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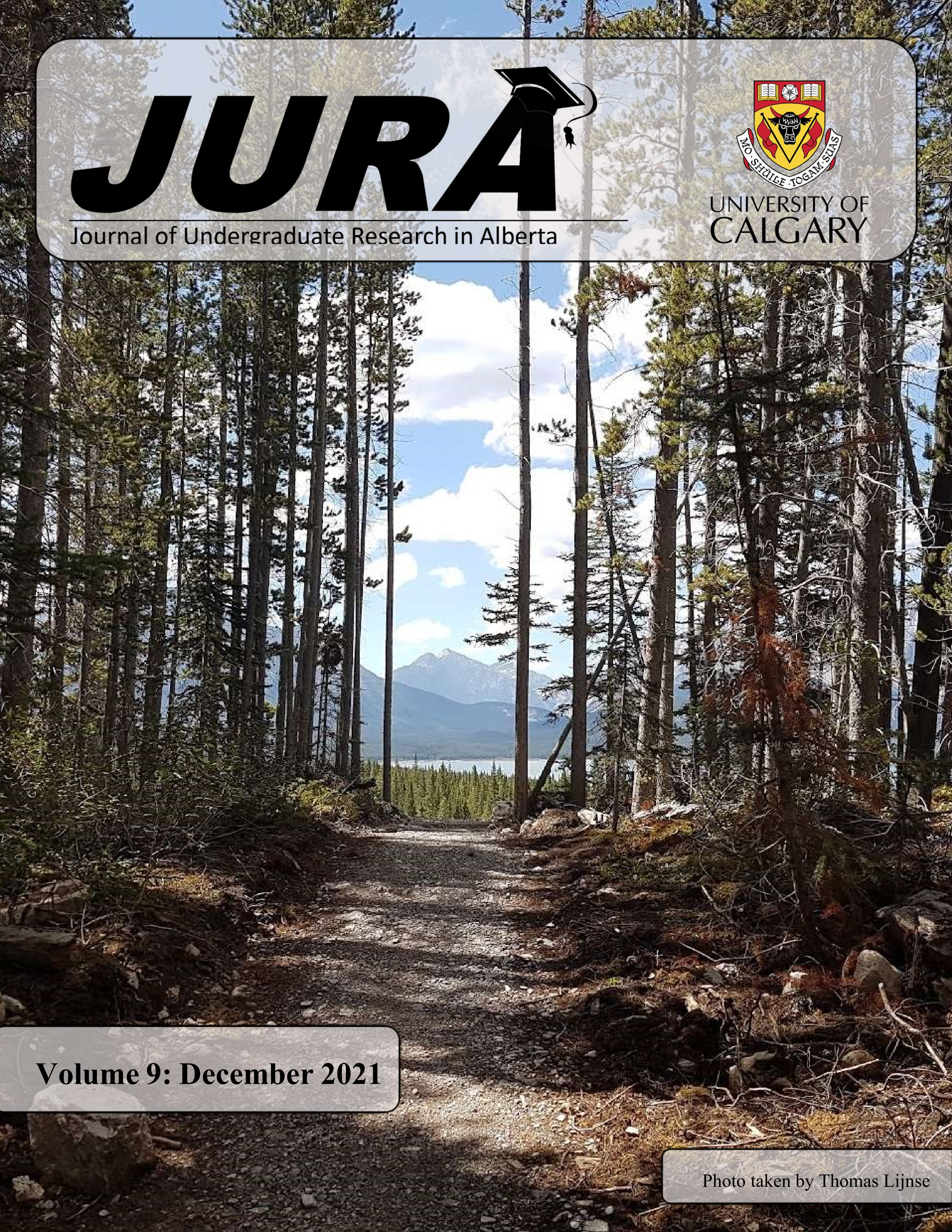

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Photo taken by Thomas Lijnse

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Editors’ Remarks

We are pleased to present the 2021 full edition of the Journal of Undergraduate Research in Alberta. COVID-19 continues to be a significant challenge to the research ecosystem in Alberta, and resulted in several barriers. Nonetheless, the resilience of the undergraduate students has proven vital to the advancement of our journal and we thank them for their contributions.

This edition features several extended abstracts and journal articles on a multitude of topics from undergraduate students in diverse backgrounds. Hot topics such as gene editing, cancer detection, and advanced age care are explored which provide further insight into their respective fields. The work of these students exemplifies the excellence in undergraduate research that we continue to strive for throughout Alberta.

We at JURA are currently encouraging further submissions of research from undergraduate students within the science realm. We understand that current circumstances are in constant flux and continue to make in person research difficult. However, students are encouraged to submit written portions from sources beyond extracurricular laboratory research such as their thesis dissertations and class research projects. Furthermore, students are encouraged to continue submitting review papers, as these are equally vital contributions.

JURA has been proud to be involved within the Albertan scientific community and create initiatives to stimulate more research from students. We hope that readers enjoy the 2021 JURA edition and we encourage you to share this journal with your peers.

Sincerely,

Jura Editorial Team

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Advance Care Planning (ACP) Education for Nurses: A Review

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Abstract— Advance Care Planning (ACP) is relevant for those patients in the healthcare system who are nearing end-of-life (EOL), living with chronic illness or comorbidities, and those who want to express their healthcare wishes to providers in the event that they lose cognitive capacity or the ability to communicate. Nurses are in a unique position to address ACP and advocate for patients; however, they experience barriers to initiation and implementation of these conversations and may require comfort, knowledge, and confidence to employ them in nursing practice. The purpose of this review was to gather evidence on how to increase nurses' comfort, knowledge, and confidence in ACP conversations with patients. The specific question that guided our search for articles was: "How does having specialized training in ACP impact nurses' comfort to engage in ACP conversations effectively with patients?" We found evidence that indicated developing staff training using a variety of educational resources improved comfort, knowledge, and confidence for health care providers to initiate ACP.

Implications for practice: Based on our review, we recommend that nurses participate in ACP training in the form of simulation with standardized patients, workshops, learning modules, webinars, and other technological aids. This will remove some of the barriers nurses face and increase their comfort, knowledge, and confidence in ACP with patients.

Conclusion: We found evidence that specialized ACP education improved nurses' comfort, knowledge, and confidence in conversing with patients to meet specific desires for health care planning.

I. INTRODUCTION

Nursing is an evidence-based practice that seeks to explore and apply new findings to improve patient health outcomes. Given diverse experiences in the clinical and classroom settings, as nursing students we saw various opportunities for quality improvement and identified a clinical issue involving nurse initiation of ACP discussions with patients. ACP is variously defined but commonly includes the clarification of patients' wishes, needs and preferences of care including future medical care [1,2, 4, 7]. In this review, we evaluated the relevance of ACP education and nurses' comfort, knowledge, and confidence in nursing practice. The scope of our review was limited to 10 selected articles reflecting the requirements of the undergraduate research course that lead to the development of this manuscript. We will discuss the search strategy used to find articles, extract data, analyze and synthesize study findings, to provide clinical recommendations for future nursing practice.

II. BACKGROUND AND SEARCH STRATEGY

Engaging patients in conversations about their values and wishes during and outside of healthcare crises would seem to be an essential component of nursing care; however, nurses may lack the confidence and training in facilitating conversations about ACP [1, 2]. Barriers to ACP that nurses commonly report include heavy workloads, lack of uninterrupted time, unclear policies and procedures, role confusion, inexperience, and limited education [1, 3]. As a result, patients receive insufficient teaching and support regarding ACP when establishing their goals of care, and instead rely on pamphlets or booklets that are not unique to them and can be difficult to understand [2]. We asked: "How does having specialized training in ACP impact nurses' comfort, knowledge, and confidence to engage in ACP conversations effectively with patients?" The purpose of researching this question was to determine how specialized training could improve nurses' comfort, knowledge, and confidence in conversing about ACP.

We performed a systematic search using three databases, Medline, PsycINFO, and CINAHL (Fig.1). The search terms we used included "advance care plan", "goals of care", "living wills", "nurses", "attitude of health personnel", "communication", "self-efficacy", "patient care planning", "teaching", "in-service", "simulation", "learning", "webinar", "education intervention", "comfort", "conversation", "willingness", "communication training skills". We imported 253 articles into Covidence, an online data screening and extraction tool; 20 duplicate articles were removed. Our research team screened 233 article titles in two separate blinded groups to prevent bias, excluded 192 and found 41 articles related to ACP. These articles were full text reviewed and 10 articles chosen (Fig.1).

The exclusion criteria included patient population less than 18 years of age, publication date before 2017, publications in languages other than English, and non-peer reviewed articles. We removed 192 articles that did not meet the inclusion criteria by reviewing the abstract and scanning the paper. We screened the remaining 41 articles through full-text reading, excluding studies focusing on specific medical conditions, unexplained high attrition rates and patient-focused interventions rather than staff-focused interventions.

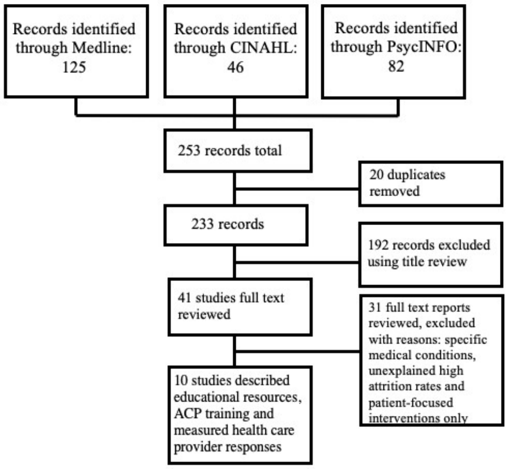

Fig. 1. PRISMA diagram for the Advance Care Planning for Nurses review illustrating exclusion and inclusion criteria.

We included studies focusing on ACP resources, training interventions to increase comfort, knowledge, and confidence of healthcare providers (HCPs), Measurement of health care providers' responses, resulting in 10 articles included in the review.

III. CRITIQUE, REVIEW AND ANALYSIS

Our selected articles were conducted in Australia (1), Canada (1), Norway (2), the United States of America (6). Study designs included five pre-tests/post-tests, one descriptive study, one randomized-control trial (RCT), a comparative study, a cross-sectional study, and one mixed methods study. Most researchers reported that HCPs participating in ACP training programs increased their comfort, knowledge, and confidence of HCPs in discussing ACP with patients [1-4, 6-11].

Sævareid et al. [4] emphasized the importance of nurses having ACP conversations within the care trajectories of patients and families in nursing homes, and specifically in medical emergencies. Sævareid et al. [4] conducted a mixed-method study, including a cluster-randomized clinical trial. The educational intervention resulted in increased communication of nurses to patients which the cross-sectional descriptive study [1] and the comparative study [6] did not. Sævareid et al. [4] created a systematic ACP guideline and offered training to nursing staff while providing long term supervision and support, as well as a documentation template. Qualitative data was collected via observation and transcription of interactions. They reported increased quality, knowledge and use of ACP between staff and patients. A limitation of this study cited by the authors was the Hawthorne effect which is the change in behavior of study participants due to the presence of observers; this can affect the validity by increasing participants' responses [5].

Rietze et al. [1] surveyed 125 nurses and reported that increasing ACP educational and mentoring opportunities were beneficial in raising their comfort levels to initiating ACP with patients. Rietze et al. [1] had a low response rate (12.8%) which reduces the confidence we have in the results. Similarly, Ludwick et al. [6] found that in-service or ad hoc training on ACP significantly raised the rates of initiation of ACP conversations for 136 registered nurses and 178 licensed practical nurses in Ohio. In a pre-test/post-test Tully [2] measured responses from 138 HCPs (nursing, social work, patient-care assistants, registrar staff, case managers, and chaplains) who had taken an instructional session. Overall, this study reported an increase in all three variables, comfort, knowledge, and confidence ($p=0.00$, CI 95%) of HCPs to participate in ACP with patients and family members. However, the generalizability of the study to nurses is not specific.

Studies by Miller et al. [7] and Wessman et al. [8] examined educational interventions of NCP for nurses in a variety of settings. Unlike other studies in our selection, these researchers explored both HCPs and patients to evaluate the effectiveness of educational interventions. Gaining patients' perspectives of the ACP experience allowed the assessment of the efficacy of nurses' ACP discussions. The educational interventions increased nurses' skill and confidence reflected through patient reports of receiving in depth, considerate, and interactive conversations helping them to achieve clarity and assurance [7, 8].

Miller et al. [7] included online modules, resources, workbooks and workshops that resulted in improved ACP conversations by five HCPs to 13 patients. Although a small sample, this qualitative study provided in depth analysis of the value of the ACP conversations with patients. Wessman et al. [8] performed pre-test/post-test measures on a larger sample of 101 HCPs. ICU staff treating critically ill patients reported decreased work stress ($p=0.04$) after conversations about ACP with their patients as well as EOL information ($p=0.006$). However non-significant changes were seen in goals of care and EOL conversations ($p=.41$). Wessman et al. [8] used a multimodal approach to train HCPs in ACP. Nurse participants ($n= 122$) engaged in role-playing, didactic sessions, and educational modules over 24 months. They had access to communication tools, pamphlets for patients and families, new computer orders, and procedures for providing support to families after having EOL conversations, part of ACP. As sustainability of interventions was not part of the study design, a longer study term is suggested.

