Involving people with lived experience in medical education pertaining to children with medical complexity or developmental disabilities: a scoping review protocol

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Abstract

Background: Involving people with lived experience (PLE) in medical education, which may occur with varying levels of patient and caregiver involvement, can be beneficial for patients, their caregivers, and medical students. Benefits have been demonstrated across both patient populations and learner level of training. Including PLE may be particularly impactful in medical education related to children who require comprehensive, individualized, and multidisciplinary care, such as children with medical complexity or developmental disabilities. Despite this, there is no summary of how children with medical complexities or developmental disabilities or their families/caregivers have been included in medical education for medical students, residents, and fellows. In order to advance the effective inclusion of lived experience in medical education related to this patient population, a synthesis of existing literature is needed.

Objective: The purpose of this scoping review is to identify and synthesize the literature related to including the lived experiences of children with medical complexity or developmental disabilities, their families, and their caregivers in medical education and the level of engagement of people with lived experience in the process.

Methods: To complete the proposed scoping review, MEDLINE, Scopus, PsycINFO, ERIC, Academic Search Premier, and Google Scholar will be searched for studies investigating patient and caregiver involvement in medical education related to children with medical complexity or developmental disabilities. Data will be extracted from studies that meet the inclusion criteria. Studies involving continuing professional development or patients that are not children with medical complexity or developmental disabilities will be excluded. Data will be extracted to identify the stage of curriculum development in which lived experience is included based on Kern's 6-step approach. Data will also be extracted to examine the level of engagement in medical education of children with medical complexity or developmental disabilities, their families, or their caregivers.

Results: Descriptive analysis will be performed to identify the findings from the included sources pertaining to the research objective. Findings will be presented in tables, diagrams, or matrices to demonstrate how lived experience has been incorporated into the six steps of curriculum development and characterize the level of engagement of people with lived experience in this process.

Conclusions: Results from this scoping review may identify areas of improvement for medical education, especially pertaining to the care of children with medical complexity and developmental disabilities. The findings could contribute to the development of medical school curricula that lead to improved patient outcomes.

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Keywords
Family as educators; family as faculty; family-centered; partnership; pediatrics

Introduction
Overview
The quality and outcomes of healthcare are impacted by providers' knowledge and attitudes. In addition to understanding the clinical aspect of a patient's diagnosis, a provider's understanding of the patient and family lived experience may play a role in the quality of health care provided. One manner by which this could be improved is through medical education. Involvement of PLE, such as patients, their families or their caregivers, in medical education is possible and can provide new insights. Furthermore, patient and caregiver experiences have already been included in multiple settings, including both educating physicians-in-training (medical students, residents, and fellows) [1–8], as well as educating practicing physicians in the setting of continuing professional development (CPD) [9–11].

Through the incorporation of PLE in curriculum design for CPD, Tajani et al. identified experiences that would have otherwise been left out of curriculum [9]. Unique student experiences were also observed when including adult patients in medical student education. Utilizing patient experiences in medical student education has been shown to provide students with unique insights and help them challenge assumptions they held prior to interacting with patients and their stories [3]. Furthermore, learning directly from patients and their caregivers has been demonstrated to help students build relationships with patients and understand challenges faced by caregivers [4], with other studies finding that students involved in sessions with patients agreed that the sessions had increased their understanding of the patient experience and the application of patient- and family-centered care [6,8]. This was also observed in the pediatrics setting [2], with students who interacted with patients and caregivers writing reflections that were more patient-based than those who did not [1].

Though there is a body of literature supporting the integration of PLE's experiences in education related to adult and pediatric patients, children with medical complexity (CMC) and children with developmental disabilities (CDD) make up a specific subset of pediatric patients that have different experiences and care needs. Cohen et al. define CMC as children who have: significant healthcare service needs as identified by their family; at least one chronic condition that is severe and/or associated with fragility, whether it is diagnosed or unknown; limited function, often requiring support from technology; and high health care utilization, including frequent hospitalizations, surgeries, and/or involvement of multiple specialists [12]. Children with developmental disabilities have chronic impairments that are mental, physical, or both; the conditions are considered severe, must be present by the age of 22, are unlikely to resolve, impact multiple aspects of daily living, and lead to individuals requiring a combination of support services [13].

Due to the various needs of CMC and CDD, the incorporation of caregiver and patient experiences in

medical curriculum development is critical. This has been demonstrated in settings of CPD [10,11], but there needs to be more understanding of how it has been included in medical education for physicians-in-training. The methods and outcomes of involving PLE in medical education need to be identified to allow for effective advancement of curriculum development, specifically when designing curriculum pertaining to treating CMC and CDD.

As identified by prior work, the current literature on lived experiences and PLE partnership in medical education has not used consistent terms and keywords, making it difficult to identify what research and curriculum design has been completed to date [14]. A preliminary search for existing scoping reviews related to medical education involving CMC, CDD, and their families and caregivers was conducted in PubMed. Three scoping reviews investigating similar education strategies were identified [15–17]; however, none of them involved CMC or CDD specifically. The purpose of this scoping review is to identify and synthesize literature on PLE involvement in medical education related to CMC and CDD.

