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Nona Attaran Kakhki

Franco Carnevale

Beatriz Ferraz Dos Santos

Mary Ellen Macdonald

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THE ORAL HEALTH IMPACTS OF CANCER AND ITS TREATMENT ON CHILDREN'S WELL-BEING: A QUALITATIVE PROTOCOL

ABSTRACT

Introduction While cancer treatments clearly improve cancer outcomes, they inadvertently damage healthy tissues and organs, including causing oral and dental complications. Oral health complications can lead to cognitive, psychological, and social impairments which can have a profound impact on children's well-being. Current knowledge of these consequences comes from clinical studies focusing on caregivers' viewpoints. Though it is important to directly involve children in research to gain a firsthand understanding of their experiences. **Objectives** The aim of this study is to better understand how oral health effects of cancer and its treatment impact the well-being of children with, or who have survived, cancer from their own perspective. **Methodology** Participants will be recruited from a tertiary care pediatric hospital. We will use a participatory hermeneutic ethnographic methodology and a Childhood Ethics theoretical framework to center children's perspectives. Data will be generated through document analysis, participant observation and semi-structured interviews. We will observe discussions among children, families, and healthcare professionals, and conduct interviews with stakeholders: children (n=10-15) who are undergoing or completed treatments; parents/caregivers (n=10-15); and healthcare professionals (n=8-10). Interviews will be audio-recorded and transcribed. Analysis will use SAMSSA methods to identify key aspects of children's experiences related to their oral health and the impact it has on their well-being, as well as health and social factors that affect this experience. **Significance:** Through this study, we will gain insight into how cancer and treatment-induced oral health complications impact children's well-being, results from which will be translated into clinical and policy recommendations.

Keywords

Children; Cancer; Cancer treatment, Oral health; Well-being.

1. Introduction

Each year, approximately 400,000 children are diagnosed with cancer globally (Steliarova-Foucher et al., 2017). Acute lymphoblastic leukemia is the most common type of cancer diagnosed in children, followed by brain and other central nervous system tumors, lymphomas, soft tissue sarcomas, neuroblastoma, and kidney tumors (García et al., 2018). Whereas childhood cancer mortality used to be dire, nowadays 80% of children diagnosed with cancer can be cured with treatments such as chemotherapy, surgery, and radiotherapy (Steliarova-Foucher et al., 2017).

Notwithstanding the vast improvement in mortality rates, cancer and its treatments can leave physical and psychological impacts on cancer survivors. These effects can be especially devastating for young people, who experience high rates of radiotherapy- and chemotherapy-induced complications (García et al., 2018). Oral complications are among the most common complications occurring either due to the disease itself or as a result of cancer treatments (Noronha & Macdonald, 2016; Parra et al., 2020). These oral complications result in pain and impaired speech, altered taste perception and eating pattern, changes in smiling and personal mouth care and can have a detrimental impact on children's well-being (Francisconi et al., 2016; Noronha & Macdonald, 2016).

Well-being is a concept defined as the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfilment, and positive functioning (National Center for Chronic Disease Prevention and Health Promotion 2018).

To understand the impacts of oral complications of cancer and cancer treatments on children's well-being, it is essential to study all aspects of children's lives related to cancer and its treatment. Various methodologies have been used to approach the dimensions of well-being. In quantitative studies, for example, dimensions of well-being derived from a questionnaire have been added together to represent the well-being of the person (Bresolin et al., 2023; Fernandes et al., 2012; Okello, 2022; Wogelius et al., 2011). A critique by Bronfenbrenner and Morris suggests that there are "synergistic interdependencies" among the several relevant aspects of children's lives, and that the effects of those components cannot simply be conceived as additive (Bronfenbrenner & Morris, 1998). Qualitative research has helped to overcome such deficiencies by developing knowledge about children's social world using data from the direct experiences of children (Finch, 1988). Qualitative approaches allow participants (including children) to express the dimensions of well-being that are important to them, which, in turn, creates a more robust understanding about how children are faring (Finch, 1988).

Moreover, most research on children's well-being has primarily solicited adults' (e.g., parents, health care professionals) views on children's well-being; however, children's perspectives are not always consistent with those of adults (Ben-Arieh, 2005; Eiser & Varni, 2013; Jokovic et al., 2004). Further, children have the right to be heard regarding matters that affect them; which aligns with the growing recognition of young people as active agents (United Nations, 1989).