Bond et al. [9] and Brown et al. [10] both utilized simulation as a training resource for healthcare. Both research teams found that participants had increased their self-rating of competency using a pre-test/post-test design ($p<0.001$ [9]), ($p<0.001$ [10]). Bond et al. [9] found that post-test ACP knowledge scores improved (83% ± 10% to 92% ± 8% ($p < 0.001$) after the simulation intervention. Brown et al. [10] conducted an RCT using a large sample size of nurses and residents ($n=232$ intervention, 240 control) of which 406 completed the study. Brown et al. [10] conducted their longitudinal study over a period of six years, finding that providers' communication skills improved, though patient ratings of care did not. All variables measured including self-assessed competency in communication expressed empathy, spiritual conversation, and patient goals of care among staff improved following the intervention ($p<0.001$),. From this study we concluded that educational interventions resulted in increased comfort, knowledge, and confidence among study participants. There was no separate analysis of nurses in the study, limiting generalizability of results to only nursing practice.

Gullatte et al. [11] explored the use of technology-assisted continuing education (TACE) in increasing registered nurses' (RN) ($n=16$) and social workers' ($n=4$) capacity and comfort level in facilitating ACP including EOL discussions. With the implementation of TACE, over a 3-month period, participants' comfort measures on the comfort subscale increased from 7.1 to 8.3 ($p = 0.005$), and capability from 6.4 to 8.1 ($p < 0.001$). However, participants were expected to complete educational webinars on their own time without compensation, posing a barrier to completion. Aasmul et al. [3] reviewed educational interventions that were part of a larger RCT and reported a qualitative increase in the rate of ACP discussions based on care providers' records. No comparison was made with the control group regarding ACP conversation documentation making it difficult to see the scope of the increase.

IV. RECOMMENDATIONS

The Canadian Nurses Association [12] advocates the highest level of professionalism in nurses and promotes following their Code of Ethics for Registered Nurses [12]. Dinç and Gastmans [13] in their review of quantitative studies found that patients have a high level of trust in nurses. The trust of patients, and the adherence of nurses to The Code of Ethics is the foundation supporting ACP conversations.

Communication and collaboration with patients regarding their healthcare wishes for future and EOL care, preserves dignity, autonomy, and respect, which are foundations of nursing practice [14]. Izumi [15] stated that nurses' consistent presence and engagement in care gives them an advantage to initiate ACP conversations with all patients, and the potential to create a system-wide cultural shift towards improving the quality of patient care. As the aging population accesses health care, this growing sector would benefit from ACP, but we believe many patient populations require ACP. Rietze et al. [1] reported that ACP discussions prior to critical acute care admissions or prior to the time of critical sickness are more likely to result in care reflective of patients' values and preferences. In 2013, The Canadian Hospice Palliative Care Association reported that only 13% of Canadian patients were ever involved in ACP discussions [16]. Research evidence shown here indicates that education and training about ACP is necessary to promote nurses' comfort, knowledge, and confidence in facilitating these conversations, and allows nurses to fulfill this scope of nursing practice in the clinical setting. Patient education on ACP should be implemented by nurses at many points of contact during patients' trajectories in primary care and acute care.

In order to prepare for successful facilitation of ACP, we recommend that nurses participate in simulation training with standardized patients, workshops, learning modules, webinars, and other learning tools. Technological aids and programs developed specifically for the purpose of ACP training, such as TACE or Codetalk, are helpful resources for HCPs to broaden their knowledge and foster confidence in holding ACP conversations [10, 11]. Codetalk may be particularly useful as an educational tool because it includes role play and simulations with an interdisciplinary team for the purpose of practicing for a family meeting to discuss goals of care and ACP [10]. Educational opportunities could be promoted by unit educators in the healthcare facilities. Documentation of ACP conversations and patient response should be regularly included in patient records. We also recommend that ACP be integrated into the nursing curricula of undergraduate nursing programs to prepare nurses for practice of ACP [6]. To ensure HCPs motivation in the completion of ACP education, training time should be incorporated into paid work hours or otherwise compensated [11]. Established staff culture and personal beliefs surrounding ACP can be a barrier in implementing these changes into practice, however, it is crucial to standardize ACP training for HCPs in order to address patient needs [6].

V. CONCLUSION

Specialized ACP education has been shown to improve nurses' comfort, knowledge, and confidence in conversing with patients to express their wishes and values in their care. Nurses can promote autonomy, dignity, and informed decision making among patients at any time throughout a health care trajectory. However, ACP conversations are an addition to nurses' workload and care giving. Scheduling and policies are required to reflect the importance of and the expectation that ACP will be used. Through engaging in ACP training and increasing their individual comfort, knowledge, and confidence, nurses can promote system-wide quality improvement of patient care.

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Table 1. Study details of selected articles

Reference Number	Study Design	Sample Characteristics	Key findings	Limitations
1.	RCT	125 RNs	No correlation between nursing education level and attitude towards ACP Common barriers to ACP: Inexperience, limited education, lack of uninterrupted time, heavy workloads and role-confusion Organizational advocacy can ↑ ACP between nurses and their patients	Low response rate of 12.8% RNs from Ontario only Comment: Nurses from other provinces may vary in their response
2.	Pre-test/ Post-test	138 HCPs	↑ preparedness for End of Life (EOL) conversations HCPs reported ↑ knowledge even given prior ACP experience	Convenience sample Role of HCPs not identified HCP role unidentified - impossible to verify which members of the staff saw the greatest benefit
3.	RCT	105 HCPs 545 Dementia patients	ACP conversations were successfully implemented in 62% of patients Early ACP discussions ↑ opportunity for patients' and families to express their desires and preferences. Barriers to ACP: time, language skills, lack of training, staff culture, beliefs, and cultural norms	Comparisons with control group not included Study limited to only dementia patients
4.	Mixed method study including cluster RCT	8 nursing home ward clusters 48 patients	ACP adapted to nursing homes to initiate quality and use in communication ACP documentation	Developers of the training participated in implementation introducing bias Selection bias at recruitment phase Hawthorne effect
6.	Comparative study	136 RNs 178 LPNs	ACP- specific education for nurses important in implementing ACP conversations. LPNs did not view their role in ACP to be as critical as the RNs Identified issues essential to ACP implementation: ongoing staff training, inclusion in nursing school curricula, continuing education in practice. Continuous evaluation of ACP content by nurse educators required	Convenience sample Self-report Nurses subject to socially desirable answers Access to nurses inhibited by scheduling issues and time constraints

7.	Qualitative Study Thematic Analysis for patients Pre-test/ Post-test for nurses	5 RNs 20 patients identified as palliative or requiring supportive care received ACP 13 participated in interviews	Earlier initiation of ACP can ↓ patient and family decision-making burden Most patients were comfortable in discussions about ACP with nurses who were seen as approachable Pre-test/Post-test results for nurses indicated that education and training required for ACP	Query reasons for 30% (7) of patients not interviewed Limited reporting on nurses involved, no sample size, pre-test/post-test not described
8.	Pre-test/ Post-test	122 HCPs including 60 RNs pre-intervention survey 101 HCPs including 47 RNs post-intervention survey	Improvements: ↓work stress, ↑EOL information Space allotted for private family discussions positively viewed Multidisciplinary-based training program improved EOL/GOC approaches in the critical care setting	Convenience sample No survey for patients or family members to determine the impact of program
9.	Pre-test/ Post-test	67 HCPs including 49 RNs	Self-ratings of competency ↑ in HCPs after standardized patient-based simulation ACP knowledge test scores ↑ following ACP demonstration videos, lectures and simulations	Barriers to ACP not included Convenience sample with mixed HCPs Small samples over multiple sites Facilitator's competency not measured Training of actors for study can be variable affecting participant responses
10.	RCT	472 HCPs 232 intervention group 240 controls	Codetalk and facilitator training ↑ ability to express empathy, discuss spiritual issues, eliciting patients' goals of care and Palliative Care communication skills ↑ in trainee's self-assessed competency in Palliative care communication skills	Mixed sample of MDs and RNs so results may not be applicable to RNs only 14% (66) dropout rate unexplained Codetalk was palliative care focused rather than ACP
11.	Pre-test/ Post-test Pilot study	35 HCPs including 23 RNs 12 SWs	↑ Level of comfort and capability in EOL conversations TACE ↑ skills and ↑ performance in EOL communications	Using personal time for webinars was a barrier to complete study Self-selection bias Low response rate for pre-test/post-test survey Only 57% (20) completed webinars Small sample size

RCT- Randomized Control Trial, HCP- Health Care Providers, ACP- Advance Care Planning, MD- Medical Doctor, RN- Registered Nurse, SW- Social Worker, TACE-Technology Assisted Continuing Education, LPN- Licensed Practical Nurse, EOL- End of Life, GOC- Goals of Care.

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Qualitative Study: Extracurricular Volunteering with Older Adults When There Is a Language Barrier for Student Nurses

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Abstract— In an increasingly globalized society, nurses will work with patients who do not speak the same language as they do. The Canadian population is aging, so older adults are now more frequently seen by nurses in the healthcare setting. Effective communication skills are crucial to providing adequate care to older adults when there is a language barrier. New nursing graduates need to be prepared to work with this population when coming into the workforce. Knowledge and experiences, which can hone interpersonal skills, may come from sources outside of the classroom setting. This study explores the experience of nursing students who volunteered in nursing homes when there was a language barrier. Nursing students who participated in this study were in an undergraduate nursing program at a university in Western Canada. They volunteered as an extracurricular activity over three months in a Care Center where older adults predominately did not speak English, the students' first language. To identify themes, we used a thematic analysis of audio recordings from semi-structured interviews with participants. Common themes include improved communication skills, and increased confidence in working with older adults.

I. INTRODUCTION

In Canada, immigrants are a large portion of the population. According to Statistics Canada [1], one out of five people are born outside of Canada. Within Canada, most immigrants come from Asia. 96.8% of immigrants who arrive in Canada have one mother tongue, 72.8% of that group speaking neither official language, French or English. Language barriers present as a challenge for nurses when working with patients. In some settings, a lack of available trained translators complicates care provided, as it can result in an overreliance on family members, which may not be reliable [2]. In some instances, translators may not be a cost or time-efficient tool to utilize when providing day-to-day care. In a study by Tideman and Tengelin [3], nurses reported body language as a good method of communication for simple messages; translators were more effective for complex information. Nurses reported that body language helped provide psychological support and comfort for their patients. When translators were not available, nurses had to utilize other strategies to communicate, including simplifying sentences and drawing. The ability and skill required to effectively work with patients when there is a language barrier is crucial, as it is becoming more common in the healthcare setting. New nurses entering the healthcare field upon graduation need to be prepared to face these challenges, as they start their careers [3]. Findings by Flood and Commendador suggest nursing students may feel only somewhat ready to provide culturally appropriate care to those with limited English proficiency [4]. This finding may suggest there is an uphill learning curve for students after graduation, as they will be required to provide care to patients who don't speak English when joining the workforce.

Findings by Kirca and Bademli [5] suggest patients have better outcomes when nurses are more effective with their communication. Patients are better able to understand interventions and voice their concerns when communication is effective. Strong communication skills come from formal and informal experiences. Communication is essential to the establishment of a therapeutic relationship between the nurse and patient. Patient complaints are often the result of poor communication with healthcare professionals. Poor communication results in patient concerns not being addressed. In this study, they found over half of the participants report not receiving support or training to strengthen their communication skills. A systematic review found nurses who work with patients, when there is a language barrier present, felt they needed additional educational supports to provide care [6]. Language barriers complicate communication between the nurse and patient, thus increasing the risk of providing care that does not address all the patient's needs. Given the importance of effective communication skills, it is crucial to emphasize the education and the development of these skills for nursing students. Promotion of extracurricular activities to further enhance students' in-class education may be beneficial, as the authors suggest these skills may be developed through experience [5].

According to Carper, in a classic paper breaking down the constituents of nursing knowledge, there are four necessary domains of personal, empirical, ethical, and esthetic knowledge [7]. These sources are crucial to nurses when making decisions regarding the care they provide to clients. Much of the knowledge acquired by new nurses comes from their post-secondary education. However, personal knowledge is also acquired outside of clinical experience in nursing school. Volunteering provides nursing students with an experience that results in the development of critical thinking skills and overcoming stereotypes, which is beneficial to their education and training [8]. Students can develop their sense of compassion and caring for others through structured volunteer activities [8]. The development of compassion and caring is essential to the education of nursing students, and necessary for this line of work [7]. In essence, the skills gained through volunteering may be transferable to clinical practice.

We searched the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Pubmed, Science Direct, Web of Science, Scopus, Ovid Healthstar and Ovid Medline (2017-2021) for recent studies within the past five years on the educational benefits of volunteering with older adults for nursing students when there is a language barrier. The search with Science Direct was limited by the database maximum of eight boolean connectors. We were unable to identify any research specifically on nursing students' learning from volunteering with older adults in a nursing home setting, when there is a language barrier present. See Table 1 for full search terms. Without data on how volunteering with this specific population may influence nursing students' education, it is unclear if this experience is beneficial. This qualitative study aims to explore the experience of nursing students who volunteered in nursing homes when there was a language barrier.

Table 1. Search terms used based on PIO question

Population	Intervention	Outcome
Nurse* Student*	Nursing home* Long Term Care* Older adult* senior* elder* aged Volunteer* Language barrier* Communication barrier* Communication	Experience* Education* learn*

II. METHODS

This study was conducted in a large city in western Canada. Nursing students from a university Bachelor of Nursing program were recruited by offering volunteer opportunities at a nursing home via email within the city the university was located. These emails specified an opportunity to work with clients who did not speak English, since the facility served the Chinese community and most residents spoke only Cantonese. The language barrier provided a challenge for the students who would be working at this site, none of whom spoke Cantonese. Study participants were informed they would be required to undergo the care center's volunteer interview and screening process. The care center was notified before participants applied for volunteer positions and gave consent for the study. A total of four applicants acquired a volunteer position at the care center. Participants could volunteer as frequently as they desired with no restrictions on which volunteer role they would assume. Furthermore, no restrictions were in place on which facility participants volunteered at, as the care center has two locations. Participants were interviewed 3 - 4 months after their initial volunteering. One participant left the study and did not take part in the interview due to external personal factors. The remaining students who did participate included two who had finished their second year of nursing, who had had one practicum placement in a long-term care center and one who completed their third year and also had hospital experience. We accepted nursing students with variable clinical experience, as the objective was to explore their experiences and learning from volunteering in nursing homes where most people did not speak English. We did not believe the hospital experience was likely to influence the results of the study, as all participants had rarely cared for patients who did not speak English. The sample size was not pre-determined beforehand since the objective of this study was not to establish a causal relationship, but to explore the experiences of our participants to better understand how volunteering with this population may have impacted them [9].

A. Setting

The care center primarily provides care for Chinese seniors across two nursing homes in western Canada. These facilities have a variety of healthcare professionals which include registered nurses, licensed practical nurses, physiotherapists, healthcare aides, and physicians. The care centers also have a diverse group of volunteers who aid with feeding, events, exercise programs, socializing with residents, etc.

B. Participants

All participants were nursing students in the Bachelor of Nursing Program. Students varied in how far along they were in their studies, ranging from second-year students to students entering their fourth year. All participants who volunteered did not speak any Cantonese. As Cantonese was the primary language spoken by the residents of the Care Center. All participants had received the same education related to communication in their second year of the degree.

C. Interviews

Participants were interviewed 3 - 4 months after they started their volunteer positions. A semi-structured interview format was used when collecting data from participants. See Table 2 for semi-structured interview questions. A set of open-ended questions was prepared beforehand, and further unplanned questions were asked to elaborate upon the responses from the participants. All interviews were recorded with two audio recorders. Questions did not focus specifically on the language barrier, but it was a theme that emerged from questions about communication which this study is highlighting.

Table 2. Semi-structured interview questions

Volunteering questions

- What motivated you to volunteer or how come you decided to volunteer?
    - What did you do as a volunteer?
    - What did you enjoy when volunteering? / What did you not enjoy?
- Reflecting on this what does this experience mean to you now?
- What was it like being a volunteer and being part of the team? - this can tell the social environment and the perspectives of the participant (if they see themselves as part of the team or as “just a volunteer”)

Working with older adults

- What was the most memorable experience you’ve had with this activity?
    - follow up question - tell me about a resident that made an impact on your perspectives of older adults
- Tell me about your contributions to the care of older adults within this setting?
- What have you learned from this experience?
- Have your perspectives of seniors changed after this experience and how (before and after)?
- How comfortable are you with approaching and talking to seniors?
- Before volunteering did you think that you would have worked with older adults?
- Do you think you would want to work with this population in the future?
- Do you feel like this training will help you in your future practice as a health care professional? or help you with your practicum? and how?

D. Data Analysis

The recordings were transcribed into two tapes and then listened to and read multiple times independently by each research team member. The data was interpreted with a thematic analysis approach following principles derived from phenomenological research to guide data analysis [10]. The principles included were: being aware of personal biases or perspectives, viewing the experience beyond the words or text, and reflecting on the lived experience of the participants. Both the first and second authors volunteered with older adults during nursing school and found it beneficial to the development their communication skills; thus, there was a risk of interpreting statements from volunteers as reports of improved communication skills. Being familiar with our own personal biases made us more conscious of the potential to interpret the experience through our own eyes rather than the participants'. It was crucial to analyze what was said based on the context of the events, as it helps identify emotional experiences for the participants. Quotes used were based on the context and what was said to identify common themes. The team had a discussion after each member analyzed the data to talk about the findings and themes. There were minimal disagreements regarding themes identified or results, but when they occurred, they were discussed and debated until all team members agreed.

E. Ethics

We obtained ethics approval through the University Conjoint Health Research Ethics Board. The research team made participants aware of the purpose of this study. Informed consent was obtained in writing and verbally. The care center took responsibility for risks associated with participating in this study. Applicants applied through a regular volunteer application process and were treated no differently from standard volunteers.

III. RESULTS

Audio recordings were listened to prior to being transcribed. The data was studied through multiple reviews of the transcriptions and repetitive listening of the audios to better understand the participants perspective. Quote selection for this study was based on communication and learning from this experience. Quotes were categorized by similarity of their ideas. Ideas were later reviewed to identify similarities to further categorize them into an overarching theme. By organizing the quotes into ideas and later themes, we were able to identify the most prevalent topics that were voiced by participants. Titles of the themes were made based on the overarching idea that encompasses all the ideas and the statements made by participants.

A. Communication

One participant experienced a changed perspective of how they are supposed to communicate and interact with older adults who do not speak the same language as them. Upon reflection, they initially expressed anxiety and discomfort with the idea of working with older adults. They did not feel they would be able to develop rapport with these residents successfully. They perceived their interactions as sitting with them and not doing anything beneficial for them. After their experience, they realized they do not necessarily need to be talking to convey their presence in the interaction: “We didn’t even have to be talking. We weren’t having a conversation cause she didn’t know English. So, we were just smiling at each other and looking through the book.”

They learned other strategies and methods to communicate and establish rapport with the residents. Participants were able to identify a human connection when interacting with clients. Primarily, they were able to see the human connection as an outcome of being present and attempting to communicate with clients. They saw the human connection as a beneficial factor to the care of clients, and something that can be created even in the presence of a language barrier: “It doesn’t really matter if there is that language barrier. I think it shows that human connection and just being there makes a big difference.” Having worked with clients who did not speak their language and struggling to communicate, participants were able to become more patient when working with people: “I think I might be a lot better at body language. I’m hoping that it will help me become more patient and focus on them ... I think it will help with that.” In this setting, volunteers needed to practice their non-verbal communication skills with the Cantonese-speaking residents because of the language barrier. Participants emphasized facial expressions and body posture when interacting with residents. They saw their body language as a key to demonstrating to the resident they have their full attention: "I'll just like be really bubbly and smiley and ask them how they are doing. I'll just light up their day at the very least if I can't do anything else." Volunteers learned to be more attentive to the body language of residents when interacting with them. Through their interactions, they were able to develop rapport with the residents: "yeah, some of them you could tell its ok to hold their hand. Some of them you want to give them space. Some of them there's something wrong." Participants report tying in their experience with their learning during nursing school. They reported not seeing the value in learning about communication in class but were able to see the importance of this learning through this experience: "In School, they taught us communication, which I didn't think was important at the time. I thought it was common sense."

B. Increased Confidence

When asked to reflect how they felt before working with older adults before the volunteer experience, participants expressed fear, anxiety, and uncertainty with interacting with seniors in general. Their stress was associated with a perception of the difference between themselves and older adults. They initially believed age was related to topics of interest, which would inhibit their ability to converse with older clients: "even in my practicum in the seniors home … I was scared, because I don't relate that well to the older population."

After volunteering, participants expressed increased confidence in working with older adults. Some were able to see past the chronological age difference between themselves and the residents and were able to engage in more meaningful conversations with them. With practice, they said they became more comfortable approaching and starting conversations with residents, as opposed to waiting for them to start talking first. Respondents saw this change in behavior as personal development for themselves: "I am probably a little bit more outgoing than I would have been before. And making conversation instead of waiting for them to say something". Participants report being more confident in their non-verbal communication skills and being able to identify key elements like being mentally present when working with someone. One participant reported, "I think I might be a lot better at body language … more patient … focusing on them". Participants viewed this activity as something that helped them grow and they were able to identify positive learning outcomes from it.

IV. DISCUSSION

Students who volunteered compared the volunteering role to student practicum placements. They described a more calm and relaxed environment where they did not feel there were any expectations placed upon them to achieve set goals. The experience and learning in the volunteer role primarily focused on honing their communication skills as students mostly spoke about interacting with residents and getting to know them. These findings are consistent with the statements made by Dyson et al. [8], as it suggests participants have more control over what they are learning when in a volunteering environment as opposed to a clinical practice environment [1, 5]. In a volunteer environment, there is less pressure to perform tasks on demand, and there is the opportunity to pursue activities that are of interest. The opportunity to pursue volunteer activities of interest provides the chance to hone desired skills or gain learning that is not taught in a classroom setting.

Participants demonstrated increased empathy, and some reported a heightened awareness of their feelings after working with older adults. Participants attempted to view the care received by residents through the older adults' perspective instead of their own and adjusted their care accordingly. Participants would attempt to understand the kind of treatment the older adult would like to receive if they were to be fed during meals and adjusted how they would be feeding approach. Additionally, they viewed their social interactions with residents as meaningful to each of their lives, and participants took this to heart and thought about their interactions after leaving the facilities. Kaya et al. [11] suggest activities that focus on the emotions of students are beneficial to the development of their critical thinking skills; the authors point out this education is important to start early on in their program. Critical thinking skills are essential to the profession, as situations will vary between clients and may be complex requiring nursing judgment when performing interventions. The results from the study by Codier and Odell [12] suggests emotional intelligence is positively correlated to academic performance and practice post-graduation.

Participants experienced increased confidence and improved communication skills after working with older adults. Before their experience, participants were concerned about not knowing how to instigate and continue a conversation with the residents, and also being able to relate to them. After their experience, participants believed there was growth in their personality in that they were more willing to approach and initiate a conversation with the older adults, and they realized that age does not mean there are no common interests or topics they can discuss. They learned the value of presence and active participation when communicating with residents, as it translates to better care and attentiveness during the interaction. Volunteers working in the care center had to hone their non-verbal communication skills to a further degree, as there was a language barrier between participants and most residents. By the end of the experience, participants appear to be more observant and sensitive to non-verbal cues from residents when interacting with them. One volunteer expressed interest in working with older adults in the future. This is consistent with the findings from Chi et al. [13], as they found students with more positive attitudes towards, spent more time with, or volunteered with older adults were more likely to want to work with that population. The authors suggest providing students with more opportunities to spend time and work with older adults may influence their career choices to work with that population.

V. CONCLUSION

Volunteering with older adults when there is a language barrier appeared to make positive impacts on the learning of nursing students in this study. These experiences influenced the image of older adults in the minds of the nursing students in a positive manner, by helping them acknowledge not every older adult will fit the negative stereotypical attributes they assigned to them. Both the clinical experience and volunteer role helped develop the communication skills for nursing students through practice. Volunteering gave participants experience in a different role, where they were less focused on educational requirements and more comfortable in forming relationships with residents. Practicing communication with older adults helped students develop their confidence when working with these clients. Through interacting with residents, nursing students developed increased empathy for older adults. Nursing students perceived the volunteer role as less impactful and stressful, but they still found it beneficial in the development of their skills. We recommend the promotion of volunteering with the older adult as an extracurricular activity to supplement and help further the learning and development of nursing students.

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Monitoring Breast Treatment with Microwaves: Consistency of Scans of the Healthy Breast

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Abstract— Microwave imaging has been proposed for monitoring breast cancer treatment. Detecting changes during treatment requires insight into the consistency of images of the healthy breast over time. A prototype microwave transmission system is used to image the breast at time-points 6 weeks apart for sixteen volunteers who had previously undergone lumpectomy. In this paper, only the healthy breast data is analyzed. Average permittivity of tissue is estimated using a technique called Time Domain Spectroscopy and reconstructed into a 2D map. The dielectric permittivity of breast is generated using data collected from an array of five ultrawideband (UWB) sensors operating between 100MHz and 10 GHz. Permittivity distribution of initial scan at week 0 is comparable to that of subsequent scan at week 6.

I. INTRODUCTION

One in eight Canadian women are expected to develop breast cancer during her lifetime, making it the most commonly diagnosed cancer among women. These statistics are similar in the United States, with breast cancer diagnosis making up an estimated 276 480 new cases in 2020 [1]. For most patients, diagnosis happens in the early stages of breast cancer. Lumpectomy or breast conserving surgery and radiation therapy is the most commonly prescribed treatment for early-stage breast cancer. Statistically, the rate of local recurrence in 10 years is about 3-15 percent [2]. Early diagnosis as well as treatment monitoring techniques can be used to increase the chance of survival.

After diagnosis, treatment monitoring in the breast has been achieved using several different tools in the past, including x-ray, ultrasound, and magnetic resonance imaging (MRI). Currently, x-ray mammography is the gold standard approach for breast cancer detection. However, it has a number of shortcomings including harmful radiation and reported false negative rates ranging from 4%-34% [3]. Ultrasound provides good soft tissue contrast, and is a painless, non-ionizing method of screening but may often be unreliable for catching early signs of breast cancer and distinguishing between benign and malignant tumors. MRI is routinely used to clarify questionable findings and for screening evaluation before lumpectomy or mastectomy. Due to high costs however, it is not suitable for monitoring or early detection screening. Microwave imaging is an alternative and complementary imaging method for breast cancer treatment monitoring that is non-ionizing, cost-effective, and painless. It is relevant because it uses the scattering wave that arises due to difference between dielectric properties of tissues. The collected backscattered signals can also be analyzed to reveal changes in dielectric properties overtime which is ideal for cancer monitoring purposes.

The range of dielectric properties of the breast is dependent on its composition. A recent study found that the dielectric properties of malignant tissues are much higher than that of normal adipose dominated breast tissue -- up to 10:1 in contrast [6]. This can be attributed to the higher water content of malignant tissues than that of healthy tissues, which translates to a significant increase in microwave scattering [5,6]. Specifically, changes in breast health lead to changes in dielectric permittivity, which is a physical property that characterizes the tissue’s ability to polarize under the influence of an external electric field. Tracking changes in permittivity, and hence tissue properties during chemotherapy and after radiation treatments can therefore give us insights into the treatment progress itself.

The purpose of this preliminary study was to evaluate the effectiveness of the microwave imaging prototype system [8] in processing real patient signal data starting with the healthy breast. A comparison of microwave images of a patient’s healthy breast overtime is important as a baseline from which diagnosis of malignancies can be made as well as to assess the performance of the developed prototype against an expected result. The dielectric properties of healthy breast tissue are expected to stay relatively consistent, and therefore 2D images showing distribution of permittivity will also be consistent across measurements collected at different time points.

II. METHODS

Sixteen Participants were recruited from those enrolled in the ACCEL (Accelerated Partial Breast Irradiation) clinical trial. The study was approved by the Health Research Ethics Board of Alberta (HREBA.CC-17-0322). As part of the ACCEL trials, all patients have undergone breast conserving surgery. The main inclusion criteria for the ACCEL trial included being a female, aged

50 and older at diagnosis of invasive or in-situ ductal carcinoma with primary tumor diameter of 3 cm or less. These inclusion criteria are based on the recommendations for partial breast irradiation by the American Society for Radiation Oncology [7]. Patients enrolled in the ACCEL trial were invited to participate in the microwave imaging trial, and no additional inclusion/exclusion criteria were applied. Breast scans were taken before radiotherapy and at 6-week follow-up for both the treated and healthy breasts. Before each measurement session, the volunteer is seated facing the system that has previously been secured onto a cart for portability.

The volunteer then removes her upper garment and with the help of a registered nurse, positions her healthy breast (e.g., the breast that did not undergo lumpectomy and was not being treated with partial breast irradiation) on the bottom array. The upper array is lowered until the breast is lightly compressed. This procedure is repeated for the treated breast. Verbal communication ensures that the volunteer remains comfortable throughout the process. Scan signals were collected in the frequency range of 100MHz to 10 GHz using a transmission system consisting of 2 arrays of 5 UWB (ultrawideband) antennas each [4,5].

Figure 1: Microwave Transmission system consisting of two sensor arrays and its user interface on a cart. The upper and lower array encloses five ultra-wideband antennas each, distributed in a honeycomb pattern.

For each of the 25 possible sensor pair combinations between the upper and lower arrays, the two-port S-Parameters are recorded by a vector network analyzer that is connected to the prototype and calculated as follows:

$$\begin{bmatrix} b_1 \\ b_2 \end{bmatrix} = \begin{bmatrix} s_{11} & s_{12} \\ s_{21} & s_{22} \end{bmatrix} \begin{bmatrix} a_1 \\ a_2 \end{bmatrix}$$

$$s_{11} = \left.\frac{b_1}{a_1}\right|_{a_2=0} \qquad s_{12} = \left.\frac{b_1}{a_2}\right|_{a_1=0} \qquad s_{21} = \left.\frac{b_2}{a_1}\right|_{a_2=0} \qquad s_{22} = \left.\frac{b_2}{a_2}\right|_{a_1=0}$$

Where b_1 and b_2 represent reflected waves from each port and a_1 and a_2 represent waves incident on each port. The S12 measurement represents the wave transmitted from the upper to the lower array and is therefore the measurement of interest. Each scan takes approximately 15 seconds, which is practical for the purposes of routine monitoring. Additionally, 2 scans are taken for each patient per session, a few millimeters apart to increase the data pool for analysis. In order to estimate permittivity, another set of signals has to be taken in air with the same separation distance. Both sets of measurements are recorded in the frequency domain.

In the first step of signal processing, the data are transformed to the time domain for analysis using the inverse chirp z-transform [5]. The increase in travel time of the signal travelling through the breast is then extracted, compared to that through air and used to estimate average relative permittivity of breast tissue as follows:

$$\varepsilon_r = \left(1 + \frac{\Delta t * c}{d}\right)^2$$

Where c is the speed of light in vacuum, Δt is the time of arrival difference between signals travelling through breast and air signal, and d is the separation distance of sensor pairs. The average permittivities are mapped to form a 2D image and mean average permittivity is calculated [5]. Statistical values calculated include mean, median, minimum, maximum and standard deviation of permittivity.

III. RESULTS

There exists striking consistency between the scans taken at different time points for the healthy breast of most volunteers. Figure 1 shows the images generated for Baseline, and 6-week healthy breast scans for volunteer F as an example. This consistency in mean relative permittivity values (unitless) can be demonstrated with 7 other patients as shown in figure 2. The baseline and 6-week mean values for volunteer F displayed in figure 2 are 5.16 and 5.18 respectively, taken from scans with the least separation distance.

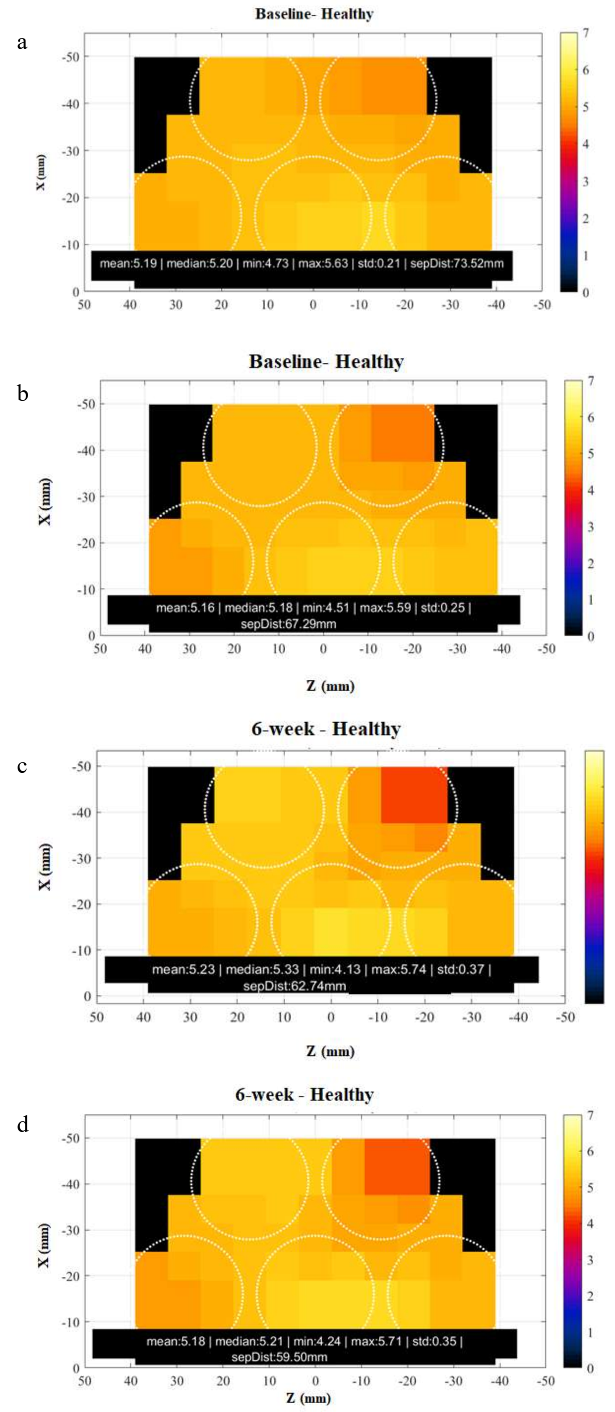

Fig 2: a. Relative permittivity distribution of Baseline healthy breast scan with separation distance of 73.52mm. b. Relative permittivity distribution of Baseline healthy breast scan with separation distance of 67.29 mm. c. Relative permittivity distribution of 6-week healthy breast scan with separation distance of 62.74 mm. d. Relative permittivity distribution of 6-week healthy breast scan with separation distance of 59.50 mm.

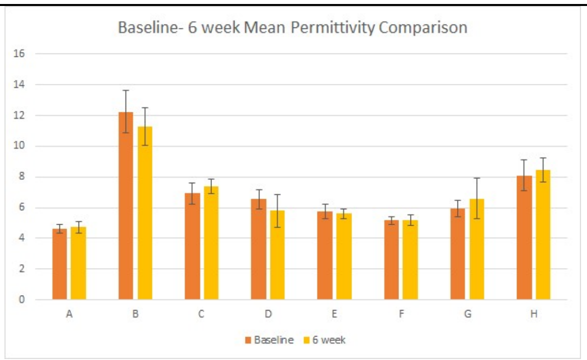

Figure 3: Mean permittivity extracted from Baseline and 6-week scans for 8 volunteers. Error bars show standard deviation of scan results.

IV. DISCUSSION

In a previous system validation study, the system estimated a mean value of 15.5 for a test slab with a known relative permittivity of 15 ± 3%. When compared to 15, there exists 3~4% measurement error. [5]. The results presented above then also assume this error.

The average permittivity percent difference calculated for 8 patients stayed in the range of 0.3 % to 12%. For volunteer F, healthy breast scans show reasonable consistency not only between separation distances but also across measurement taken 6 weeks apart. Patient F has relatively uniform permittivity estimates, suggesting uniform breast tissue compositions. These differences between Baseline and follow-up images might be due to breast placements not being identical between scans as well as non-identical separation between sensor arrays. The influences of breast positioning will be predicted to be even greater when measuring the treated breast (breast undergoing partial irradiation treatment) because contact with sensors may be more uncomfortable. For patients with varied breast tissue compositions, mean value estimates alone cannot be used to evaluate performance of the prototype because standard deviation may be greater. Individual signals in the frequency domain for sensor pairs at a region of interest may have to be analyzed for consistency between baseline and subsequent scans in such cases. Currently, other than by marked nipple placements, we do not have a method to determine the exact location of breast tissue relative to sensors, which makes the analysis more difficult to perform. This is a preliminary look at results of a pilot study with only a few data points in which statistical analysis outside of consistency in average permittivity is not appropriate. The obtained results were promising because they demonstrate consistency of the transmission system over a time frame of 6-weeks. This expected consistency in images for the untreated (healthy) breast gives an encouraging outlook for the next step of this study, which is analyzing the treated breast data.

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Reflections about Gene Editing: A Scoping Review

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Abstract— Gene editing is a rapidly growing biotechnology, both in capability and use. The goal of gene editing is to modify traits related to the expression of genes of interest. While gene editing holds promise for addressing socio-economic challenges in medicine, agriculture, food and conservation, it is a novel technology that warrants broader attention to its social implications. Reflecting on the social dimensions of gene editing is at the forefront of academic and public conversations alike. This research catalogued initiatives and recommendations surrounding reflection in academic discussions about gene editing through a scoping review of the peer-reviewed English language literature published from 2000 to 2020. Key themes included governance, engagement, ethics, regulation, risk, inequalities, and education. Each theme was explored in depth to map trends and gaps in the literature pertaining to reflection surrounding gene editing. Findings will inform the development of post-secondary education modules on the governance of gene editing.

I. INTRODUCTION

Gene editing technologies consist of fast-moving, cutting-edge, targeted molecular systems that facilitate the precise alteration of genetic material without the insertion of foreign DNA into the gene of interest [1]. These high-profile biotechnologies such as CRISPR (clustered regularly interspaced short palindromic repeats) offer many advantages in that they are relatively affordable, efficient, and accurate. Gene editing is already transforming practices in diverse fields such as medicine (medical applications), agriculture, food, and conservation (agri-environmental applications).

Nonetheless, gene editing warrants deeper reflection about its social implications. Conversations about the need to reflect on the broader social dimensions of gene editing are taking place across a wide range of disciplines including medical contexts [2-22] and agri-environmental contexts [1, 23-43].

Reflection refers to the process of examining the activities, assumptions and limitations that frame our knowledge commitments while keeping in mind that these commitments may not be universally held [44]. For example, gene editing founders and recent recipients of the Nobel Prize in Chemistry, Jennifer Doudna and Emmanuelle Charpentier, highlighted the "urgent need for open discussion of the merits and risks of human genome modification by a broad cohort of scientists, clinicians, social scientists, the general public and relevant public entities and interest groups" [45]. The integration of formal reflexive frameworks such as Responsible Research and Innovation (RRI), Ethical Legal and Social Implications/Aspects of bio-, neuro- and nanotechnology (ELSI/ELSA) and the precautionary principle into multidisciplinary academic initiatives are gaining traction, ex. [24, 25, 27, 34, 43, 44, 46, 47], especially in Europe [47] signaling the importance of reflection for the governance of science and innovation.

The objective of this research was to examine how 'reflection' is described in the academic literature on gene editing. Methods involved a scoping review of the relevant peer-reviewed English language academic literature published from 2000 to 2020. This project was devised within the context of a larger team research initiative that sought to inform teaching and learning at the post-secondary level about responsible science and innovation through the proxy of gene editing.

To date, and to the best of the author's knowledge, no comprehensive review of reflection and gene editing exists in the academic literature. This research provides an exploratory overview of the current state of the academic literature on reflection and gene editing to identify key themes and gaps to inform future research. 54 articles were analyzed, and findings revealed that governance, engagement, and ethics were the most prominent themes while regulation and risk were underrepresented in comparison. A single article was opposed to prioritizing reflection in conversations about gene editing [48]. A key conclusion of this paper is that more attention and opportunity for reflection about gene editing is urgently warranted to ensure that the pace of technological change does not override our capacity to examine the associated social implications.

The remainder of this paper is structured as follows: First, the research design is outlined, including strategies for data collection and analysis. Next, the organization of findings is discussed, highlighting themes and gaps in the literature. Finally, the implications of the findings are examined in detail to inform key takeaways and directions for future research.

II. METHODS

A. Data Acquisition

Data was gathered through a scoping review of peer-reviewed English language academic literature. A scoping review is a structured review process that summarizes the key themes in a body of literature to outline trends and gaps [49]. Scoping reviews are an exploratory phase of research and are not intended to assess the quality of research as a systemic review would.

Searches were conducted in six databases (Google Scholar, CAB Abstracts, Environment Complete, SocINDEX, Web of Science, and BIOSIS Previews) using key terms pertaining to gene editing and reflection. Databases were selected for their comprehensive representation of both scientific and social scientific views. Search criteria were devised in consultation with a library scientist at the University of Calgary. Additional data were derived by snowball sampling the reference lists of key articles (see Fig. 1 for an overview of databases and search terms).

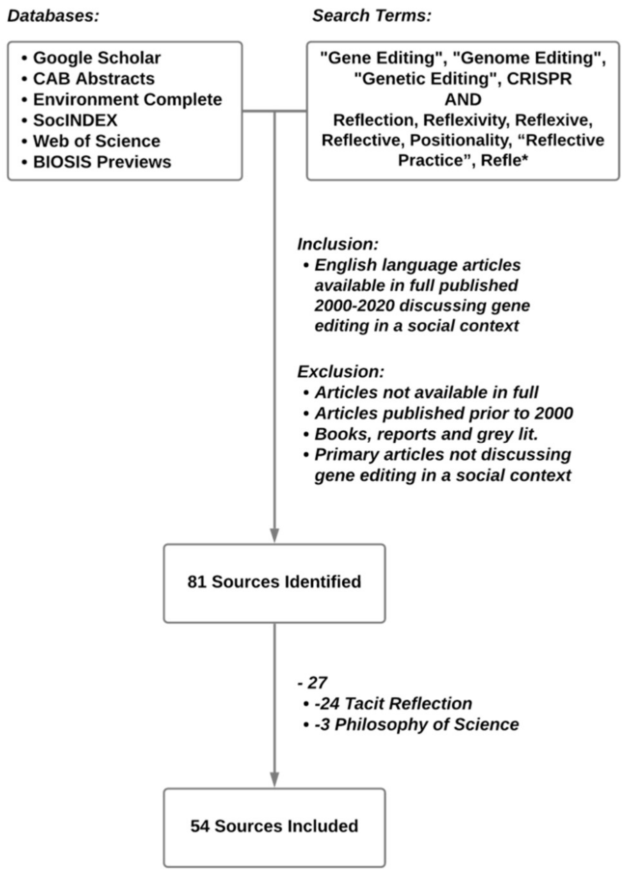

Fig. 1. Flow diagram of scoping review process

Inclusion criteria were as follows: English-language peer-reviewed articles published from January 2000 to December 2020 inclusive that address ‘reflection’ and ‘gene editing.’ The following were excluded from this review: Books, meeting reports and grey literature. Research descriptions about laboratory experiments were also screened out. Inclusion criteria were chosen to keep the dataset manageable. Although gene editing did not gain widespread notoriety until the mid-2010s, the inclusion criteria was devised to capture any corresponding ideas circulating prior to its development and implementation.

81 articles were initially identified based on title and abstract screening. 24 articles were removed based on relevance: while they addressed the social dimensions of gene editing, they did not specifically talk about reflection. These articles were flagged as tacit reflection since they conveyed themes contemplating the values and assumptions of science without openly expressing that they were doing so. Three additional philosophy of science articles were screened out prior to analysis as they did not relate to gene editing. After full-text screening, 54 articles were included for further analysis (see Fig. 1 for an overview).

B. *Data Analysis*

Key information from included articles was entered into an excel spreadsheet according to the following categories: area of focus (medical, agri-environmental or broad-spectrum applications), author-provided keywords (if available), and any additional notes from the abstract pertaining to reflection and/or the social dimensions of gene editing to help identify key themes.

From the onset, it’s worth noting that reflection was not necessarily defined throughout the literature in an explicit sense. Articles that met the inclusion criteria treated reflection as an actionable item that facilitated the examination of values, assumptions and biases, even in the absence of a formal definition. Themes were developed based on the context of reflection in each article. Themes were derived inductively from the data (e.g. article title, abstract, keywords) and refined in consultation with team members. Articles were screened in full if additional information was required.

III. RESULTS

The following themes were identified: Governance, regulation, engagement, ethics, risk, and opposition (Fig. 2). Each of these themes will be described in turn below.

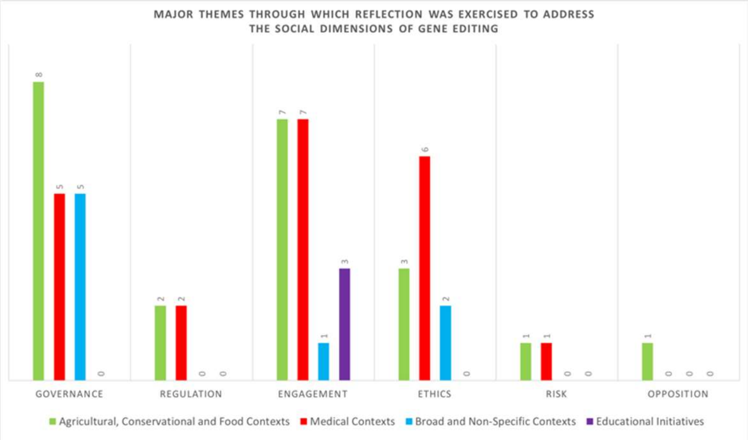

Fig. 2. Frequencies of the major themes through which reflection was employed to address the social dimensions of gene editing.

A. *Governance*

Governance is a broad term that generally refers to processes of representation and authority, encompassing “the ways problems and issues are framed, terms of debate are set, and particular ways of speaking and thinking come to be privileged over others” [10].

One third of the articles (18/54) addressed reflection in the context of the governance of gene editing. Of these 18 articles, five focused on medical contexts, eight on agri-environmental contexts, and five on broad-spectrum contexts (Fig. 3).

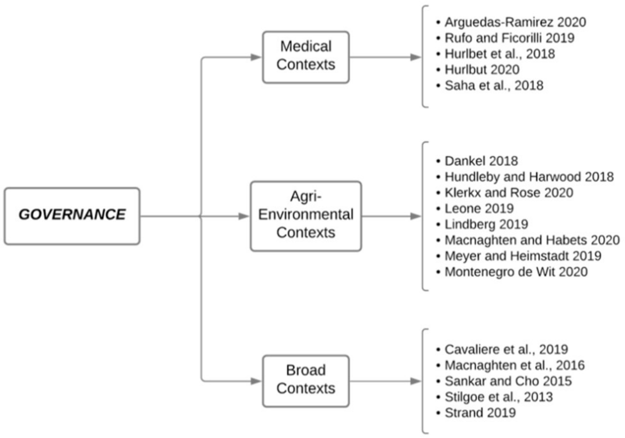

Fig. 3. Distribution of articles pertaining to reflections surrounding the governance of gene editing.

Five articles across medical, agri-environmental and broad-spectrum application contexts referred to the institutional culture of science. For example, in reference to medical applications, Hurlbut [10] provided an in-depth analysis of the elements of institutional governance that preceded the 2018 He Jiankui case of human germline editing, and the aftermath that followed. Rufo and Ficorilli [18] drew an active comparison between the recombinant DNA technologies of the seventies and current CRISPR systems to reflect on our current conceptions of knowledge related to the applications of gene editing. Arguedas-Ramírez [2] sought to expand the discourse on human germline editing beyond science and called for a hold on current governance proceedings to allow for reflection. In an agri-environmental context, Lindberg [35] provided an active assessment of scientists' reflexive tendencies concerning gene editing, determining that the current institution "privileges scientific knowledge while dismissing the legitimacy of non-scientific knowledge and concerns" [35]. In a broad-spectrum context, Macnaghten et al. [50] provided a review of the intersection of responsible innovation with synthetic biology and posited changes needed for institutional governance, extending to the "questions of purpose, values and future synthetic biology seeks to create" [50].

Others called for more broad-reaching changes to the institutional culture of science highlighting the need for a global infrastructure to advance reflexive practice through public deliberation on the governance of gene editing [11, 19]. A portion of the articles were situated within the European Union [1, 29, 37, 43]. Formal reflexive frameworks in industry [25] and sustainability initiatives [31] were also explored. Several articles discussed the need for formal reflexive frameworks as a way to promote democratic governance across broad-spectrum applications [44, 47, 51, 52]. In one article, epistemic justice, e.g., the recovery of knowledge systems lost to scientism and colonialism [38], was noted as essential to facilitate reflexivity surrounding the democratic governance of gene editing [38].

B. Regulation

Regulation addresses factors that are influenced by local and/or global policy determination related to the research and commercialization of gene editing technologies. Articles that addressed regulation (4/54) were comparatively fewer than those that addressed governance (18/54). These four articles addressed the regulation of gene editing in the context of reflecting on the associated implications of past, current and future regulatory initiatives (Fig. 4).

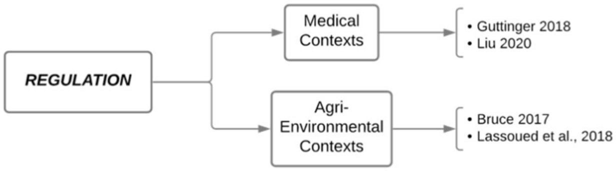

Fig. 4. Distribution of articles pertaining to reflections surrounding the regulation of gene editing.

Concerning agri-environmental applications, Bruce [23] and Lassoued et al. [34] outlined some of the regulatory challenges that materialized from the commercialization of genetically modified crops and sought to apply associated lessons to the agricultural products of gene editing.

Regarding medical applications, Guttinger [7] and Liu [13] examined regulatory concerns around editing the human germline by analyzing the successes and shortcomings of past regulatory initiatives and future direction to enforce current restrictions

C. Engagement

Engagement refers to the direct and indirect acknowledgement and/or enrollment of stakeholder/public perceptions and values.

A significant portion of the articles (18/54) discussed reflection in the context of stakeholder and public engagement beyond the scientific community (Fig. 5).

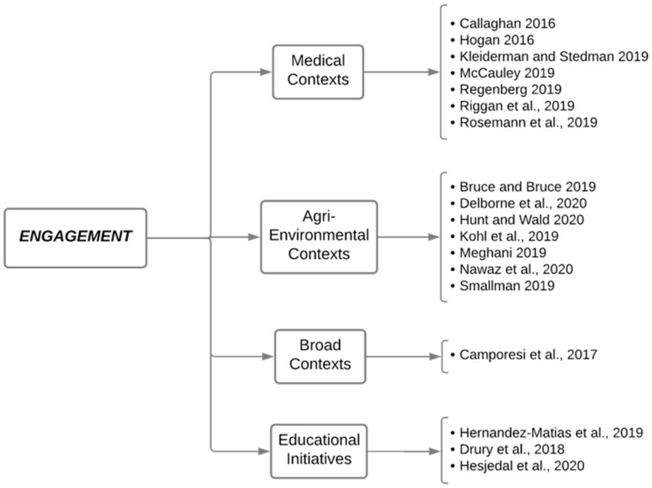

Fig. 5. Distribution of articles pertaining to reflections surrounding stakeholder engagement with gene editing.

Of these 18 articles, two were industry-focused within an agri-environmental context. Nawaz et al. [39] directly engaged with organic sectors in Canadian and American contexts, (proponents of resistance to genetic modification), to contemplate current challenges associated with the gene editing of plants. Bruce and Bruce [24] sought to explain the need to embed RRI into agricultural practices pertaining to the gene editing of livestock in hopes of facilitating broad stakeholder engagement. They argue that the rapid and divergent development of gene editing poses a policy challenge to RRI, essentially "overwhelming attempts to achieve a more reflective pace" insofar as RRI requires a slower pace to foster public engagement and ethical reflection in advance of implementation [24].

Two articles explored formal engagement frameworks for gene editing. In a medical context, Callaghan [5] discussed the implications that citizen science will have on bioethical theory and practice, including an associated need for reflexivity. In an agri-environmental context, Delborne et al. [26] explored the shortcomings of applying 'social license to operate' to the field of synthetic biology, including gene editing.

Several articles, spanning medical [16], agri-environmental [30, 32, 42], and broad-spectrum applications [53] focused on public trust in scientific expertise, speaking to stakeholder perception of the processes and products of gene editing.

Within a medical context, two articles focused specifically on germline applications of gene editing. Hogan [9] reflected on the continued lessons learned from and the persistent challenges associated with an Asilomar-like script for public engagement. Rosemann et al. [17] directly engaged with stakeholders by conducting a multi-stakeholder study to evaluate challenges concerning the governance of gene editing in the UK. The role of the media was also highlighted, presenting new avenues for public reflection and engagement in response to reporting on medical applications of gene editing [14, 15].

Out of the 18 articles that examined engagement, only two highlighted underrepresented perspectives. Uniquely, one examined the necessary obligation to involve indigenous perspectives in conversations about the environmental release of genetically engineered organisms [36]. The other sought to provide representation for the rare disease community in conversations about novel genetic treatments [12]. Although both attempted to diversify current narratives surrounding applications of gene editing in both agri-environmental and medical contexts by reflecting on which viewpoints are under-prioritized, neither directly engaged with stakeholders.

Educational initiatives were also described as a way of encouraging reflection on gene editing. These initiatives ranged from secondary (high school) to postgraduate training. CRISPR was employed as a module or case study to teach and assess tenets of scientific reflection such as self-perception of scientific competence [54], deliberation [55] and strategies for teaching RRI [46]. All demonstrated active engagement by working directly in classroom settings.

Of the 18 included articles about engagement, only a third (6) directly engaged with stakeholders [16, 17, 39, 46, 54, 55]. Avenues of direct stakeholder engagement included semi-structured interviews, participant observation, focus groups and classroom engagement. The rest of the articles discussed the review and analysis of pre-existing literature, data or historical case studies.

D. Ethics

Ethical questions refer to value and moral-based discussions of gene editing. In total, 11 of the 54 articles discussed ethics in the context of reflection. A dichotomy was observed between individual and collectivist ethics in both medical and agri-environmental contexts (Fig. 6).

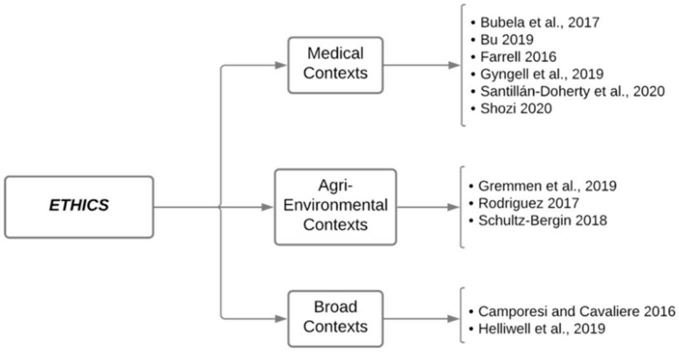

Fig. 6. Distribution of articles pertaining to reflections surrounding the ethics of gene editing.

Individual ethical questions in a medical application context relate to somatic treatments and the need/right to try novel treatments on a case-by-case basis. Collectivist ethical questions reflect on the permissibility of editing the human germline and unforeseen consequences that could restrict the autonomy of future generations. Ethical questions in this field largely reflect on our obligation to and potential power over future generations.

Approximately half of the articles (6) were situated within a medical context. Four addressed ethics through a collectivist lens. Bubela et al. [3] called on healthcare leaders to reflect on the broad ethical challenges posed by gene editing. Bu [4] reflected on the acceptability of editing a human genetic future. Shozi [21] platformed an underrepresented African perspective to weigh in on the ethical implications of editing the human genome. Santillán-Doherty et al. [20] reflected on the bioethics that were overlooked in the He Jiankui case. Two articles drew on individual and collectivist ethics, arguing that gene editing is a moral imperative for individuals, broader society and future generations [8] in both somatic and germline contexts [6].

From an individual standpoint in an agri-environmental context, questions relate to the individual consumption of gene editing crops and the desire to be exempt from the effects of such technologies. From a collectivist perspective, there are broader environmental concerns associated with the unforeseen consequences of introducing gene editing organisms into nature. Ethical questions in this context posit reflection on what grounds we inhabit and have the right to alter the natural world.

Three articles were situated within an agri-environmental context, all of which considered ethics through a collectivist lens. Gremmen et al. [27] employed a formal reflexive framework and argued for the consideration of the ethical dimensions of gene editing through RRI. Rodriguez [40] reflected on bioethical concerns with respect to how gene editing will impact and alter human-nature relationships. Shultz-Bergin [41] sought to fill an ethical gap concerning species boundaries and animal welfare by drawing active comparisons with previous gene editing techniques for non-human animals.

Two articles considered bioethical questions concerning gene editing in both medical and agri-environmental contexts. Camporesi and Cavaliere [56] called for reflection surrounding the ethical dimensions of these widespread applications contexts. Helliwell et al. [28] contrasted agri-environmental NGOs' bioethical concerns about gene editing to the formal 2018 bioethical assessment made by the Nuffield council on human genome editing. The comparatively limited efforts made by the Nuffield council's official report to expand reflexive discourse was noted [28].

E. Risk

Only two articles explicitly weighed the risks and benefits that could arise from gene editing technologies through formal assessments (Fig. 7). One article was situated in an agri-environmental context and devised a procedurally robust risk assessment framework of which reflexivity was a key tenet [33]. The other was situated in a medical context and reflected on the potential to create, define and manage risks and uncertainties pertaining to the editing of human embryos [22].

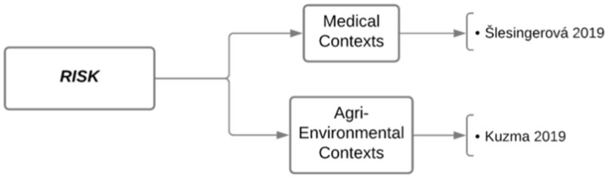

Fig. 7. Distribution of articles pertaining to reflections surrounding the risks of gene editing

F. Opposition

Although not constituting a single theme per se, one article was expressly opposed to the integration of reflective practice into academia, extending to the applications of gene editing, positing that such a move would constitute "an assault on science" [48].

IV. DISCUSSION

A. Implications of Thematic Distribution

Although this review sought to explore a broad timeframe, most included articles were published within approximately the last 5 years, with the earliest in 2013 [44]. Most of the articles were situated within a European and US context, perhaps in part due to the focus of this review on English language literature.

Across both medical and agri-environmental applications, governance, engagement and ethics were the most prominent themes. Despite reflection on questions of governance yielding widespread discussion on democratization, diversification of current narratives and integration of formal reflexive frameworks, very few articles in either disciplinary context examined underrepresented perspectives or addressed socio-economic inequalities. This is further emphasized by the limited geographical scope covered.

Ethical questions within a medical context were largely streamlined to focus on the permissibility of human germline editing. In comparison, the myriad of agri-environmental applications provided the opportunity for more diverse reflection. Interestingly, it's noted that formal bioethical assessments such as the heavily cited 2018 Nuffield Council on bioethics report on human genome editing had limited reflective capacity and failed to significantly expand current discourse [28].

All engagement was seen to extend beyond the scientific community, appearing to prioritize the consultation of a diverse stakeholder base. However, most articles failed to interact directly with stakeholders and relied on pre-existing literature and data. The sentiment to broaden the current discourse is apparent, but initiatives taking the extra steps to directly facilitate this diversification and push the envelope to create new avenues for participation are few and far between. If science seeks to engage a broader public on the social dimensions of gene editing, who does this public consist of? Is it one that holds socio-economic privilege that grants easy access to the scientific community, or does it acknowledge marginalized groups that face systemic barriers and do not have the same access to scientific knowledge or the means by which to make their viewpoints heard? At this point, the literature would suggest that the former is more accurate.

The intersection of reflection with the regulation of/risk associated with gene editing is limited. The integration of reflection into regulatory questions of policy and protocol often provides a transitional step towards questions of governance. To this effect, it's not surprising that few articles address regulation in comparison to governance. Likewise, few articles address risk since formal risk assessments are often used for regulatory decision making. Additionally, reflecting on different conceptions of risk requires different knowledge systems and other ways of knowing to be present in the dialogue at hand, which is limited at this point.

A small vocal minority opposed to prioritizing reflection [48] represents a persistent desire to adhere to the received view of science. Despite there only being one included article backing this stance, it is indicative of an ever-present challenge to integrate reflection into science research and practice on an institutional level. This is supported by Lindberg's [35] findings that the agricultural sector of gene editing remains largely unreflexive on both individual and institutional bases.

Several key implications can be drawn from these findings. First, the literature suggests the ongoing need for reflection on gene editing and highlights the challenges of doing so in the context of its rapid development. It's noted that the fast-paced and divergent development of gene editing, per its affordability, efficiency and accuracy, continues to overwhelm initiatives seeking to implement a more "reflective pace" [24]. Without the necessary time to establish a solid foundation, the application of reflection to the complex topic of gene editing is largely superficial.

Second, while there is a persistent desire to promote reflection surrounding the social dimensions of gene editing, there are notable shortcomings in practice. In particular, the English language literature appears to be biased towards a European/US perspective with limited consideration for unrepresented perspectives and ways of knowing, such as Indigenous perspectives. As mentioned, a key tenet of reflection involves keeping in mind that guiding beliefs may not be universally held [44]. In practice, one would expect this to translate into the acknowledgment of diverse ways of knowing. This suggests further research is warranted to examine reflection across multiple knowledge systems.

Third, promising arenas for reflective practice lie with educational initiatives ranging from secondary to postgraduate training which aim to incorporate reflective practices into science studies through the proxy of gene editing. The integration of reflection into science education at various levels indicates applicability to broader conversations on the topic. Educational initiatives prioritizing reflection will have the potential to set the tone for new waves of science-citizens that will go on to frame this conversation in society and actively engage in reflection in academic and public discussions alike.

B. Study Limitations

This research was conducted as part of an undergraduate research training program, from May to August 2020. While this project facilitated personal learning in terms of foundational research skills and the development and execution of a structured review, there were limitations associated with the accompanying learning curve. A longer planning period would have allowed for a more refined protocol development and a longer pre-search phase. This would have helped to narrow the scope of the research question and focus the included literature, especially concerning the nature of reflection. Additionally, a longer pre-search phase would have permitted the expansion of inclusion criteria beyond English-language literature. This would have likely broadened the geographical scope of the debate and made space for underrepresented perspectives in a non-European/US context. It's important to keep in mind that a scoping review is an exploratory phase of research intended to provide a high-level overview of the current state of the field, and further research is warranted to refine these themes.

V. CONCLUSIONS

A. Summary of Findings

This scoping review found that reflection pertaining to the governance, engagement and ethics of gene editing were the most prominent themes across both medical and agri-environmental application contexts while regulation and risk were limited in comparison. Despite widespread sentiment to diversify the discourse surrounding the social implications of gene editing, articles platforming underrepresented perspectives were few and far between. The majority of the included literature originated from European and US perspectives. Direct engagement with diverse stakeholders to actively expand on existing avenues for participation in science was limited. Opposition to reflective practice in science sustained by a small but vocal minority is worth noting. Overall, while the importance of reflection is highlighted in the literature, inconsistent and diverging meanings alongside the rapid development of gene editing technologies pose significant challenges. Despite these challenges, the integration of reflection into science education at various levels is a promising area to facilitate broader public deliberation about the social implications of gene editing.

Overall, there is a persistent and urgent necessity to create opportunities and spaces to promote diverse collective reflection about gene editing. A precondition to achieve this end will be the enrollment of different social groups in reflective practice with attention to underrepresented and minority perspectives to promote meaningful and lasting diversification of the current narrative. While educational initiatives are beginning to chart this course, further expansion beyond academia is required.

B. Future Direction

The preliminary findings from this project point to trends and gaps in the literature that warrant further investigation. To date, the findings from this initial scoping review will help to inform further research on reflection surrounding the governance of gene editing. Ultimately this will facilitate the development of post-secondary education modules on the governance of gene editing and the

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Maintaining and Reinstating Community Water Fluoridation in North America: Health Professional Stakeholders' Views of Best Practices

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Abstract—Community water fluoridation (CWF) is a preventive health measure with 75 years of evidence demonstrating its efficacy, and with no valid evidence of significant harms at the recommended 0.7 parts per million (ppm). Nevertheless, there remains vocal, minority opposition to CWF. In an attempt to identify best practice in defending the public health measure from unjustified attack based on false and misleading information, this study considered the relationships among public opinion, policy, health services, and fluoridation, and the roles played by various stakeholders in advocating for CWF. Semi-structured interviews were conducted with 14 stakeholders, such as medical officers of health and oral health professionals in Canada and the United States to learn how CWF has been defended in North American municipalities. Participants discussed: (1) the challenges of advocacy given fluoridation opponents' false, misleading, and often emotive claims and the importance of reliance on research evidence; (2) the fact that CWF's cost-effectiveness is underappreciated; and (3) the practical importance of a good working relationship between the medical officer of health and elected decision-makers, and the need for medical officers of health to be skilled advocates. The findings provide insight into how vocal minority opposition is addressed and might help advance knowledge of how best to maintain and reinstate CWF.

I. 1 INTRODUCTION

The mineral, fluoride, exists naturally in water in North America [1]. Community water fluoridation (CWF) is a public health measure that adjusts existing fluoride levels in community drinking water to reduce dental decay. Fluoridation inhibits tooth demineralization and enzyme activity of oral decay-causing plaque bacteria [2–4]. Dental decay is the most common chronic disease of childhood [5]. Untreated dental decay causes pain, leading to poor sleeping, eating, playing, school attendance, and concentration, thereby delaying development [6]. Approximately 45% of Canadians [7] and 66% of the United States (US) population [3] have access to optimally fluoridated water. CWF is a proven, evidence-based, safe, effective, and cost-effective oral health preventive measure [4, 8–10]. The recommended fluoride concentration in drinking water is 0.7 ppm; this level provides the best protection against tooth decay while limiting the occurrence of dental fluorosis [11]. Several research studies reviewing CWF have concluded that there is no significant adverse health impact associated with water fluoridation [12–14].

Despite continued evaluation of CWF safety and efficacy, and the CDC's recognition of CWF as one of the "top ten great public health achievements of the 20th century" [15], opponents have made false and misleading claims about CWF. Such claims are often based upon an inadequate analysis of scientific evidence and/or low health literacy; they are disseminated through an increased number of websites, social media, and email messages [3]. The rhetoric of fluoride opponents can be employed to undermine public confidence in CWF by presenting misleading evidence through an increased number of websites and social media [16]. Techniques used by anti-fluoride individuals often contribute to cessation in some North American cities [17]. CWF implementation and cessation are under municipal jurisdiction in all Canadian provinces and most states in the United States [7, 18].

When fluoridation ceases, dental decay increases. In Calgary, Alberta, the number of decayed tooth surfaces increased by 146% in the period of the study that ended two years after fluoridation ceased [2]. In the study's 7-year follow-up evaluation, the results were consistent demonstrating the prevalence of caries as significantly higher since cessation [19]. In Windsor, Ontario, cavities increased by 51% among children and by 300% in low-income families in 6 years [20][1]. In Juneau, Alaska, researchers reported a 47% increase in decay in children under 18; for children under 7 years, caries treatment costs due to decay increased by 73% [21]. The lack of fluoridation most affects children, lower-income, and other health-disadvantaged populations due to barriers to access adequate oral health care [22]. The greater health gain from CWF occurs for those with the highest socio-economic disadvantage [23].

Public health recommendations favoring CWF are based on an entire body of high-quality evidence created over decades that continues to demonstrate that CWF is effective in reducing dental decay with an acceptable safety profile [13, 14, 24]. The researchers support public health's CWF recommendations. None of the authors are in a conflict of interest. In this study, maintaining, defending, and

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[1] In December 2018, Windsor city council reinstated CWF [20].

reinstating CWF was discussed. Maintaining CWF means continuing to provide fluoride into a community's water supply. Reinstating CWF is the act of reimplementing CWF after cessation. Defending CWF is the act of advocating for maintaining or reinstating CWF within a community.

The framework of this study was developed in light of the CWF debate in Calgary, Alberta which led to CWF cessation. The study investigated how CWF has been defended in North American cities and to identify best practice in supporting CWF in municipalities.

II. METHODS

The aim of our study is to understand best practice in maintaining or reinstating CWF. While the scientific evidence surrounding CWF heavily supports fluoride as a preventive health measure, anti-fluoride sentiment affects the decision-making process regarding CWF. Our aim is to further understand why there is a disconnect between the scientific evidence of CWF and the implementation of CWF as a public health intervention in municipalities across North America.

A. Participant Selection

Qualitative descriptive methods were used [25]. The researchers identified 35 potential participants in 33 US and Canadian cities who held employment positions related to maintaining and reinstating water fluoridation in North American cities where CWF has been maintained or has ceased. These included elected officials, medical officers of health (MOHs), and other providers of healthcare, especially oral healthcare. Participants were recruited from both the US and Canada to solicit a wide range of responses regarding barriers and supports to CWF.

This study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB18-0820). Participants were recruited by emailed invitations to engage in a semi-structured, telephone interview, and followed up with a second message. Interested recipients responded with the signed consent form. Prior to the interview, one interviewer read aloud a standard paragraph reminding the interviewee of the purpose and nature of the survey and asked for that person's verbal consent to participate; all participants gave their consent.

The researchers sought to interview stakeholders about best practice because these participants have previous knowledge of the scientific evidence of CWF; how the decision-making process affects preventive health measures; and, have had personal experience with individuals with anti-fluoride sentiments. The participants' insight on best practice, reinstating, or maintaining CWF is an important addition to the literature. Despite overwhelming scientific evidence about CWF effectiveness, decision-makers' implementation of the preventive health measure is affected by anti-fluoride sentiment. Therefore, the participants chosen understood the scientific research behind CWF and were able to speak to how decision-makers drive the oral health outcome of his or her community.

B. Participant Interviews

The interviewers asked participants 15 open-ended questions (Appendix A) regarding their CWF activities, and their opinions about CWF and CWF practice. The questions were derived, in part, from the current debate in Calgary, Alberta, and from discussion with local city councilors, four of whom were not knowledgeable about the practice but were responsible for deciding whether to reinstate CWF. Some of the questions aimed to elicit responses from participants about how to bridge the knowledge gap. The interviewer asked subsequent questions to elicit clarification or elaboration when needed. One interviewer (AHA) conducted each interview to ensure uniformity, with another (JRG) initially listening to three interviews. The interviews lasted 60 to 90 minutes and were recorded and transcribed verbatim.

C. Data Analysis

The researchers analyzed the data using content analysis and reviewed transcripts iteratively. Using QSR International's NVivo 12 software and the interview questions as a guide, transcripts were read line-by-line and coded by hand. The interview guide worked as an analytical tool to guide our analysis. The in-depth information gathered in responses provided the researchers with an effective way to explore the opinions and experiences of participants. The researchers coded the similar responses given in each transcript. The responses eventually emerged into three themes with sub-themes.

Following the initial review of the data, two authors (AHA, JRG) agreed upon codes to be used throughout data analysis and, to enhance reliability, 80% agreement was sought between each author's respective interpretations of codes derived from the data. Codes were compared with one another, and categories were derived from the significant and repetitive codes. Themes were derived from codes. Each author moved iteratively among transcripts, analysis, and the manuscript to develop and refine themes. All authors studied the outcome until eventually, three themes emerged using inductive reasoning based on the data.

III. RESULTS

Of 35 people contacted, five declined, 15 did not reply and 15 accepted. All participants were from the healthcare community. No elected official accepted our invitation to participate. Six were female and eight were male. Some chose not to reveal their stakeholder role and are therefore described as "anonymous." One interview was lost because of an electronic malfunction. Of the 14 responses studied, 11 individuals resided in cities with CWF (Table 1).
Of the three themes that emerged, one has three sub-themes.

A. Theme One: Advocacy and Evidence

All participants were advocates for CWF. They each described how their advocacy sought to maintain and/or reinstate CWF in their community. Each participant described the importance of evidence-based decision making to support CWF, and how they used the scientific evidence behind CWF to support their advocacy.

1. Sub-theme: Participants' Roles in CWF Advocacy

Of participants whose professional roles were to continually assess evidence of CWF's efficacy and safety, all stated that such assessment remains favorable. Such assessment is a pre-condition to their offering an evidence-based health perspective to elected officials and to enhancing public awareness of CWF's benefits. All stated that they based their recommendations on scientific evidence. Seven reported interest in increasing the body of CWF literature. Ten tried to work

Table 1. Demographic Characteristics of North American Participants in Interviews Regarding Best Practice in Defending or Reinstating Community Water Fluoridation, Conducted in the Summers of 2018 and 2019 from Calgary, Alberta

Participants	Country	Participant Role	Community Fluoridated?	Participants' Advocacy Work
Participant 1	Canada	Municipal MOH	No	Reinstating
Participant 2	Canada	Anonymous	Yes	Maintaining
Participant 3	Canada	Involved with a Provincial Public Dental Health Association	Yes	Both
Participant 4	Canada	Municipal MOH	Yes	Maintaining
Participant 5	Canada	Municipal MOH	No	Reinstating
Participant 6	Canada	Municipal MOH	Yes	Both
Participant 7	Canada	Municipal Public Health Dentist	Yes	Maintaining
Participant 8	Canada	Dental Health and Public Policy Relations Expert	Yes	Maintaining
Participant 9	USA	State Oral Health Officer	Yes	Both
Participant 10	USA	Oral Health Care Provider	Yes	Reinstating
Participant 11	Canada	Anonymous	Yes	Maintaining
Participant 12	Canada	Provincial Dental MOH	Yes	Both
Participant 13	Canada	Municipal MOH	No	Maintaining
Participant 14	USA	Public Health Nurse	Yes	Reinstating

with their local elected officials to demonstrate support from the healthcare community for fluoridation. As Participant 5 stated:

> *I think my role as an MOH, is to support, or to promote the health of the entire population and in particular to advocate on behalf of vulnerable populations and using evidence to do all of that and so I'm certainly a consultant and an expert who can be brought in to help support discussions at various levels of government on the issue and to advocate around it.*

Participant 2 discussed the role of MOHs thus:

> *Medical officers of health are independent. We're advocates. We're scientists. We're political, small "p" political, and we're advisors. We're collaborators. We're organizers. We're health promoters, and we work in an often relationally-based context to improve health. It's the reason why I show up to work every day. I just want to improve the health of the public.*

Some participants are members of associations that advocate for public health policy. They expressed interest in engaging communities and writing to local city council members to support CWF. Many participants mobilized community support for fluoridation through active lobbying groups which, for example, encouraged local political action to maintain and reinstate CWF. Participant 13, a public health officer, analyzed the data in his community to produce a report for the local council, which subsequently voted to reinstate CWF:

> *Dental health [for individuals] is covered by the employer and not the province. There are limited [government-funded] programs available depending on where you live. Our community didn't have any special programs other than the provincially funded program for children. So, we advocated [for CWF]. Our recommendation includes reintroducing community water fluoridation to protect the oral health of our community.*

Participants commonly emphasized a similarly comprehensive oral health approach. In their various local roles, some participants promoted CWF as one component of good oral health and overall wellbeing, especially for disadvantaged members of the community. Participants' roles were a major contributing factor to reinstating or maintaining fluoridation.

2. *Sub-theme: Controversy and Challenges: The Effect of Opponents' Rhetoric and Efforts to Overcome it*

All participants stated that misinformation significantly challenges CWF. They described social media's power to disseminate misinformation and to unite opponents online. Most participants reported that such opponents have diminished trust in preventive health measures such as vaccinations and CWF. Participant 5 reported seeing "a very steady decline" in communities that fluoridate because of opposition groups whose emotional arguments make CWF controversial, thereby threatening CWF maintenance in municipalities. To identify how opponents' misstatements and rhetoric might be overcome, Participant 10 stated:

> *The main challenges are combatting the misinformation […] that has enabled the fluoridation opponents to get out volumes of misinformation spontaneously all over everywhere and it's a matter of combatting that misinformation constantly and making people aware of the accurate facts and evidence that fully support [CWF] and not support the misinformation that's being put out.*

The misinformation online is largely unchallenged. According to some participants, paranoia has led to distrust towards officials and western medicine. Participants recommended that individuals with health literacy should comment online under news articles and on social media to reduce the effect of anti-fluoridation rhetoric.

Participant 5 stated that "Very well organized, opposition groups […] unfortunately have been very successful in eroding trust and in instilling unfounded fear around CWF." Participants generally agreed that the members of these groups were few but had a disproportionate effect by being vocal and provocative, eliciting media engagement. Most participants described opponent methods as "scare tactics." Participants argued that, because CWF is decided by city councilors (rather than being a health mandate such as routine childhood immunization), CWF has become a political issue. In this highly charged context, the opinion of a vocal minority can falsely appear to be a majority opinion. Nevertheless, the minority can have an effect. As participant 8 states:

> *Because it is a political issue, they [elected officials] want to get voted back in, so they're trying to keep their constituents happy. So, if there is a very vocal group that says fluoride is bad, they might want to please that group and ensure that they're voted in at the next election.*

Participants reported fear that controversy regarding CWF, and other public health measures will harm population health. Participant 1 described a lack of "community confidence" where "The less trust that exists between the populous and the government, the less likelihood that these kinds of programs will be embraced." To combat misinformation at a local level, participant 13 met city councilors in a "non-council setting" so that they could easily ask questions;

participant 13 addressed concerns about CWF and offered recommendations for public benefit. Assisted by this method, participant 13's community reinstated CWF.

3. Sub-theme: The Role of Research Evidence

Many participants reported that a misrepresentation or misuse of research evidence is a leading cause of cessation. Participant 13 stated that opposition arguments based on emotion resonate more strongly than research evidence:

> *I think that, at the end of the day, what they [elected officials] are doing, like many other people, are making a decision on what they hear on that particular day. Very few have some background in science. They may take the time to even verify some of that information but definitely the emotional side is considered more than the scientific side.*

Such arguments can dominate when there is a lack of communication from MOHs to elected officials about research evidence. Participant 2 addressed the importance of MOHs speaking with elected officials:

> *When we chat with our politicians, [...] and [there] appears to be controversy from the usual suspects of "it's a toxic substance", [then] we have to address each and every one of those [concerns] with our partners and the municipal government. We've supported our [City B] council as shareholders [in the community's discussion about CWF]. [We have a] particular role of ensuring that we address their comments, their concerns, and possibly feedback and ensure that they are adequately resourced to understand that we fluoridate because the medical officer of health in [City B] and in the province all say that it is the right thing to do for our population, and so far that's worked.*

Participants highlighted the need to use plain language to communicate the weight of research evidence supporting health initiatives to prevent CWF cessation. In Participant 12's community, and despite significant emotional and less credible vocal minority opinion, the community's decision-makers relied upon MOHs' "oral health information campaign." Similarly, Participant 7 emphasized the importance of education:

> *I think we have to engage different levels of government, different stakeholders, and we all play a role. Healthcare providers - we play a key role in educating the public and delivering evidence - evidence-based information - keeping in mind the values and preferences of the individual. We need to educate the public and they may be misinformed by those media articles so we can help to communicate more accurate information.*

Most participants described research evidence as a fundamental basis of health policy and the leading factor when advocating for initiatives such as CWF. Participants stated each jurisdiction is unique and therefore research evidence has a different weight depending on the community. As participant 2 explained:

> *I would love research evidence to play a huge role in the implementation of public policy, but it doesn't. It probably plays about 20-30% and the balance [entails ...] things pertaining to economics, ethics, legal, public opinion, social perspectives, and that's – but that's the environment that we live in [...]. Evidence is evidence and how you apply to [sic] one jurisdiction to another is difficult and is challenging so I do my best to (and I try hard at this), but I do my best not to criticize other jurisdictions because their past, their history, their story… their stories are different. Rather, how do you take learnings from one environment and apply them in another within a particular social construct?*

One participant stated she is "fairly confident" public health decisions are evidence-based. Yet she argued, "When it comes to legislative or popular opinion in government, I think evidence doesn't always … get the credit its due because it's [political] popularity and trying to win votes that drives it [policy]." Participant 10 said decision-makers should consider, "A body of literature that's developed over time that creates evidence to support policy. It's pretty rare that a single study, for example, will really have that much of an effect on policy and often it shouldn't." Most argued that valid evidence should have a larger role in decision-making than opposition claims that have no strong evidentiary basis.

Almost all participants reported that misinformation and emotional argument might be overcome by "Articulating the evidence to the public and countering the mistruths that are being told." Participants decried opponents' misleading and emotive language:

> *We're not 'mass medicating' everyone. It's a nutrient. It's a public health measure. It's maybe, even the term 'scientific research' might not align with the average member of the public. So, being mindful of the terminology that we are using, we can engage all of the different stakeholders and help them recognize that we all have a role to play in educating the public or ensuring that our policies are evidence informed, our standards and guidelines are up to date, and best practices.*

Participants reported that attempting to change the opinion of vocal opponents is probably futile; educating the community about the opinions of medical officers of health opinions would be more effective in maintaining and reinstating CWF.

In summary, the first theme is that advocacy is vital and must be based on the evidence, which strongly favours CWF. Participants, especially MOHs, acknowledged their important role in maintaining and improving health, and the need to work with and educate communities and elected officials about CWF. Participants recognized that CWF opponents are well organized and use emotional arguments – a strategy that is often more successful than presenting evidence. Participants stressed that communicating the research evidence is challenging in such an environment but essential to protect CWF as a public health measure.

B. Theme Two: Cost Effectiveness

According to participants, the evidence is overwhelming that CWF is cost-effective. CWF lowers the cost of dental care, especially for low-income families [10, 21, 23, 24]. Regarding the importance of cost-effectiveness, Participant 3 stated:

> *Probably one of the most important factors—it's not the only one—but obviously the health evidence should be our number one driver for creating public health policy. I mean, other issues need to be taken into consideration: cost utility, cost effectiveness studies [...]. If the cost of this intervention is*

> *exceedingly expensive for the benefits that you receive, then it's a fair argument to say we should spend this money doing something else that will make our population a lot healthier instead of spending it on fluoride. But, at this point in time, the evidence strongly suggests that it [CWF] is actually cost-effective.*

Participant 6 identified cost-benefit analysis of CWF as a "proactive approach" to improving the oral health of communities. Participant 5 compared CWF to vaccines, arguing that growing vaccination opposition "does not impact our provincial and health authority vaccination programs" because the programs have a strong body of literature demonstrating their cost-effectiveness and health efficacy; the same should be true with CWF. Participants stated that CWF cost-effectiveness is not sufficiently considered when elected officials consider fluoridation. As participant 12 noted:

> *CWF is one way to provide preventative measures against tooth decay and it's the most [...] cost-effective and preventative measure at the population level against tooth decay. So, more force should be put on the important decision-makers about the cost-effectiveness of CWF. However, to achieve that [...] it is necessary that the decision-makers should be well intended and benevolent, with long-term benefits in sight.*

To summarize Theme Two, participants accepted that saving tax dollars is valued by elected officials and by the general public and argued that the economic value of fluoridation is insufficiently communicated. Participants stated that the large benefits of CWF at a low cost ought to be emphasized when advancing the case for CWF.

C. Theme Three: The Respective Roles Played by Medical Officers of Health and Elected Officials in Maintaining or Reinstating CWF

Participants in the US and Canada appeared to have similar experiences with the decision-making environment in their respective communities. All participants stated that elected officials play an important role because they decide whether the evidence-based policy will be instituted in practice. However, many participants suggested that the elected officials' goals can be at odds with evidence-based health policy. According to Participant 1, "They can do whatever they feel is going to get them re-elected."

Given that opposition rhetoric can confuse elected officials about the quality of CWF evidence, we asked participants whether MOHs should have offices geographically close to elected decision-makers to facilitate the MOH addressing elected officials' concerns about fluoridation. Thirteen participants stressed the importance of MOHs and elected officials having a good working relationship. Five thought co-location is necessary, five thought it is necessary only if there is not a good working relationship and four did not think co-location is important (Table 2).

All participants stated that open lines of communication were crucial to the decision-making process in public health, especially regarding CWF. As participant 6 asserted:

> *There should be continued development of a relationship with [the MOH's] politicians because politicians change. They are elected, some are re-elected, some are not. So, you need to be able to monitor the politicians who are in a decision-making position and be able to have conversations with them on an*

Table 2. Participant views regarding co-location of MOHs and decision-makers expressed in Interviews Regarding Best Practice in Defending or Reinstating Community Water Fluoridation, Conducted in the Summers of 2018 and 2019 from Calgary, Alberta

Participants	**Does the MOH have an office near or next to the CWF decision-makers in your community?**	**Is co-location of public health officials and elected decision-makers important to maintaining or reinstating CWF?**	**Comments**
Participant 1	No	No.	Not necessarily co-location but a "closer working relationship to government."
Participant 2	No	Possibly	Not if there is an "ongoing relationship" on multiple issues.
Participant 3	Yes	Yes	A formal relationship, such as co-location, is necessary.
Participant 4	Yes	Yes	Co-location is important.
Participant 5	No	No	"I think it's actually a conflict of interest" because they represent separate entities. Recommended a relationship where the council can ask MOHs for advice when necessary.
Participant 6	Possibly	Possibly	Not needed if there is "continued development of a relationship with your politicians because politicians change."
Participant 7	Possibly	Possibly	Not if there is a working relationship.
Participant 8	No	Yes	It would lead to "a lot more collaboration."
Participant 9	Yes	Yes.	"Especially at the state level."
Participant 10	No	No	It is more important for a health department to have a close relationship with city council.
Participant 11	No	Possibly	Undecided.
Participant 12	No	No	A relationship between local and provincial MOHs and local council is important.
Participant 13	Yes	Possibly	"Just having a good relationship or an opportunity to have that discussion is good."
Participant 14	Yes	Yes	"It doesn't exist so it would for sure be helpful."

> *ongoing basis to understand their concerns and understand what their issues are and to respond appropriately and be able to give them the information they need to be appropriately informed. If being physically located helps to facilitate that, it might. But not necessarily. It depends a lot on relationship building.*

To summarize Theme Three, participants agreed public health officials should strive to build close working relationships with decision-makers; the majority (10 of 14) stated that co-location is a means to that end.

IV. DISCUSSION

Opposition to fluoridation is not new (Roemer, 1965). Indeed, conspiracy thinking that the government is "tampering with the water" (Martin, 1991) is longstanding. Yet, as participants emphasized, social media has greatly amplified opposition and wrongly encouraged elected officials to believe false claims about CWF and that CWF opponents are in the majority. Participants underscored fluoridation's importance as a health measure. They emphasized that best practice in maintaining and reinstating CWF requires using the weighted scientific body of literature to create an evidence-based policy that will best protect the oral health of populations in a cost-effective manner. Participants noted that misinformation and the misuse of research reports can have a strong effect on policy. Most participants believed that controversy arises from, "certain social networks that increase the misinformation out there about fluoride and its effects (Participant 7)." Eight participants had or were advocating to maintain or reinstate CWF in their communities. They regarded lobbying and encouraging local political action as an effective way to advance decision-making based on research evidence.

Participants stressed the importance of a comprehensive oral health approach that emphasizes the importance of CWF to help protect the populations' most vulnerable members.

Future efforts to maintain or reinstate fluoridation might be aided by these study participants' understanding of CWF opposition and by replicating their actions to overcome such opposition. Professionals supporting the maintenance and/or reinstatement of CWF must be well organized in their approach to communities and elected officials. These professionals must develop the skills to present scientific evidence in a way that is heard and leads to implementation. Participants described the effectiveness of emotional arguments in subtheme 3.1.3. Participants who had advocated to maintain or reinstate CWF explained how anti-fluoride activists' were successful in using emotive statements. 11 of 14 Participants said that emotional arguments influenced decision-makers. Participants expressed the importance of scientists and advocates mirroring emotional arguments because such arguments are powerful. Advocates can use emotional arguments, such as stories about children with systemic infection originating from dental decay. Doing so is not a betrayal of science but the essence of science. Emotional arguments act as buttresses to scientific evidence. Stories give life to statistics and are likely to ensure the maintenance and/or reinstatement of CWF.

The Cost-effectiveness of CWF is a strong advocacy point. Cost can be a central issue for elected officials who often understand cost issues better than scientific literature. It is helpful to communicate directly about cost: "for every $1 spent on oral health preventative measures, such as CWF, taxpayers can save $50 in annual treatment costs for each low-income citizen who relies on state and federal subsidies for dental care" [21]. As noted, cost savings similarly come from vaccinations, which, like CWF, have an acceptable safety profile. A 2019 Canadian Agency on Drugs and Technology Health report underscores the cost-effectiveness of CWF: "the savings from averted caries treatment generally outweigh the costs of implementing CWF". In communities without CWF, high oral care costs are borne by individuals and employers, and in some cases municipal, and provincial or state governments. By preventing dental decay by approximately 25%, CWF can save public funds. CWF fosters equity because it helps protect people unable to afford dental care. Stories of resulting suffering are emotive and can also advance the argument of cost-effectiveness.

As revealed by Theme Three, participants thought it was necessary for MOHs to have a close relationship with their local city council members to maintain or reinstate CWF because such a relationship permits MOHs to counter both emotional misstatements and research evidence misunderstandings. In the absence of a close relationship between the MOH and elected officials, co-location is necessary to foster the communication needed to maintain or reinstate CWF.

V. STUDY LIMITATIONS AND STRENGTHS

This research attempted to elicit information from key stakeholders about how to maintain and reinstate CWF in municipalities, a subject that is not well-studied. As a qualitative study based on the opinions and experiences of 14 medical officers of health and healthcare providers, its results might have limited transferability. Only people who support CWF agreed to be interviewed and, therefore, the perspectives of people who oppose fluoridation were not canvassed.

VI. CONCLUSION

The results identify the participants' views regarding best practice in maintaining and reinstating CWF. All participants lamented that a vocal minority who oppose a demonstrated public health measure can cause harm, particularly to vulnerable populations: children, seniors, and people of low socio-economic status. Participants described the central role they play in advocating for CWF in their municipalities, the challenges CWF faces because of opponents' use of social and mainstream media to make false claims and to create the impression that many people oppose CWF. Participants regard anti-fluoridation activists as a loud minority that creates controversy regarding CWF and reduces reliance on the weight of evidence when decision-makers vote to maintain or reinstate CWF. Participants emphasized the cost-effectiveness of CWF in ensuring the oral health of a municipality's citizens. Finally, participants considered the respective roles of MOHs and elected officials. To ensure that elected officials can receive information about the science easily, thirteen participants asserted a need for a close working relationship between medical officers of health and elected decision-makers. Of the ten participants who were in a political position to comment, eight said that there should be, or is, a shift from the municipal mandate on CWF to the provincial or state level. Our study suggests that people committed to advancing public health measures based on scientific evidence require the skills to defuse unscientific claims that harm the public.

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