "medical undergraduate" OR "teaching rounds" OR "curriculum" OR "program") AND ("patient perspective" OR "patient perspectives" OR "patient story" OR "patient stories" OR "patient narrative" OR "patient narratives")
MedEdPORTAL	(oncology OR cancer) AND ("medical education" OR "medical student" OR "nursing education" OR "nursing student" OR "curriculum") AND ("patient's perspective" OR "patient perspective" OR "patient perspectives" OR "patient's story" OR "patient story" OR "patient stories" OR "patient's narrative" OR "patient narrative" OR "patient narratives" OR "narrative medicine")
Google Scholar	(oncology|cancer) AND ("medical education"|"medical student"|"nursing education"|"nursing student"|"curriculum") AND (patient perspective|patient story|patient narrative|"narrative medicine") -intitle:review

PCC in cancer, and to provide some recommendations for future application of these principles for enhancing oncology education programs.

Methods

Search strategy

Key search terms were agreed upon by all researchers and are presented in Table 1. These search terms were then applied to literature searches of Ovid Medline, Ovid Embase, The Education Resource Information Center (ERIC), the MedEdPORTAL, and Google Scholar databases, with the final search completed on October 25, 2023. Because Google Scholar indexes a wide range of articles, a total of 18,400 results were received from the Google Scholar search, however, as per the recommendations of Haddaway et al,[15] only the first 300 results sorted by relevance were included in this study.

Inclusion and exclusion criterion

Included articles describe a method of involving people with cancer in health professional education program development and/or delivery, with a focus on oncology education. A "program" was defined as a structured and organized set of activities or initiatives designed to provide learners with specific knowledge, skills, and experiences. This included those that can be integrated as formal curriculum at an educational institution, as well as informal models such as a learning activity within a cancer care center. Only articles published between January 2013 and October 2023 were considered for inclusion into this review in order to most accurately reflect the current state of oncology education and prevent the inclusion of pedagogical approaches that may no longer be in use and/or relevant. Article language was restricted to English and only published full-text articles were considered to prevent the inclusion of programs with insufficient data about the success or status of implementation. Articles were excluded if they did not meet the inclusion criteria described above, did not describe the creation or delivery of an oncology education program, were focused on patient education, and/or did not involve the perspectives of people with cancer.

Data charting and data synthesis

Search results from all databases were consolidated into Covidence, a web-based collaboration software platform that streamlines the production of literature reviews, and duplicate items were removed to include unique articles only. Articles were then screened by title and abstracts by all researchers for relevance. Conflicts were resolved through discussion between all researchers. Agreed upon articles were then screened by a full-text review for validation of adherence to inclusion and exclusion criterion. Articles that passed through every step of

this process were included in the scoping review. From each accepted article, the location of program, the pedagogical approach, the learner description, and the outcome assessments (quantitative and/or qualitative) of the program were obtained. The study has been registered with the Open Science Framework (OSF; DOI 10.17605/OSF.IO/X4GZY).

Results

Description of included studies

Relevant articles were identified as outlined in Figure 1. Briefly, 1018 articles were obtained from the search results of all databases. 992 unique articles were obtained after removing duplicates and were then screened via title and abstracts. Only 36 potential articles moved to full-text review for thorough assessment using the inclusion and exclusion criterion described in the Methods section above.

Summary characteristics of identified oncology education programs

In total, our search revealed 15 unique articles describing 12 oncology education programs which incorporated the perspectives of people with cancer. Of these, 2 involved continuing medical education (CME), 6 involved undergraduate medical education (UME), 2 involved postgraduate medical education (PGME)/residency training, 3 were for nursing students, and 2 were for radiation therapy students (Figure 2A). Education programs attempting to incorporate patient perspectives were located in 7 different countries around the world, with 6 from the USA, 3 from the UK (England, Ireland and Scotland), 1 from Canada, 1 from France, and 1 from Slovenia (Figure 2B).

The studies can be separated into themes based on their type of educational approach and were defined as follows: (1) Classroom-based learning sessions used instructors to actively present educational material to a student audience; (2) Clinical skills learning programs involved learners interacting with patients and/or patient narratives, often followed by learner reflections on the interactions; and (3) Asynchronous online modules were completed individually by navigating through a set digital learning path containing educational content and activities. These program types are summarized in Figure 3 and described in greater detail below.

Classroom-based learning methods

A study conducted by Epner et al[16] used a classroom-based approach to teach postgraduate oncology learners how to navigate through difficult conversations about cancer prognosis, end-of-life care, and treatment plans and outcomes in Texas, USA. A didactic schedule was created exclusively for learners in their first year of medical oncology subspecialty training; implementing one-hour seminars each month that focused on developing communication skills about these difficult
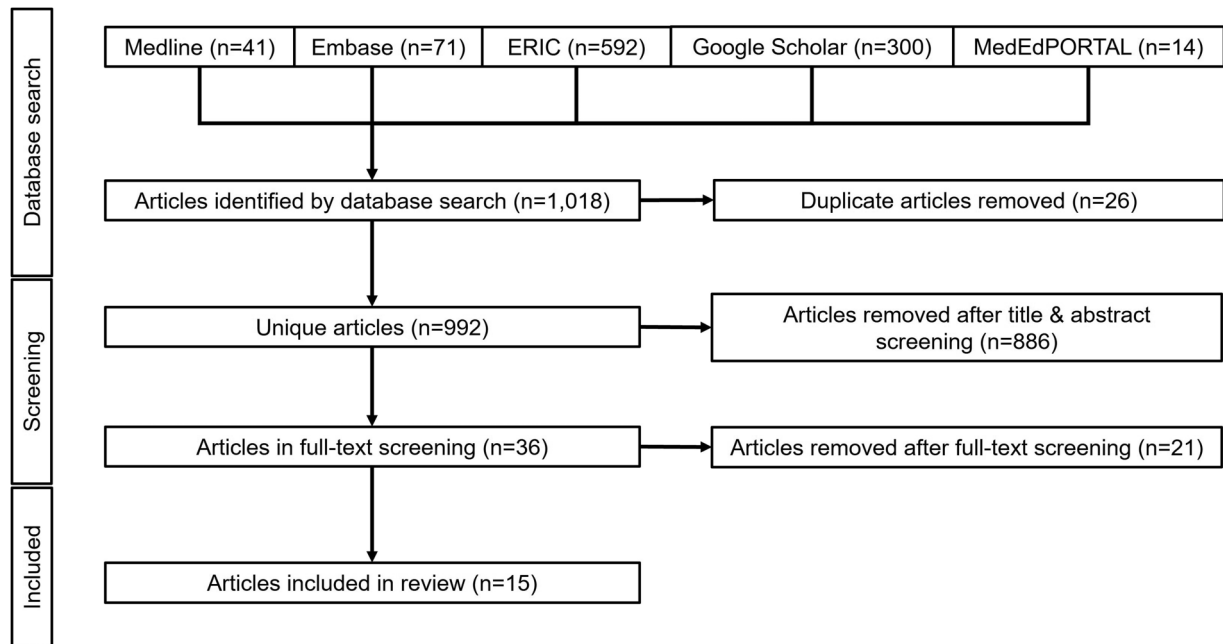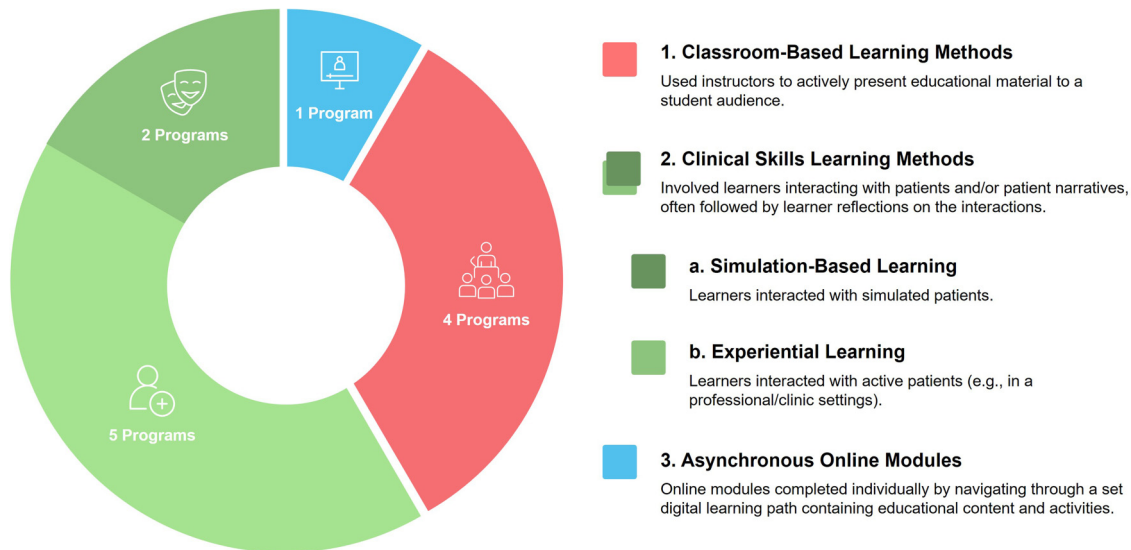
Figure 1. Literature search methodology. Key terms from *Table 1* were searched across Ovid Medline, Ovid Embase, ERIC, Google Scholar, and MedEdPORTAL databases, with the last search occurring on October 25, 2023. Results were consolidated and duplicate items were removed to include unique articles only, with n values representing the number of articles reviewed at each step. Articles were then screened by all researchers for relevance. The stages of the process are presented vertically along the left and the excluded number of articles along the right.
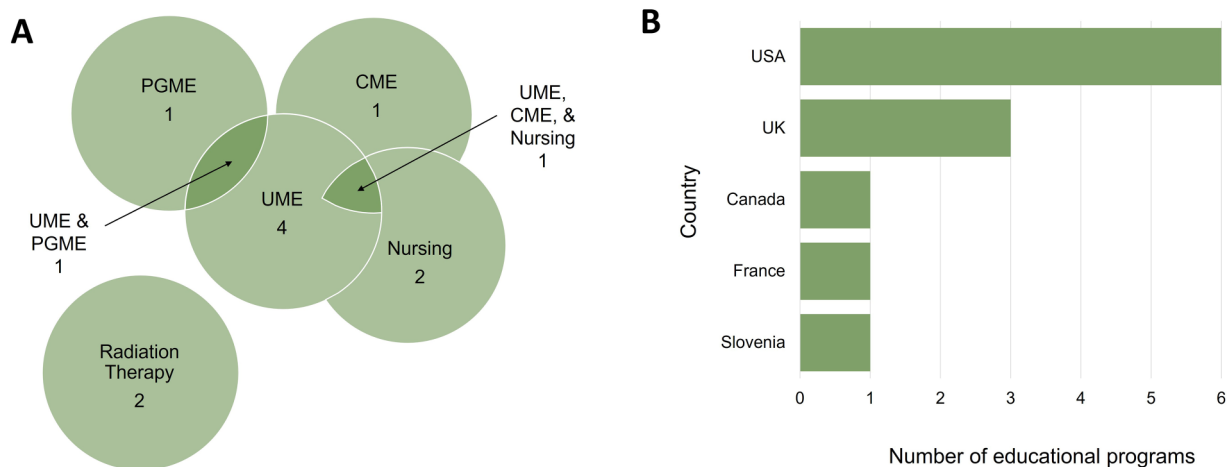
Figure 2. Oncology programs that incorporated the perspectives of people with cancer, by learner type and geographic region. Key terms from *Table 1* were used to conduct a literature search using Ovid Medline, Ovid Embase, ERIC, Google Scholar, and MedEdPORTAL databases as outlined in Figure 1, with the last search occurring on October 25, 2023. *(A)* Number and distribution of oncology education programs that targeted each type of learner including continued medical education (CME), nursing education (Nursing), post graduate medical education (PGME), radiation therapy education (Radiation Therapy), and undergraduate medical education (UME). Overlapping regions represent programs that targeted multiple learner types. *(B)* Number and distribution of oncology education programs by geographical location worldwide. USA: United States of America. UK: United Kingdom (England, Ireland and Scotland). Total N = 12 unique education programs.