Review Questions

What information is known related to involving PLE who are CMC or CDD, their families, or their caregivers in medical education?

Within this scope, the more specific questions guiding the review include:

- What has been reported pertaining to the involvement of PLE in medical education?
- What were the purposes for including PLE in medical education?
- How were PLE involved in the medical curriculum?
- What outcomes were measured and observed related to the impact of involving PLE in medical education?

Methods

The JBI methodology for scoping reviews will be utilized for conducting the proposed scoping review [18]. The Preferred Reporting Items for Systematic reviews and Meta-Analyses for Scoping Reviews (PRISMA-ScR) will be used to report the proposed scoping review [19].

Search Strategy

The review team will collaborate with a research librarian (LAC) to develop and execute a comprehensive search of the literature utilizing controlled vocabulary and title/abstract terms related to the integration of the experiences of children with medical complexity and their parents or caregivers in medical education. A search will be developed in MEDLINE (EBSCO) and translated into the following databases: Scopus (Elsevier), PsycINFO (EBSCO), Education Resource Complete (EBSCO), Education Resources Information Center (EBSCO), Academic Search Premier (EBSCO). A Google Scholar search will be performed, and the first 200 results sorted by relevance will be exported for screening. No date, language, or other filters will be applied to the results.

Eligibility Criteria

The eligibility criteria were determined based upon the purpose of this scoping review. Multiple criteria were identified based upon the target population, concept, and context. Table 1 identifies the eligibility criteria, with further discussion of the criteria found below.

Table 1: Eligibility Criteria

	Include	Exclude

Population	● Medical students ● Pediatrics residents ● Fellows ● Interprofessional education groups including any of the above medical learners	● Other health care professionals (nurses, PAs, etc.) ● Practicing physicians
Concept	● Patients/family/caregivers sharing lived experiences in curriculum ● Patients/family/caregivers involved in curriculum development/design ● Need for patients/family/caregivers involvement in curriculum ● Patients are children with medical complexity and/or developmental disabilities ● Families are those of children with medical complexity and/or developmental disabilities ● Caregivers are those of children with medical complexity and/or developmental disabilities	● Geriatric patients ● Adult patients ● Elderly patients ● Patients with chronic illness that are not medical complexity or developmental disabilities ● Families of the above patient populations ● Caregivers of the above patient populations
Context	● Medical school ● Clerkship ● Residency ● Fellowship	● Professional development ● Continuing medical education ● Patient education ● Family/caregiver education
Source Type	● Peer-reviewed papers	● Non-peer-reviewed papers ● Conference proceedings ● Conference abstracts ● Grey literature ● Editorials ● Commentaries ● Books
Language	● English	● All other languages
Location	● N/A	● N/A

Participants: The review will include any studies involving the education of medical students, pediatric residents, or fellows in pediatric specialties. Studies investigating interprofessional education (IPE) involving the previously mentioned groups will also be included. Studies focusing on other healthcare professionals will be excluded due to the differences in roles of different professionals. Studies focused on the further education of practicing physicians will also be

excluded.

Concept: This scoping review will focus on the inclusion of CMC, CDD, families, and caregivers in medical education curricula. Studies that relate to PLE involvement in curriculum development or the active participation of patients, families, or caregivers through sharing their lived experiences will be included. Additionally, studies investigating the need to involve patients, families, and caregivers in medical education curriculum will be included. All studies involving families and caregivers that will be included will pertain to families and caregivers of CMC and CDD. Patients, families, and caregivers of pediatric patients that are not considered CMC or CDD will be excluded, as will lived experiences of patients, families, and caregivers of adult patients.

Context: This scoping review will focus on medical education and curricula. This will be limited to the setting of learning in medical school, clerkship, residency, and fellowship. Continuing medical education coursework and other CPD trainings will be excluded. Patient, family, and caregiver education will also be excluded.

Types of sources: The purpose of the scoping review is to gain an understanding of what information is known pertaining to PLE involvement in medical education surrounding CMC and CDD. To do this, the scoping review will include peer-reviewed experimental studies and analytical observational studies. Editorials and commentaries will be excluded.

Evidence Screening and Selection

Results will be downloaded to a citation management software (EndNote) and undergo manual deduplication by LAC using the method described by Bramer. Unique records will be uploaded to the Covidence (Veritas Health Innovation, Melbourne, Australia) screening platform for independent review by two independent reviewers. Disagreements between the reviewers will be resolved by a third reviewer. Full text review will then be completed for studies that are not excluded based on the abstract and title. This step will also be completed by two independent reviewers, with any discrepancies being resolved by a third reviewer. The final exclusion process will be reported using a PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) flow diagram [19].

Data Extraction

Data found in the papers included in the scoping review will be extracted by two independent reviewers using Covidence software (Veritas Health Innovation, Melbourne, Australia). The data extracted will include the identified need for PLE involvement in medical education, as well as how their experiences are included in medical curricula. Data involving the outcomes for medical students, residents, and fellows after taking part in these curricula will also be extracted.