Soliciting these expressions can help ensure a richer understanding of their experiences and perspectives (Carnevale et al., 2021; Esser, 2016). Affording this opportunity to children with cancer requires designing research that actively elicit expressions of their perspectives and experiences. In so doing, researchers will have a fuller, clearer understanding of the impact of cancer-related oral complications on their well-being.

2. Aim

This study aims to better understand how oral complications of cancer and cancer treatments affect the well-being of children surviving cancer from a few perspectives: the children themselves, parents, and health care professionals.

3. Conceptual framework

This study will be underpinned by 'childhood ethics,' a theoretical framework developed by Carnevale and colleagues which recognizes children as active agents (Carnevale, 2020). This framework was adapted from Taylor's hermeneutic framework in which human agency can be understood through interpretation (Carnevale, 2013). Taylor argued that the use of empiricist frameworks can lead to misunderstandings of human experiences and called for a shift to an interpretive conception of human agency, personhood, and selfhood (Taylor, 1973).

Agency in children refers to their active contribution to the shaping of their social worlds and society (Esser, 2016). Seeing children as capable social actors, rather than "future adults," requires considering them as experts on their own lives (Christensen & James, 2017).

As active agents, children have an interest and capacity to participate in discussions and decisions about matters that affect them and have the right to be heard in such discussions and decisions, as specified in Article 12 of the United Nations Convention on the Rights of the Child (United Nations, 1989).

Recognizing children's agency and soliciting children's voices can help strengthen respectful attention to their experiences and concerns (McNeilly et al., 2020). However, it is important to actively listen to children using more participatory approaches, enabling children to have a voice in research related to them.

4. Methodology

4.1 Design

In this study, we will use participatory hermeneutic ethnography to explore the oral health impacts of cancer treatments on children's well-being. Participatory hermeneutic ethnography is a qualitative research methodology that brings together key elements of participatory research, hermeneutics, and ethnography (Montreuil & Carnevale, 2018). This methodology has been used to examine children's experiences in contextual aspects or backgrounds such as social relationships in which these experiences happen (Montreuil & Carnevale, 2018).

As such, children's inclusion in this project will lead to an interpretive account that informs on children's experiences in light of their own diverse perspectives, taking into account what they consider as meaningful (Montreuil & Carnevale, 2018). Soliciting children's perspectives and interpretations can ensure research can better address care provision according to children's needs and desires (Santos et al., 2020). Moreover, in this method the process of data gathering is iterative. This means the data from participant observation informs the content of the interviews, and data from the interviews, in turn, informs the participant observation (Montreuil & Carnevale, 2018).

4.2 Setting

This study involves two settings. The first is a university-based tertiary care pediatric hospital in a large Canadian city. This hospital has a Division of Pediatric Hematology-Oncology and a Division of Dentistry. The latter is a referral centre for the recently implemented provincial program 'Programme de soins buccodentaires en oncologie pédiatrique' (PSBOP) (English: Paediatric Oncology Oral Care Program). The PSBOP recognizes the challenging oral health problems secondary to childhood cancer therapy by providing tailored oral health services that are not covered by the provincial dental program. This program is intended for Quebec children, under the age of 18, who are undergoing or who have completed cancer treatments. The second setting is the children's homes, where we will interview and observe children and their families in their daily routines.

4.3 Participant selection and recruitment

This study will involve the participation of multiple actors as research partners. We aim to recruit 10-15 children who experienced cancer treatment, as well as one accompanying parent/caregiver, along with 10 health care professionals (e.g., physicians, nurses, dentists). Involving families and health care professionals as part of children's social environment in the research process can further inform our understanding about the contexts and the circumstances that affect children's well-being.

Eligible participants are considered as follow: (i) children who are receiving dental care under the PSBOP program; (ii) parents of these children; (iii) health care professionals working at the hospital who are involved in the care of children surviving cancer.

Child participants will be recruited using purposive sampling (Morse, 1991): we will seek a variety of ages, genders, social characteristics, cancer types, and oral effects, to help ensure data about a wide diversity of experiences. In the analysis we will query if and how the purposeful variables impact children's wellbeing.

With the help of the hospital support staff, parents will be contacted and introduced to the study. After their expression of interest, a study team member will contact those parents to describe the study for them. In addition, we will place posters in the waiting area of both the Division of Dentistry and the Division of Pediatric Hematology-Oncology. Age-adapted information will be provided to potential participants and their families to facilitate their decision regarding participation. Upon acceptance, child and parents will sign an informed consent form and will be invited to participate in an interview. Recruitment of health care professionals will occur simultaneously with the recruitment of children and parents. We will invite health care providers working with children with cancer to participate in this study. Those interested, will be invited to participate in an interview after the informed consent process.

4.3.1 Advisory committee

Following a participatory approach, three advisory committees will be formed by the research team: a children's advisory committee (3-5 children); a parents' advisory committee (2 parents); and a health care professionals' advisory committee (2 health care professionals). These members will be recruited from the participants who consent to be part of the committee.

The advisory committees will advise the researcher on different parts of the project, including study design, implementation, interpretation, and knowledge utilization strategies. Besides, they will help in creating and ascertaining the feasibility of ethical care and support strategies for children surviving cancer throughout the study.

We anticipate three advisory committee meetings for each group. The first, towards the beginning of the project will request participants' feedback regarding the research tools, such as the interview guide and plans for data generation. The second meeting will focus on the project's progression, during which we will solicit feedback regarding the project's progress, including any challenges with recruitment and data generation. The final meeting will be after the data has been generated; in this meeting, the preliminary analysis will be presented to get feedback related to our findings.

4.4 Data generation

We will use a multi-method data generation approach including participant observation, semi-structured interviews, and document reviews. Doing so, it will help ensure rich and diverse data, allowing for an in-depth examination of how oral effects of cancer and its treatments affect the well-being of children surviving cancer.

Participant observation will be conducted over six months at the hospital and, where permission is granted, from the families, in their homes.

During these field observations, we will listen to informal discussions among children, families, and health care professionals, especially discussions (or lack thereof) about the child's well-being. We will observe each child participant at least in three different appointments to help ensure the richness of observations.

Field notes will be written at the end of each participant observation session, noting data from observations and informal interviews, along with reflections relating to the data. The focus of the participant observation will be oriented by an observation guide to ensure that we explore aspects of the children's experiences that relate to the research question. (Table 1)

Conducting in-depth, open-ended, semi-structured interviews with children who are undergoing or have completed cancer treatments, their parents, and health care professionals represents the next data-gathering method.

We will schedule an interview (30-45 minutes) for each participant. They will be asked open-ended questions about the impacts of cancer-related oral complications on children's well-being. The interview guide will be used as a tool to guide what aspects are necessary to be discussed to answer the research question. (Table 2-3- 4)

Questions will be adapted for each child, depending on their capacity and communication skills. The time, format (in-person or virtually), and place of the interviews (e.g., hospital, home) with children and their families will be set according to the families' preferences.

The interviews with the health care professionals will also be scheduled based on their preferences.

Finally, documentation review will be used to complement the data (e.g., charts, policies, procedures, unit rules, and clinical tools).

This data will help us understand the institutional norms, structures, and practices in the setting, and can be used as a prompt to discuss how does the explicit norms, rules, and procedures in place mean to people in the setting.

Table 1. Observation guide

Setting
What is the general atmosphere at the hospital/dental division/home?
How is the physical environment structured/experienced at the child's home, hospital/dental division (e.g., room layout, cleanliness)?
What are the explicit and implicit norms, rules, and routines related to dental treatment of the child (e.g., waiting hour, consent, type of treatment given)?
What are the explicit and implicit norms, rules, and routines related to the child admitted at the hospital (e.g., how they eat, sleep)?
What are the explicit and implicit norms, rules, and routines related to the child's life at home (e.g., eating, sleeping)?
How does the child feel at different settings (hospital/dental division/home)?
People
Who is involved in the care of children surviving cancer at the hospital/dental division/home? (e.g., families, nurses, doctors, dentists)
What are the interactions between people involved in the care of the child at the hospital/dental division/home (e.g., nature of interactions, reasons they occur, emotions expressed)?
Time
What are the routines of the children and their families during the day? Do these routines change over time?
How do the children and their families seem (e.g., rushed, stressed, calm), as they move through their day?
How do different cancer treatment protocols vary through time (day/week/month)?

Table 2. Interview guide for children

For children with advanced communication skills
1. How do you feel when you think about your life?
a. Prompts: Good? Bad? Happy? Unhappy?
why/ why not?
2. How do you feel about your mouth and teeth (e.g., happy, sad, pain, anxious, depressed, anxious, worried, distressed)
3. What do you think causes problems in your mouth and teeth?
4. What makes you feel better or worse about your mouth and teeth?
5. Do you brush your teeth every day? How do you feel when brushing?
6. How does food taste to you? (e.g., more sweet, bitter, sore...)
7. How do you feel when eating? Do you enjoy eating?
8. How do you feel when talking with your friends? Do you enjoy talking?
9. How do you feel when sleeping? Do you like sleeping?
10. What do you want to do when you grow up? How do you think your mouth and teeth will help or hurt you in achieving this dream?
11. When do you feel bad or good with your mouth and teeth?
12. Does your mouth and teeth make your life hard?
13. When your mouth and teeth feel bad, what do you do to make it better?
For children with less-developed communication skills
1. What makes you happy at home/school? What makes you unhappy at home/school?
2. How many teeth do you have? Do you like your teeth/mouth? What is special about your teeth? Is there anything you don't like your teeth?
3. Would you like to change your teeth/mouth (with magic/a fairy)? What would you like to change about your teeth/mouth?
4. Do you brush your teeth every day? Do you like brushing? (if yes) why do you like brushing? (if no) why don't you like brushing?
5. Does your mouth ever hurt? Where does it hurt more? Does it always hurt, or does it hurt sometimes? What about when you eat/speak/sleep? What does mommy/daddy do when it hurts? Do they give you syrup?
6. Do you like chocolates? Do you like to eat chocolates? Is it sweet? Do you like sour gummies? Do you like to eat sour gummies? Isn't it too sour?
7. Do you like to share your chocolates and sour gummies with your friends? Do they like them? Have you asked them? Do you speak with your friends at school? Do like to invite your friends to your home? Will you speak and play with them? (if yes) what do you like to talk with them about? (if no) why don't you like to invite them?
8. Do you like your bed? Do you sleep on your bed? Is it comfortable? Do you like sleeping on it?
9. What do you want to become when you grow up? Do you think a (police officer /singer/pilot...) teeth are like yours? (if yes) Do they smile like you? Do they speak like you? Do they eat like you? (if no) what can we do for that? Do you want to change your teeth/mouth?
10. Can you tell me a real story that happened about your teeth and mouth?

Table 3. Interview guide for parents

1.	How does your child feel about their oral condition?
2.	How much do you think your child is satisfied with their oral condition?
3.	How do you describe the oral complications of your child in the last year/month/week?
4.	Can you please tell me more about your experience with your child's oral health?
5.	How do you help your child with their oral conditions? What are the challenges you face?
6.	Can you tell me about a recent event that stands out for you as being particularly difficult or hopeful regarding the oral complications that your child has?
7.	How does your child cope with these difficult situations?
8.	How do you think your child's oral condition influences her/his social interactions?
9.	How do you think your child's oral condition affects their well-being?

Table 4. Interview guide for health care professionals

1.	How might children surviving cancer receive care differently than other children at the hospital? (e.g., extra sanitary measures, psychological assistance, collaboration with other departments)
2.	How do you describe the oral complications of [specific child] in the last year/month/week?
3.	Can you please tell me more about your experience with this child's oral health?
4.	Can you tell me about a recent event that stands out for you as being particularly difficult or hopeful regarding the oral complications that a child surviving cancer has?
5.	How do you think the oral condition of children surviving cancer influences their well-being?
6.	How do children surviving cancer experience oral complications related to their cancer?
7.	How do children surviving cancer cope with these complications?
8.	How do children surviving cancer feel about their oral health condition?
9.	Are analgesics usually prescribed for the oral conditions of children surviving cancer? If not, when are they prescribed? Are they effective?
10.	What else is used to treat their complications? (list each complications) How successful are these treatments (for each complication)

4.5 Data analysing and interpretation

Data analysis will be conducted iteratively throughout the data generation phase. Data will be analysed continuously, comparing old to new data in a progressive and ongoing manner. Data produced from each interaction will be used to reform and design the questions in subsequent interactions.

We will use SAMMSA as a method for analysing the data (Macdonald et al., 2023). SAMMSA is a 5-step-by-step analytic method committed to both clarity of process and rich 'quality' qualitative analysis (Figure 1). (Macdonald et al., 2023). SAMMSA For the first step, in each interview and fieldnote, relevant text segments will be highlighted and summarized with a 'synthesis code' (S) and then interpreted with an 'analysis code' (A). The S/A codes will be grouped into micro-themes through an inductive process according to common content. Micro-themes will then be grouped into meso-themes based on similarities. All sets of meso-themes will be comparatively analysed to identify common themes across participants. The next step will be the narrative synthesis of data units.

Cross-synthesis analysis and interpretation is the final step. In this step, the primary researcher will compare all narrative syntheses to generate transversal themes and recognize and reveal any uniqueness or discord in data. The SAMMSA process has theoretical roots in hermeneutics and methodological roots in ethnography. It is attentive to data holism and tries to avoid the data fragmentation that can occur in some versions of thematic analysis. It moves from coding through to synthesis and interpretation of the whole of the data (field notes, interview transcripts and key documents). In this method of data analysis, the main researcher leads all coding with frequent meetings with their supervisory team.

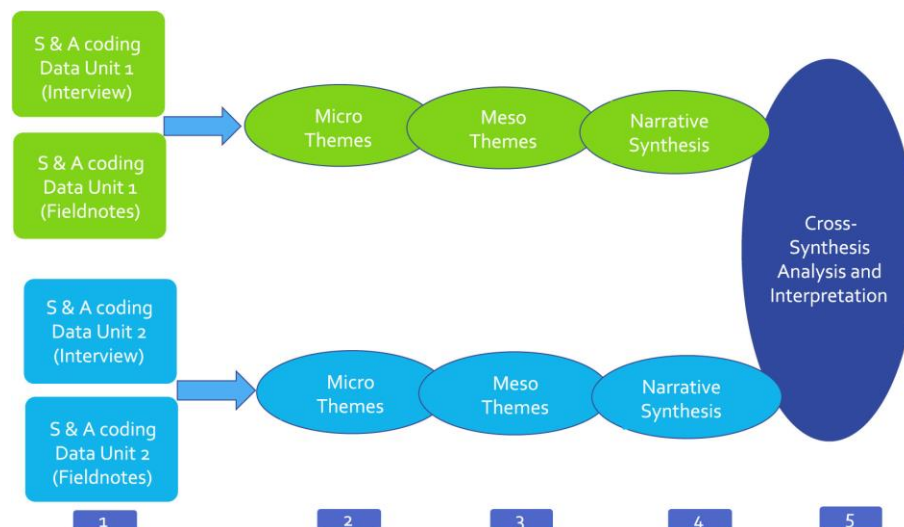


Figure 1: SAMMSA 5-step process (Macdonald et al., 2023)

Throughout data analysis, the perspectives of children regarding the oral effects of their illness and relevant treatments and the impact on their well-being will be prioritized. Perspectives of parents, and health care professionals will further contribute to an understanding of how children experience oral complications from cancer treatment and will provide supplementary information about the children's worlds and how they interpret their well-being.

To ensure methodological rigor and trustworthiness, several strategies will be employed as follows: The researchers will ensure reflexivity by conducting a thorough self-analysis and confronting any influence that may affect data collection or analysis.

Member checking with participants (children, parents and HCP) and committee advisors throughout the data collection and analysis process will ensure the dependability and credibility of the study.

Moreover, we will apply debriefing throughout the research process with expert reviewers and advisory committees to ensure trustworthiness of the study. All of these activities will encourage critical thinking and enhance the credibility of interpretations.

5. Ethics

Ethical approval has been obtained from the Review Ethics Board of the McGill University Health Centre (#2024-10107). Participants who agree to participate will be informed about the purpose and the procedures of the study and their right to withdraw at any time without consequences for their healthcare received.

Children aged 14 and older, parents and health care professionals will be required to provide written informed consent according to the province of Quebec regulations. For children under 14 years, in addition to seeking their verbal assent showing their willingness to be part of this research, their parents/caregivers must provide written informed consent. This informed consent and assent will be continuously reaffirmed from participants throughout the study to ensure participants confidence to withdraw in any stage of the study. Given the challenges these families face in their everyday lives, families who feel uncomfortable at any time during the research project will have the right to withdraw their consent whenever they wish to.

Undoubtedly, parents and children facing life-threatening conditions like cancer, experience a significant physical and psychosocial burden that becomes more pronounced if the child's condition worsens. Despite the context of these complex conditions, obtaining children's and parents' distinctive experiences and perspectives through participatory research will provide unique insights, contextual information, and valuable answers to scientific and clinical inquiries. Therefore, it is important to recognize the complexities, challenges, and immense rewards inherent in children's participation (Collins et al., 2020), and create a supportive and inclusive environment where children and their parents feel comfortable and respected.

The confidentiality and privacy of each participant will be respected. Identification codes will be assigned to all participants. All data containing identifying information (audio recordings, interview transcripts, and field notes) will be securely stored by the researcher in a password-protected locked file within the research institution and will be destroyed 7 years after publication. Only de-identified data will be shared among the advisory committee and other study partners. These confidentiality protection measures will be described in the consent form.

6. Limitations and Mitigation Strategies

One of the potential limitations of this study is related to recruitment and participation. Children with cancer and their families undergo difficult and intense emotional and physical periods that can influence their participation in any study, even in interviews. Therefore, families' potential unwillingness to participate is a limitation for this study. In this situation, giving accurate and useful information about the aims and steps of the study can expand the children's and their families' knowledge about the study and its risks and benefits, which may increase their trust towards the research and the researcher and their willingness to participate.

Additionally, despite the lifting of nearly all of Quebec's restrictions, the ongoing COVID-19 pandemic may be a limitation in this study. Knowing that children with cancer are more susceptible to infections, parents might be hesitant to expose their children to close, face-to-face interviews and observation encounters with the research team. This reluctance might result in increasing the length of the data-generation period and some data-generation techniques may also need to be modified.

7. Significance

This study offers important insights into the experiences of children surviving cancer. Further, it contributes to the broader field of qualitative research by demonstrating the value of participatory hermeneutic methodology for the first time in this patient population. This approach allows for a deep engagement with the participants' experiences, giving voice to their unique perspectives. By employing SAMMSA for data analysis, this study also introduces an innovative method for understanding the experiences of this population, advancing qualitative research methodologies in the field of pediatric oncology.

These contributions underscore the relevance of qualitative research in capturing the subjective experiences of social actors, which are often overlooked in quantitative approaches. We expect this exploratory project will uncover important experiences regarding the oral health effects of cancer treatments on the daily lives of children who survive cancer. For example, we anticipate that personal and social characteristics (e.g., age, social support, self-esteem) may mitigate effects of treatment on well-being. We expect that health care professionals' engagement in the design of the project and their interest in the results will provide important opportunities for clinical reflection regarding the oral effects of cancer treatments on children. It will also uncover important experiences that were not explored in past research on the oral health impacts of cancer and cancer treatment on children's well-being.

This may enable the development of innovative new policies and services in relation to children's care after and before cancer therapy. Centring children's perspectives and experiences will give us insight into how they perceive the oral effects of cancer and its treatments and how caregivers can best ensure quality care during and after these treatments. These compelling insights can potentially translate into significant implications for policy and practice among stakeholders who support children experiencing cancer.

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Nona Attaran Kakhki

Faculty of Dental Medicine and Oral Health Sciences, McGill University Montreal, QC, Canada

 <https://orcid.org/0000-0002-5875-3131>

✉ nona.attarankakhki@mail.mcgill.ca

Franco Carnevale

Ingram School of Nursing, McGill University, Montreal, QC, Canada

 <https://orcid.org/0000-0001-7255-9979>

✉ franco.carnevale@mcgill.ca

Beatriz Ferraz Dos Santos

Faculty of Dental Medicine and Oral Health Sciences, McGill University Montreal, QC, Canada

 <https://orcid.org/0000-0001-6469-9963>

✉ beatriz.ferrazdossantos@mcgill.ca

Mary Ellen Macdonald

Faculty of Medicine, Dalhousie University, Halifax, NS, Canada

 <https://orcid.org/0000-0002-0581-827X>

✉ maryellenmacdonald@dal.ca