conversations. The curriculum consisted of engaging and interactive educational tools such as sociodramatic techniques, roleplay, reflective writing, and Balint-type case discussion groups. Medical oncology residents in their second and third years of training served as peer mentors and teaching assistants. These seminars served as an opportunity to practice communication skills during each seminar and with patients between sessions. The purpose was to learn, simulate and implement newly developed clinical skills into real life practice. A quality assurance survey coupled with end-of-seminar written reflections pieces revealed positive feedback regarding clinical relevance and acquired skills.

Figure 3. Summary of pedagogical approaches for incorporating the perspectives of people with cancer into oncology education programs. Key terms from *Table 1* were used to conduct a literature search using Ovid Medline, Ovid Embase, ERIC, Google Scholar, and MedEdPORTAL databases as outlined in Figure 1, with the last search occurring on October 25, 2023. A total of 12 unique programs were identified and classified into 3 different pedagogical approaches. This included 4 programs that used classroom-based learning methods, 7 programs that used clinical skills learning methods and 1 program that used asynchronous online modules. The numbers presented in the circle chart correspond to the number of programs using each approach, with details provided in the legend on the right.

A follow-up study to Epner et al[16] conducted by Shaw et al[17] used learner reflections to evaluate student satisfaction, organization, content and efficacy to further improve the current program. Additional stories from people with cancer were added to each session, resulting in workshops of 3–4 h in duration. To supplement these stories, learners read medically-themed reflective pieces or watched reflective films, followed by group discussions where each individual shared their opinion on what they learned and connected it to their own clinical and non-clinical stories within small groups. The purpose was to effectively implement a core component of narrative medicine into education and help learners establish professionalism, communication, and empathetic listening skills to develop better understanding of and connection to people with cancer. All sessions were concluded with an end-of-seminar written reflection piece. The learners' opinions mirrored the results of the original study, which consisted of positive feedback regarding clinical relevance and acquired skills.

A qualitative study by Flood et al[18] found that shared stories and experiences from people with cancer were helpful in understanding the patient perspective in Ulster, Ireland, UK. One-on-one interviews with people with cancer were conducted to reveal cancer treatment experiences with learners in an undergraduate Radiotherapy and Oncology program, a program similar to radiation therapy in Canada and the US. The prominent reason for patient participation stemmed from intrapersonal factors aimed at sharing unique stories and positively influencing behavior and understanding of future healthcare providers. Results of this study show positive

learning experiences for learners and therapeutic healing from psychological trauma associated with cancer-related treatment.

Art-based workshops aimed at enhancing empathy were developed by Clements et al[19] specifically for people with ovarian and uterine cancer experiencing chemotherapy-induced alopecia in Florida, USA. This 90-min workshop included anonymous patient interviews and stories to provide learners with a greater understanding of the emotional and physical impacts of chemotherapy. Undergraduate learners from biology, nursing, psychology, and communication programs were then tasked with designing scalp tattoos on mannequin heads, to depict their perspective about individuals coping with hair loss and chemotherapy. Surveys were completed post-workshop to assess overall learning experiences of the learners. Overall, 83% of the class felt an increased connection with people with cancer and their experiences, and 73% reported an increase in empathy towards patients.

Finally, a prospective randomized control study by Klein et al[20,21] in Aberdeen, Scotland, UK found the integration of people with cancer for interview preparation to be effective in developing communication skills. This study used six interview sessions, consisting of third year undergraduate medical students and patients with cancer or patients with a non-cancer diagnosis. The students were required to video record an interview with their assigned patient and complete an Attitudes Questionnaire before and after the sessions to assess their improvement throughout the course. This was then assessed by researchers to rate overall interview and communication skills of the student. Overall, this study showed significant

improvement in empathy, assessment of symptom impacts on daily lifestyles, and communication within the group of learners who were taught by people with cancer.

Clinical skills learning methods

Clinical skills learning methods can be subcategorized simulation-based learning, where students interact with simulated patients; and experiential learning, where students have direct interactions with patients. Both present ideal opportunities for the integration of perspectives of people with cancer.

Simulation-based learning. Simulation-based learning is a well-established modality for learning in healthcare education. It is used to prepare learners prior to and/or concurrently with experiential learning opportunities in clinics with real patients.[22–26] Palmaria et al[27] took an intuitive approach to integrating patient perspectives into simulations by engaging survivors of cancer as simulated patients in simulation-based teaching of radiation therapy students in Alberta, Canada. They used a phenomenological approach[28,29] by collecting first-hand accounts from students and analyzing students' perceptions of their interactions with the cancer-survivor simulated patients using three focus groups of five students each. The cancer survivors integrated their experiences to provide a rich and representative experience for students to explore, thus helping develop their technical, communication, and patient care skills. Ultimately, Palmaria et al[27] observed improvement in PCC skills and development of professional identity as future radiation therapists, demonstrating the potential of patient perspectives for enhancing simulation-based learning.

Aubin-Auger et al[30] used the perspectives of people with cancer to develop a CME training module to improve the communication of general practitioners (GP) about colorectal cancer screening in Paris, France. To evaluate the current state of communication during colorectal cancer screening and to identify areas and methods of improvement, the authors conducted 24 interviews of people with cancer and five focus groups with GPs and analyzed 35 recorded patient interactions with nine GPs. Themes were investigated using qualitative analysis; revealing that GP communication needs improvement to enhance PCC. These themes were then used to design two simulated patient scenarios in which GPs engaged in role-play and observed pre-recorded videos of simulated patient interactions followed by a reflective discussion. Overall, Aubin-Auger et al[30] demonstrated the power of patient perspectives as a tool to identify gaps in practice and to enhance training modules through representative narratives of patient experiences with healthcare professionals.

Experiential learning. Lorenz et al[31] evaluated the impact of integrating the perspectives of young people with cancer through a unique experiential learning rotation where third-

or fourth-year medical students followed patients in paediatric oncology in a ratio of one-to-two or one-to-three (compared to the traditional method of shadowing a physician). For two weeks, medical students in Pennsylvania, USA accompanied patients wherever possible to observe their disease progression and care journey. Students were required to keep an unstructured narrative journal to describe their observations and reflections focused on the non-medical factors of care including their relationships with patients and families. This study also took a retrospective approach and conducted qualitative analysis on 120 narrative journals. They found that humanism was cultivated in students through the relationships they formed with patients and their families which served as a catalyst for narrative formation and deeper reflection. Thematic analysis revealed that students had a deeper understanding of patients' point of view and developed a more humanistic appreciation of non-medical factors that encircle disease. The benefits were not limited to the students, as patients and caregivers reported attentiveness to emotional needs and improvement in their care. Ultimately, Lorenz et al[31] demonstrated that an experiential rotation focused on the patient perspective developed transferable skills in empathy, setting the foundation for PCC in future practice.

Kotnik et al[32] demonstrated another method of using patient narratives in understanding the patient perspective and its impact on learning, this time in second-year nursing students. Consideration of the perspectives of people with cancer was taught to second-year nursing students in Ljubljana, Slovenia by requiring them to read a book written by a person with cancer and writing a reflection on it during an experiential learning rotation at the Institute of Oncology Ljubljana. Qualitative analysis was carried out on 108 reflections using the content analysis method which revealed the needs for a more structured approach to focus reflections on the themes including patients' perceptions of illness, communication, and students' experiences. The question-based reflection tool was implemented in the next cohort of 28 second-year nursing students and resulted in a deeper understanding of the patient perspective on disease and care.

Kerr et al[33,34] approached teaching the patient perspective by using theater in Ohio, USA as a vector for teaching communication, ethics, and emotions (including empathy) to a variety of clinicians. A 90-min stage reading of a theater performance based on patients' and families' experience dealing with cancer, navigating the healthcare system, and the life-altering experience of caregiving was observed by clinicians, followed by a 30-min reflective discussion. Qualitative analysis of a post-theater focus groups revealed that the session was effective in teaching the perspective of people with cancer and their families to clinicians,[34] the public, nurses, social workers and undergraduate medical and nursing students.[33]

Similarly, Bharadwaj et al[35] took a performance-based approach to teaching the perspective of people with cancer to

medical students by using the classical Indian dance of Bharatanatyam in Massachusetts, USA. Medical students trained in Bharatanatyam collaborated with patients, caregivers, and medical professionals to elicit the experience of a cancer diagnosis. Through reflection and an iterative process including feedback from the collaborators, learners choreographed and performed a dance piece conveying the complexities of a cancer diagnosis and its emotional impact on patients, caregivers, and oncologists. Reflections from the students demonstrate that by understanding the perspective of the people with cancer, the medical students were better able to empathize with the patient experience and gained a direct understanding of the importance of non-verbal communication between the patient and the physician.

Finally, a student-led initiative in Exeter, England, UK by Patel et al[36] took an immersive approach by pairing 15 undergraduate medical students (years 1-4) with people with cancer who shared their personal stories and experiences through structured interviews. The learners completed 48 1-h patient interviews with 30-min for the patient narrative and 30-min of follow up questions by the learner. Follow-up structured interviews with the learners were conducted to facilitate reflection and to gain the learner perspective. These interviews revealed 3 fundamental themes: (1) finding the right words to say in difficult conversations, (2) the significance of recognizing the individuality of each person they were caring for, and (3) understanding the consequences associated with ineffective communication resulting from erosion of empathy. Ultimately, Patel et al[36] demonstrated that this humanized perspective of the patient through narratives fostered empathy and compassion, promoting an increased willingness by learners to provide PCC.

Taken together, these studies demonstrate that clinical skills-based approaches to learning about the perspectives of people with cancer coupled with reflection are an effective method for teaching current and future clinicians about the importance of PCC. Furthermore, such approaches have the potential to improve the patient experience by promoting more empathetic responses from healthcare providers.

Asynchronous online modules

Bishop et al[37] developed a series of online modules on PCC communication skills in Tennessee, USA based on qualitative data on challenging experiences with cancer care communication. The program was intended for undergraduate medical students and postgraduate medical learners, including resident physicians and oncology fellows. The goal of each module was to improve learners' appreciation for PCC and improve their understanding of the importance of tailoring their communication according to individual patient situations and preferences. Semi-structured interviews of people with cancer, family members, and treating physicians were completed and analyzed to reveal five common themes regarding challenges with communication. Data and quotes from each theme informed the educational content of the associated training module. Modules also began with video recordings of relevant stories from people with cancer, family members, and physicians to introduce educational content and encourage emotional engagement by learners before completing the rest of the module.

A randomized controlled trial (RCT) carried out by Gorniewicz et al[38] found the breaking bad news (BBN) module described by Bishop et al[37] improved communication skills in medical students and residents. Participants from both groups completed simulated patient (SP) interactions before and after completing the online module. Objective structured clinical examination (OSCE) scores improved with training, particularly in terms of communicating bad news to patients, and with attention to patient responses after BBN. Overall, the online module incorporating patients' experiences achieved its objective of improving PCC communication skills among students in the context of BBN.[38] This provides proof of concept for the development of similar asynchronous online modules for use in oncology education.

Discussion

Dr Rita Charon, a physician and literary scholar, introduced the term "narrative medicine" into medical education; defined as the study of patient narratives to improve patient care, understand patients' experiences, and promote empathy and compassion in clinicians.[39] Since then, there have been many publications on the topic and today narrative medicine is recognized as an integral component of medical education. Although the articles mentioned above used various teaching modalities, interaction with the patient narrative was the central focus. Each study elicited the patient narrative through the perspective of people with cancer and not the clinician. This resulted in a richer and more authentic experience for learners and therefore had the potential for a greater impact.

Many students struggle with uncertainty and a lack of confidence, connectedness and motivation when interacting with patients. Patel et al[36] demonstrate this in their structured interview with undergraduate medical learners when they encountered difficult conversations and when patients shared deeply personal and distressing experiences. Reflections from learners on the lack of training and preparedness in clinic exposed a sense of fear to communicate with patients stemming from a lack of knowledge, experience, and understanding of the person beyond their disease.[27,31,36] A study by Cave et al[40] found that although a majority of undergraduate medical graduates received oncology teaching, 31% of student reported seeing less than 10 people with cancer throughout medical school and over 40% identified the need for more communication training. This emotional complexity creates a sense of unease or inadequacy, as students are often unsure about how

to appropriately interact and respond to the individuals they are treating. Interestingly, Cave et al found that a sense of preparedness was positively correlated with exposure to people with cancer.[40] Therefore, in addition to cancer biology and clinical aspects of oncology, training should emphasize understanding the human aspects of patient care, including effective communication, empathy, and active listening; and there should be greater involvement of people with cancer in this teaching.

Based on the studies described in this review, the narratives of people with cancer can be highly effective when delivered via several different teaching modalities. Using a classroom-based model, Epner et al,[16] Shaw et al,[17] Flood et al,[18] Clements et al,[19] and Klein et al[20,21] all demonstrated the ability of patient narratives and perspectives to enhance traditional learning. By implementing clinical skills learning methods, Lorenz et al[31] demonstrated the effectiveness of using narrative medicine through clinic-based experiential learning and reflective journaling, and Kotnik et al[32] observed similar results through reading a patient narrative and writing a reflective statement. Kerr et al[33,34] also demonstrated the same via theater and post-reflective discussions, while Bharadwaj et al[35] additionally demonstrated this via an iterative process of reflective choreography development and post-performance reflection. Finally, Bishop et al[37] and Aubin-Auger et al[30] demonstrated the importance of patient perspectives as a tool to identify gaps in practice and to design teaching tools for clinicians. On a fundamental level, the direct approach by Patel et al[36] involving structured interviews to elicit the patient narrative and learner reflections exemplifies the capacity of narrative medicine from the perspective of people with cancer to educate learners on concepts related to PCC and to instill in them the motivation and confidence to deliver PCC.

Simulated patient learning using standardized patients was first introduced into healthcare education in 1963 by Barrows and Abrahamson at the University of Southern California.[41] Since then, the use of standardized patients in simulated learning has become a regular component of healthcare education across various disciplines in North America. To improve this practice even further, Palmaria et al[27] demonstrated enhancement to simulation-based learning by using individuals who were survivors of cancer as simulated patients. This raises a unique opportunity for a more accurate portrayal of clinic patients and allows experience-based feedback for trainees. The insight from people who have current/previous experience with cancer directly reflects the current state of care and provides pertinent feedback to improve clinical skills in future clinicians. This is supported by a comprehensive analysis of 115 articles across 26 different regions by Klufas et al[42] that showed that clinical practice, simulation, and role-play appeared to be the most effective methods of oncology education in medical school. In fact, they found 97% of articles that looked at clinical practice and/or simulation reported a positive impact on oncology education of medical students.

Academic program directors may choose to add established modules to supplement existing BBN training. In particular, the inclusion of recorded patient stories may be a critical component to the success of such modules. Hearing patient stories has previously been shown to improve student confidence and OSCE scores.[43] Current BBN training methods in Canadian medical schools often teach the (SPIKES) approach (Setting, Perception, Invitation, Knowledge, Empathy, Summarize), which has been well-validated for its ability to increase learner confidence and competence in BBN to oncology patients.[44] While the approach was originally developed without patient consultation, the SPIKES model does reflect patient preferences.[45] Nevertheless, the addition of modules developed using the input of people with cancer will likely enhance student communication skills and translate to better PROs. The comprehensive study by Klufas et al[42] found that only 50% of computer/web-based programs (including asynchronous online modules) presented a positive impact. The addition of patient perspectives may be the missing piece in enhancing computer/web-based programs and modules.

Classroom-based learning methods represent some of the most classical approaches to medical education and may therefore be the easiest for educators to conceptualize. Of the published reports reviewed, discussion between students and individuals with cancer was a common element. Facilitating student interactions with patients to discuss difficulties in care within the classroom setting may be a simple approach for educators to consider.[36] Engaging people with lived cancer experience to get their perspectives on previously developed curriculum components may also be important for revealing limitations in training applicability to the clinical setting.[46] Feedback from students can also be used to adjust sessions according to their needs.[17,47] Although positive loop of feedback from students and continual improvements to educational programs is well-established, additional feedback from people with cancer may be the necessary missing link to the improvement of classroom-based oncology education.

Regardless of the educational approach used, there are potential challenges with involving patients in formal education. Such involvement may add additional psychological burden and raise ethical issues with regards to confidentiality.[48] Improper practices with gathering patient consent for student involvement in clinical interactions may also be a concern.[49] However, some have argued that volunteerism and proper patient engagement can provide sustainable partnerships between patients and educators.[50,51] Survivors of cancer have previously found personal benefit to their involvement in clinical and research teaching.[52] Thus, patient–educator relationships may be mutually beneficial when managed appropriately. Strategies to ensure this include increased communication between groups, appropriate recruitment strategies, and reinforcing patient contribution as voluntary. The diversity of patients involved is another important consideration.

Including the perspectives of patients from underrepresented groups promotes equity within oncology education. The pool of people with cancer providing their contributions should be intentionally diversified to be inclusive of important aspects such as gender, race, age, economic status, as well as other intersectionality that may contribute to different experiences with patient-HCP interactions. To date, the inclusion of diverse perspectives in oncology education remains limited.[53,54]

Integration of the perspectives and lived experiences of people with cancer into oncology education programs can be achieved through a stepwise process, via formal and informal models, that gradually immerses learners into the world of patient experiences and narratives. As a first step, we recommend developing formal curriculum components that integrate the perspectives of people with cancer without direct one-on-one interactions. As highlighted in the studies discussed above, this can be achieved via classroom-based and asynchronous modalities, where instructors can use workshops, panels, group interviews, video-based responses, and online modules to incorporate the perspectives of people with cancer. This allows learners to participate in a low-risk environment where they can engage in discussions with their peers and instructors, make reflections, and ask questions to initiate their exposure to patient interactions. Additionally, this step allows learners to understand individuals' narratives and background separate from the disease, serving as a catalyst in building the foundation for empathy, active listening, and effective communication. Subsequent to incorporation of these formal curriculum components, education programs can move towards the second step of increasing direct one-on-one interactions with people with cancer in order to prepare them for situations they would experience in active clinical practice. This can be done through simulated patient interactions with cases written with the aid of a person with cancer or having these individuals act as the simulated patient (similar to Palmaria et al[27]) or via informal experiential learning opportunities such as eliciting patient narratives and experiences with cancer care in a community setting (similar to the approach taken by Patel et al[36]). Here, learners can gain hands-on experience by applying the skills acquired through the initial curriculum components to situations that resemble the professional clinic environment. This gives learners the opportunity to develop their knowledge and skills around communication and empathy in a low-risk but authentic environment, thus gaining a deeper understanding of the human side of medicine that facilitates confidence and preparedness for delivering meaningful and effective PCC in oncology.

Our scoping review is not without limitations. Terminology used to describe "patients living with disease" and "incorporating the patient perspective" is not universally defined or standardized. This stems from the term "patients" also being referred to as clients, service users and occasionally, "sick persons". Learning strategy definitions may also be ambiguously defined. Consequently, this impedes both the accuracy of literature search strategies and the effective implementation of person-centered education programs into oncology education. In addition, published research pertaining to the involvement of cancer patients in developing and/or delivering medical education programs is limited. While there is ample evidence for cancer patient involvement in research through PROs and co-design, involvement of people with cancer specifically in oncology education programs (outside of experiential interactions in the clinic) is comparatively limited. This presents a challenge for educators interested in adopting these changes, since evidence is required for successful implementation and stakeholder buy-in. Further research is therefore required to established evidence-based guidelines for educators and institutions seeking to enhance PCC in their oncology curricula such that this approach can be implemented on a broader scale. Finally, the programs evaluated in this review are based around the globe, and oncology education and treatment guidelines may vary significantly between countries. This potentially limits the applicability of existing programs to other countries. However, given that many of the existential challenges faced by people with cancer may be similar regardless of geographical location, rigorous evidence of the effectiveness of a patient-centered educational approach could support the development of international guidelines for oncology education programs through collaboration of researchers, educators, patient partners, and learners from around the globe.

Conclusions

The published research described in this review demonstrates the value of incorporating the perspectives of people with cancer into oncology education programs. Programs employing the learning strategies of classroom-based methods, simulated or experiential learning, and asynchronous online modules have all been reliably designed using various forms of input from people with cancer. These existing programs may serve as a template and/or inspiration for the adoption of similar education programs across the field of oncology. Given the relative paucity of published literature describing current oncology education programs that have formally incorporated the perspectives of people with cancer, we strongly encourage existing oncology education programs that have taken this approach to publish their methodology and the assessed impact of these programs. Recognizing the human aspect of cancer patients as individuals beyond their clinical disease is a necessary step for future physicians to learn in order to deliver the most effective person-centered care.

Ethics and consent

Scoping review; not applicable.

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