A draft of the data extraction form is attached (see Appendix A). The form will be altered throughout the extraction process as needed, with any alterations being discussed in the scoping review. Disagreements that arise between the reviewers during the data extraction process will be resolved by a third reviewer.

Analysis

The extracted data will be mapped against PLE engagement in the curriculum as well as the step in curriculum development that lived experience was included. Six levels of PLE engagement—leadership, collaborative, advisory, consultative, give information, and receive information—are adapted from several models of patient and community engagement [20–22]. Details about the characteristics of each level can be found in Appendix B. The steps of curriculum development that

will be mapped to are Kern's steps: (1) problem identification and general needs assessment, (2) targeted needs assessment, (3) goals and objectives, (4) educational strategies, (5) implementation, and (6) evaluation and feedback [23]. Thematic analysis may be performed if there are multiple pieces of literature identified that map to the same intersection of the level of engagement and Kern's step.

Results

The extracted data will be presented in diagrams or tables to best illustrate the findings related to the review questions. The mapping of PLE engagement against Kern's steps will be presented in a matrix (see Appendix C). In addition to the diagrams or tables and a matrix, narrative descriptions of the findings will be included. The findings will be published in a scoping review.

The scoping review began with the article search being completed in April of 2024. The screening process began in April of 2024. The anticipated date of completion for the analysis is August of 2024, with an intended submission date of the completed scoping review occurring in September 2024.

Discussion

Principal Results

The curricula that may be identified will provide important insights into whether PLE involvement in medical education is effective. It also may shed light on the most successful manners by which their experiences are included in education. This would provide support for the development of more curricula including PLE's stories and experiences. Overall, this provides the potential for improved medical education, resulting in better patient care.

Limitations

The scoping review results will be limited by the language selection, which may exclude relevant literature that is not in English. Furthermore, grey literature will be excluded, and therefore the results may miss medical education contributions from patients, family, and caregivers.

Conclusions

It is the authors' understanding that this is the first scoping review focused on the involvement of CMC, CDD, their families, or their caregivers in medical education. It will expand the understanding of the benefits of lived experience in medical education, while identifying where there is room for further investigation.

Acknowledgements

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Conflicts of Interest

None declared.

Appendix A: Draft of Data Extraction Form

Study Identification			
	Consensus	Reviewer 1	Reviewer 2

Article Title			
Journal/Book/Magazine Title			
Year of Publication			
Last Name of First Author			
Institution			
Country			
Methods			
	Consensus	Reviewer 1	Reviewer 2
Study Design			
Methodology			
Aim of Study			
Setting			
Purpose for Lived Experience Inclusion			
Population			
	Consensus	Reviewer 1	Reviewer 2
Learner Level (pre-clinical medical students, clinical medical students, residents, fellows)			
Number of Learners			
Person with lived experience (patients, parents/caregivers, both)			
Number of Students per PLE			
Other Information About PLE			
Interventions			
	Consensus	Reviewer 1	Reviewer 2
What Learners Experienced (home visit, lecture, video, etc.)			
Step of Curriculum Development			

(Kern's Step)			
Level of Engagement (Leadership, Collaborative, Advisory, Consultative, Give Information, Receive Information)			
Results			
	Consensus	Reviewer 1	Reviewer 2
Validated tool used (Y/N)?			
If yes, what tool?			
Learners Evaluated (Y/N)?			
If yes, results?			
Families Evaluated (Y/N)?			
If yes, results?			
Outcomes			
	Consensus	Reviewer 1	Reviewer 2
Author's Conclusions			
Reviewer's Comments			

Appendix B: Levels of Engagement

Engagement Level	Characteristics of Level of Engagement
Leadership	PLE serve in leadership roles and share in decision-making.
Collaborative	PLE serve as ongoing collaborators/partners in the work in ways that shape project priorities, aims, approach, and/or strategies used.
Advisory	PLE fill recognized, ongoing advisory roles. The PLE advisory relationship may be limited to project leadership rather than full project team. PLE have some influence on, but are not the decision-makers about, how and when their input is used.
Consultative	PLE are consulted on a sporadic basis using bidirectional communication strategies. PLE have little to no influence on how and when their input is used.
Give Information	PLE provide information on a one-time or sporadic basis through surveys, interviews, storytelling, and other methods. PLE are not involved in shaping how and when the information is used.
Receive Information	Project information is disseminated to PLE.

Appendix C: Draft of Intervention Matrix

		Kern's Steps					
		Step 1	**Step 2**	**Step 3**	**Step 4**	**Step 5**	**Step 6**
Level of Engagement	**Leadership**						
	Collaborative						
	Advisory						
	Consultative						
	Give Information						
	Receive Information						

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Abbreviations

CDD	Children with developmental disability
CMC	Children with medical complexity

CPD	Continuing professional development
PLE	People with lived experience
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews