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# "I'm not your reality show:" Perspectives of bereaved mothers' engagement with the news media to advance drug policy reform



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#### ABSTRACT

North America's overdose crisis is one of the most urgent public health issues of our time and parents bereaved from substance use are a prominent voice within the news media. To date, however, the experiences of bereaved mothers who have shared their stories with the media has not been well-documented, leaving a significant gap in our understanding of their political advocacy efforts.

In 2017, we conducted qualitative interviews with 43 mothers across Canada who participated in drug policy advocacy following the substance-related death of their child. We used a narrative interview approach and thematic analysis to distill key themes in recounting bereaved mothers' stories of engaging with reporters, their perspectives on media representation and the personal impacts of sharing their stories with news media.

Participants viewed the news media as powerful allies in educating the public, changing attitudes, and ultimately influencing policy in support of people who use substances. However, there was a personal cost that accompanied this media advocacy which included the potential for sensationalism, news media complacency, insensitive comments by journalists, and having one's story misrepresented.

Our study highlights the complex relationship between mothers bereaved by substance use and the news media who hold tremendous power in framing their stories. By examining bereaved mothers as social movement actors and reflecting on the structural context in which news stories are delivered, we outline strategies to ensure parents bereaved by substance use can safely share their stories with media and continue their work in countering stigma and misinformation.

#### 1. Introduction

North America continues to experience a crisis in overdose deaths largely driven by an increasingly toxic and unregulated drug supply centered around illicitly-produced fentanyl and its analogues (Centers for Disease Control and Prevention, 2020; Public Health Agency of Canada, March 2021). This mortality has worsened during the COVID-19 pandemic, likely due to disruptions in the illegal drug market leading to more unpredictable and toxic drugs, elevated levels of stress and isolation, and service restrictions for people who use substances (Canadian Community Epidemiology Network on Drug Use, 2020; Public Health Agency of Canada, March 2021). Families, in particular mothers, who have lost a loved one to substance use, have been vocal supporters of

expanded access to substance use treatment, harm reduction interventions and other drug policy reforms in response to this crisis. In Canada, two grassroots, volunteer organizations have been particularly active: Moms United and Mandated to Saving the Lives of Drug Users (mumsDU) and Moms Stop the Harm (MSTH). Both organizations bring a family perspective to Canada's drug policy landscape by advocating for a public health approach to substance use, inclusive of harm reduction philosophy and interventions. Harm reduction is an approach to psychoactive substance use that aims to reduce morbidity and mortality by non-judgmental and compassionate care for people who use drugs, irrespective of whether they wish to reduce or abstain from using substances (Kerr & Ti, 2013). Some examples of harm reduction practices include community distribution of naloxone kits, the provision of sterile

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injecting equipment, drug checking services and supervised consumption services. Harm reduction policymaking is often politically contentious and resistant to rational decision-making that accounts for scientific and economic evidence of the effectiveness of this approach (Zampini, 2018; Hyshka et al., 2013). As such, it provides a quintessential example of a 'morality policy', in which actors frame issues and develop policies based upon strongly held beliefs and principles about what is morally 'right or wrong' (Euchner et al., 2013; Knill, 2013; Permoser, 2019). Thus, because substance use disorder is often seen as a personal moral failing, research supporting harm reduction approaches (Irvine et al., 2019; Kennedy et al., 2017; Kennedy et al., 2019; Potier et al., 2014) is often dismissed by those who disregard the science, which in turn, threatens harm reduction efforts in many parts of the U.S. and Canada.

In our previous analyses with bereaved mothers we have found that the overarching goal of their advocacy was to save lives (i.e. preventing overdose and drug-related deaths), in addition to enhancing kindness, empathy, understanding and support for people who use substances (Moms Stop the Harm, 2021). While members of these two organizations draw from multiple advocacy strategies, their use of media advocacy has played a central role in their attempts to influence decision makers and achieve policy change. Such media advocacy comes at a critical time, as substance use and substance use disorders have the potential to be framed by the news media in ways that stigmatize and dehumanize people who use substances and their loved ones. For example, past media portrayals have emphasized the criminality of illegal drug use and characterized addiction as a personal choice or moral weakness, othering people who use substances, and suggesting they are deserving of any harm that befalls them (Kennedy & Valleriani, 2017; Kennedy-Hendricks et al., 2019; McGinty et al., 2016, 2019). Yet recent evidence suggests that media messaging that includes factual information about substance use paired with a sympathetic narrative from a bereaved mother, can have a positive impact on public support for drug policy reform, including harm reduction policies (Bachhuber et al., 2015; Sumnall et al., 2020). Indeed, both public support (Burstein, 2003) and the media (Bou-Karroum et al., 2017) have a strong influence on health policy.

The members of MSTH and mumsDU exemplify social movement actors, or advocates who strive to challenge existing frames of injustice that directly impact health and justice systems (Benford & Snow, 2000). The news media is an important tool used by advocates because it can "... legitimate movement issues, provide social movements an opportunity to shape public understandings of political problems, and mobilize a broader public to action" (Rohlinger & Vaccaro, 2013, p. 1). Social movements frequently utilize members' stories, shared through the media, to change opinions and garner broader support for a cause. The use of 'authentic voices', or people who can share their lived experiences (Dorfman & Krasnow, 2014; Jernigan & Wright, 1996; Wallack & Dorfman, 1996) is central to media advocacy. However, it also runs the risk of exploiting the individuals who advocates are trying to support (Jernigan & Wright, 1996), especially when the news story focuses more on an emotional 'victim' narrative and less on policy solutions (Clark, 2017; Wallack & Dorfman, 1996).

As social movement actors using personal stories to challenge existing public perceptions and policy perspectives, bereaved mothers have worked tirelessly to uphold the health and human rights of people who use drugs. Surprisingly, there have been limited empirical studies on the experience of mothers engaging with the media while advocating for changes in health policy in mental health and substance use reform (Evans & McGahan, 1998; Hoagwood et al., 2018; Milliken, 2001; Olin et al., 2010). While a few studies have explored the grief experiences of parents who have lost a child to substance use (Feigelman et al., 2020; Nowak, 2015; Templeton et al., 2016; Titlestad et al., 2019), specific consideration of how media is leveraged to change drug policy is lacking. The advocacy undertaken by MSTH and mumsDU is perhaps most comparable to that of Mothers Against Drunk Driving (MADD). While both types of grassroots organizations were started by bereaved mothers and pertain to substance use, members of MADD are advocating for

people who have been, or could be, harmed by others' substance use. In contrast, mothers who are members of MSTH and mumsDU advocate for people who use substances, and may face shame and stigma that sometimes accompanies the death of a child from substance use. Despite the existence of several studies showing the efficacy of MADD's advocacy (Asbridge et al., 2004; Fell & Voas, 2006), research has not specifically examined how these mothers engage with the media to advance their policy platforms. Thus, despite many instances where they have shared their personal stories with the news media to advance their policy platforms and shift stigma about substance use, accounts of how bereaved mothers engage in media advocacy have been absent from the Canadian research literature. In contributing to addressing this gap, our manuscript centers the research question: How do mothers who have lost a child to substance use view their experience of media advocacy to advance harm reduction and other drug policy reform?

#### 2. Materials and methods

#### 2.1. Study design & partnerships

Our analysis draws from a broader community-engaged, qualitative research study designed to collect and analyze stories from Canadian mothers whose children had died from substance use and who engaged in advocacy for drug policy reform. Further details can be found at Jenkins et al., 2021. We drew from narrative approaches to qualitative research to examine both the content and structure of mother's stories (Wells, 2011) while considering social and cultural context (Patton, 2015). In our study a substance-related death was defined broadly as any death associated with the use of substances (e.g. drug poisoning or overdose; substance-related suicide; physical illnesses due to substance use). Our team consisted of a group of university researchers working in collaboration with three community partners representing Moms Stop the Harm, mumsDU and The Voice of the Family (the latter being an advocacy organization whose leadership has since stepped away from advocacy work). All team members played a central role in establishing the study design and developing the background questionnaire/interview guide, and supporting data collection. Our study protocol was approved by the human research ethics boards at the University of Alberta, the University of Calgary and the University of British Columbia.

#### 2.2. Recruitment & data collection procedures

Mothers were recruited with the assistance of our community partners who reached out to their membership and advocacy networks via social media, word of mouth and email. Mothers were eligible to participate if they lived in Canada, spoke English and had first experienced the loss of a child to substance use at least 6 months prior to data collection. Potential participants informed the community partners and were then contacted by the researchers on the team to arrange an interview, which lasted between 26 and 135 min following informed consent. Interviews using a narrative approach were audio recorded and subsequently transcribed and the majority of interviews (36/43) occurred in-person (remainder conducted via phone). Participants were offered a \$50 gift card in recognition of their time, and each participant was offered a copy of their transcript to review for accuracy. While we did not have a formal approach to achieving saturation, we aimed to recruit a broad sample from across Canada. In this context, we continued to work with the two organizations until no new participants came forward. There were diverse family experiences, but we heard similar/ shared themes from women about what it means to advocate for drug policy reform after losing a child to overdose or other substance-related causes. Questions posed to study participants were wide ranging and designed to elicit views on drug policy advocacy. Questions pertained to the purpose of their advocacy, activities/actions undertaken, media, advocacy messages, facilitators and barriers, motivating factors, perceived impact and the role of motherhood in advocating for drug policy reform. It is participants' responses to the broad code entitled 'media' that we present here.

#### 2.3. Data analysis

Thematic analysis was undertaken as described by Braun and Clarke (2006), using NVIVO 12 for data management. Transcripts were initially read by HM who developed an initial list of codes using both an inductive and deductive approach. A proportion of transcripts (10%) were co-coded with R H-S (study lead) and discrepancies were subsequently resolved by way of consensus (Morse, 1997; Patton, 2015). HM read through the data coded as 'Media' multiple times while simultaneously taking memos and coding relevant words, phrases and concepts together under various categories and subcategories. Relationships between coded excerpts and their categories were identified and refined prior to grouping categories under larger themes. Finally, coded material, both 'within' and 'across' these larger themes were reviewed and revised in generating a 'thematic map' (Braun & Clarke, 2006). Careful consideration was taken to achieve methodological and analytic rigor. These steps included ensuring prolonged engagement and eliciting thick descriptions by study participants; frequent meetings between the research team to discuss emerging findings; attending to negative analysis; ensuring data saturation; using an audit trail; and being reflexive in our analysis (Cohen & Crabtree, 2006; Forero et al., 2018; Lincoln & Guba, 1985; Morse, 2015; Richards & Morse, 2013). To protect anonymity, pseudonyms are utilized and details that may potentially identify participants have been changed. While the mothers in our study spoke of many elements of their experience with media advocacy, particularly salient in this analysis were the themes of news media as allies for advocacy, contrasted with the challenges and personal 'costs' of this engagement.

#### 3. Results

#### 3.1. Participant characteristics

A total of 43 interviews were conducted between June and November 2017. Mothers were recruited from the provinces of Ontario, British Columbia, Alberta, Manitoba, Saskatchewan and one Maritime province. The majority were married and half of those reporting their age stated they were between 55 and 64. Most had a household income greater than \$50,000 and identified as 'white' or Caucasian. Most had children who were male and in their 20s at the time of their death. In the majority of cases, mothers expressed that their child's death was a result of drug poisoning ('overdose' or 'tainted drugs') and over half of the mothers had participated in a media interview for advocacy purposes (See Table 1).

#### 3.2. News media as allies

The mothers we interviewed highlighted the critical role that the media has had in their advocacy, with many referring to the media as one of their most important allies. Forging positive relationships with members of the news media, who were seen as helping to educate the public, to change attitudes, and ultimately to influence policy, was recognized as essential to successful advocacy. Furthermore, there was wide recognition that it would be incredibly difficult to disseminate messages without media support. Evelyn articulated the important role of the media when she stated, "I've used them as an ally, and to help press for change," while Freya commented, "... it is important that they are on our team and that they don't become jaded." Hope pointed to specific reporters she had worked with in the past, stating, "there are some people in the media who've just been amazing in their support. They tell our stories over and over, and give us a voice ...", later adding, "they believe in what we do, and they do an important job informing the public." Likewise, Olivia reflected on the role of the news media in shaping and driving culture when stating, "... they have the power to change ... public opinion, to change the language, to reduce stigma through their lens of ... what

**Table 1** Participant characteristics<sup>a</sup>.

Participant characteristics <sup>a</sup> .	
Age	
35–44	2
45–54	8
55–64	16
65+	6
Missing	11
Regional Representation	
Ontario and Maritimes	10
Alberta	12
Other Prairie provinces	4
British Columbia	17
Household Income	-,
Less than \$10,000	1
\$10,000 – \$50,000	11
\$50,000 - \$100,000	14
\$100,000+	16
Missing	1
Ethnicity	-
White	41
Multiple Ancestries	1
Missing	1
Marital Status	_
Married	22
Separated/Divorced	10
Common-Law	3
More than 1 answer provided	4
Single	3
Widowed	1
Time Spent in Advocacy	_
2+ years	13
6–11 months	11
1–2 years	11
Unclear	8
Gender of Child	
Male	35
Female	10
Age of Child at Death/Passing	
17–19	4
20–24	14
25–29	15
30–39	9
40+	3
Year of Child's Death/Passing	
Before 2012	3
2012	4
2013	3
2014	7
2015	5
2016	17
2017	5
Unclear	1
Was passing/death a result of drug poisoning? <sup>b</sup>	
Yes	39
No	3
Unknown	3
What substance(s) caused the passing/death?	
Fentanyl	20
Carfentanil	1
Polysubstance	14
Other opioid (e.g. hydromorphone, morphine, heroin)	3
Methadone	2
Unknown	3
Other (suicide or N/A)	2
<sup>a</sup> N = 42. Total number of children = 45 as two participants had 2 children	

 $<sup>^{\</sup>rm a}$  N = 43; Total number of children = 45 as two participants had 2 children whose death was attributable to substance use.

happens," adding, "... they would be the  $\underline{most}$  powerful ally in making a difference and in educating."

#### 3.2.1. Rationale for engaging with the news media

Mothers reflected on the reasons why it is important to engage with the news media, with many discussing the media's role in educating the public about such polarizing topics as harm reduction, the toxic illegal

b May be called 'overdose' or 'tainted drugs' by some.

drug supply, community substance use resources, and the family experience of supporting people who use drugs. Alison explained that "... I think we have a role as the Moms to educate the media, and then they in turn have a responsibility to relay the proper messaging to the public." Evelyn chose to use the media extensively in her work, believing, "what's going to make the change is by going to the media, showing the public what is going on, what's not being done and what needs to happen ..." Similarly, Hope expressed the role that media plays in amplifying mothers' voices:

It's incredibly important because it's our way to get our story out. We don't have any advertising budget. You know, I can't drop a few million for TV ads, but if the CBC [Canadian Broadcasting Corporation] or Global [national news network] will give me a few seconds at six o'clock in the evening, that's worth a big chunk of change that I don't have to pay for ... so the media has been huge in terms of ... giving us a voice ... uncovering facts ... reporting the numbers ... and sharing individual stories over and over.

Mothers described additional reasons for engaging with the media, one of which was to decrease stigma by opening space for conversations about substance use. Many of the mothers we interviewed felt that the media played an important role in challenging societal assumptions that substance use only affects those living in marginalized communities or that parents are to blame for their child's death. Several mothers spoke of how their own stigmatized views had evolved since the death of their child, and how the media had a role in supporting such changes:

I remember the week before [Daughter] died that there had been some overdoses down at Tent City [homeless encampment], and I remember thinking, like, 'Oh, thank God, that's not in my world' .... And yet, it was. And so, I think maybe the media has had to try and reach people that are resistant to even relating to a story like that ... (Norma)

Mothers also acknowledged that a key reason for engaging with the media was to contribute to framing the story, rather than solely relying on reporters or officials to do this on their behalf. This allowed for greater control in sharing the message they wanted to convey. In reflecting on advocacy and the circumstances that surrounded the death of her son, Alison commented that it was important for her to speak out "... so that you don't leave the story to the media. You're framing that story yourself. You're shaping that story." Finally, many mothers believed that media engagement held the potential to influence political views. Sophie illustrated this when she spoke of writing letters to various politicians but that ultimately, "... it really wasn't until I went to the media that ... I got the health minister to sit down with me because he knew he was going to meet me at a press [conference]." Evelyn articulated this when she spoke of her frustration with the lack of funding from provincial and federal government in responding to the overdose epidemic:

I'll be the first one to shame them [politicians] in the news, but I'll be the first one to give accolades where accolades are due. So it's holding them accountable, and unfortunately, that is the only way to get government to move. So I've learned that the hard way, and I have the media partners, I have the media presence. Our family, unfortunately, has become the face of fentanyl, and so we will use that to move forward and try as best as we can to get things moving quickly enough, because people are dying every single day.

A number of those we interviewed recognized that part of why their message may resonate with elected officials was that they shared many of the same social and demographic characteristics as those in power. Sydney stated that it was a newspaper story that portrayed her son as a "... boy that had opportunities [and] had family that cared about him" that captured everyone's attention at City Council, adding, "... it could have been any one of those council members" [that lost a child to substance use.]. This sentiment illustrates not only how bereaved mothers

were aware of media dynamics but also how they must make strategic use of this narrative to achieve their advocacy aims.

#### 3.3. The challenges and personal 'costs' of engaging with news media

Despite highlighting the benefits of using news media to share their family story and advocacy messages, mothers also spoke at length about the challenges that are inherent in doing so. Many had encountered a sensationalist approach to media reporting, either personally or when viewing stories featuring other parent advocates or people who use substances in the media. As such, some were hesitant to engage with the media for fear that their own story might be taken out of context, that it might focus on graphic or shocking details, or center on the 'drama' or 'heartbreak' of the death, rather than on the need for specific policy changes. Alison shared this view when she stated, "... they're looking for the sound bite. They're looking for the thing that's going to catch people's attention. Sometimes we wish that they would focus less on the personal story and more on the messaging." This focus on the 'sad story', while minimizing discussion of policy changes, had the potential to create additional damage in stigmatizing people who use substances and their families. Edith, whose son struggled with a chronic and debilitating mental illness for much of his adult life expressed her concerns that such media coverage simply 'added fuel to the fire':

And so when I see media like that, I think it's just crap, and I don't see how it could have a positive impact. I think it further substantiates the public's impressions, which is, 'these are people that use drugs by choice. They should just stop'.

Some mothers described that they felt pressured to show emotion, as was the case with Fiona who stated, "I know they want you to cry. I'm past crying ... that's not who I'm portraying anymore." Mandy also felt the need to express to a journalist that she did not want to be made to cry on camera, stating "I'm not your reality show. I'm here because ... I want to give you facts and information [about] how you can save your child."

Participants recounted their tremendous disappointment when stigmatizing language or images appeared in the news. There was the widespread perspective that photos of people injecting drugs on the street or terms such as 'junkies' or 'drug addicts' were deeply harmful. Some mothers took it upon themselves to try and educate journalists to end the use of such language in their reporting but felt that their concerns were dismissed. For example, when she made a complaint to a news organization about stigmatizing terms, Alison expressed that the responses were pithy, such as, "'Oh we didn't know', or, 'Sorry, we forgot,' or, 'Our copy editor created the headline'". Several mothers felt that the public attention that accompanied their story was positive, but at the same time, it came with downsides. Melanie, for instance, expressed "... any publicity is good publicity at the end of the day" while Grace stated,

... they want to sell a newspaper. They want to get the public watching their programs. So they want the grit of the hard part of your story, so you have to accept that when you're dealing with them.

In addition to the potential for sensationalist media accounts of their stories, mothers recounted their fear that the media would become complacent with the topic of substance use and the overdose death crisis. Nancy discussed her concern with a conversation she had with a journalist who conceded to her, "It's kind of like if we had to report the rate of cancer deaths each month. Over time, people just kind of get immune to the numbers." Mothers also recounted several instances where they spent time being interviewed for a story that was never published. Sophie shared how upset she was when, after working hard to convince her husband to join her for a televised interview, the station never aired the story: "... that was very upsetting for me and my husband because I'll probably never get him to do another interview again. And it took ... days to get over that."

While many participants said they had worked with journalists who

were caring and compassionate, mothers also at times contended with insensitive comments from journalists or the public. Usually this was subtle, however, Isla described an incident where she had reached out to a high profile journalist after her daughter passed away and was rebuffed, stating "... she told me that I think it's an epidemic because it happened to me." The most derogatory and hurtful comments, however, were shared by anonymous 'trolls' in response to media stories that appeared online. While many said they tried actively to avoid reading such comments, others could not help noticing or hearing from other advocates about the harm such posts create. Annie spoke of 'crying for days' following a radio interview to which people posted public comments that included statements such as, "They're druggies. Like, 'go shoot them in the head'. Things like that." This created a sense of ambivalence for mothers who wished to use the media to convey anti-stigma messaging and advance drug policy reform knowing that it may not only lead to personal trauma but also allow for online public responses which may have the opposite effect of what they were trying to achieve. Cindy expressed gratitude that the news agency she worked with told her before her interview that it was their official policy to refrain from allowing online public comments:

... I think it could have sent me down a path, and not a very good path, to see that ... because believe me, most of these mums ... they've already blamed themselves for every single thing they could blame themselves for ... but the bottom line is we love our children. We've tried our best. We did what we could do with what we knew at the time.

Finally, some mothers spoke of instances of having their story misrepresented or journalists framing the story differently than what they would have liked. While some viewed this as the wrongdoing of an individual journalist, there was also an understanding that reporters work under editorial constraints (e.g., length limitations), which might influence how the story is framed. Claire, who went to the media to warn the public about the contaminated drug supply when her daughter was alive and actively using drugs, stated, "... they [media] pick and choose what they want to put in, and sometimes they're curving it towards what they want it to look like ...". Occasionally, a journalist might share the story with a participant before it goes to print, however, if this did not happen or if there were errors in the reporting, some mothers spoke of asking for a retraction or correction. For example, Grace shared, "No matter how you want to use my story, just make sure that what you do say are the facts ... or I'll have you change it ..."

In requesting necessary changes, mothers demonstrated that they retained a degree of power in a relationship that holds the potential to be fraught with inequity. Many of the mothers we spoke to commented on this and other strategies that they undertook for engaging with the news media (see Table 2). The strategy mentioned most often was, 'Clear messaging on policy or practice solutions'. One example of this was when Alison commented, "So we try and elevate our language ... I will be clear on what my message is ..." (which at times meant steering the

 Table 2

 Bereaved Mother's strategies for engaging with the news media.

What Kinds of Strategies Did Bereaved Mothers Use When Engaging with the News Media?

Reach out to the media outlets directly

Be strategic in media work

Focus on one issue per interview

Prepare talking points ahead of time

Clear messaging on policy or practice solutions

Learn to 'pivot' back to your message when necessary during the interview

Negotiate ground rules with journalists in advance

Educate journalists

Take the opportunity if it is presented to review the article before it goes to publication Hold media accountable for their mistakes

Take measures to ensure privacy (from members of the public)

Interview with another advocate (joint interview for support)

conversation past details about her child). Additional skills such as preparing one's talking points ahead of time, pivoting back to one's main message when necessary, and taking measures to ensure privacy (e.g. releasing limited photos of their child) were developed over time by many of the mothers as their experience with the media grew and with the support of other group members. Such skills proved to be critical in helping bereaved mothers shift the media discourse away from their personal grief experience and towards advocating for policy changes and wider structural solutions to the overdose crisis.

#### 4. Discussion

Our research adds to the literature on how people and communities are impacted by the overdose crisis in Canada, providing perspectives from mothers whose children have died from substance use and have engaged with the news media for the purpose of advancing drug policy reform. This work also contributes to the field of social movements and advocacy, in particular those which feature bereaved mothers whose activism is driven in large part by collective grief (Al'Uqday & Adomako, 2018) as well as the use of maternal frames to advance a political cause (Stavrianos, 2015). Mothers described how contributing to news media represented a critical tool in their advocacy, allowing them to communicate to the public and policymakers in an effort to bring about meaningful changes at all levels of government. While overall the news media were viewed as allies in mothers' advocacy efforts, several risks accompanied going public with one's bereavement story.

Our findings point to the complexities of drawing on and centering lived experiences when taking on an advocacy role. Scholars have described the relationship between advocacy or social movements and the media as one of interdependency - between advocates who need the media's attention to amplify their message and members of the news media who rely on movements to help create newsworthy content (Vliegenthart & Walgrave, 2012). A primary skill for media advocacy is framing the story, something that the mothers in our study expressed as being a critical element of their own advocacy work. Advocates who are part of a larger social movement often engage in two different types of framing: 1) Framing for access that involves shaping a story to attract the attention of journalists and 2) Framing for content that involves sharing the story in a specific way to convey a particular message (Wallack & Dorfman, 1996). However, an additional theoretical underpinning of media advocacy involves recognition of the default frame. In North America this frame is often one of "... rugged individualism that emphasizes personal responsibility for solving problems" (Dorfman & Krasnow, 2014, p. 296). The mothers we spoke to were well aware that what makes their story salient with journalists is the suffering caused by the death of their child from substance use, something which holds the potential to 'be the story' itself. Further, the default frame in this instance is that their child 'made choices' and was ultimately responsible for their own death. Such an emphasis on personal responsibility over social policy responses is tied to substance use related stigma, which Urbanoski et al. (2020) state "... is deeply embedded in health and social systems as a result of current policies that criminalize drug use and neo-liberal beliefs that people who use substances are solely to blame for their problems" (p. 2). In interviews, our study participants explained how they addressed this delicate balance by shaping their story in such a way as to ensure that the interview focused less on their child as a 'victim' and more on what policy changes are needed (e.g. decriminalization of minor drug possession; supervised consumption services). Achieving this balance, however, was not easy. Although framing skills have the potential to improve with experience, there is no guarantee for mothers that their message will be conveyed in the way they intend, leaving many in a vulnerable place. Our previous findings on the personal impact of political advocacy (Moms Stop the Harm, 2021) point to the high costs of this work for mothers. Further, engaging with the media involves placing enormous trust in journalists and renders these mothers vulnerable to harm if their stories are inaccurately portrayed or their advocacy

messages are misinterpreted.

Our findings have led us to consider recent critiques in the academic literature, and from communities, highlighting how media in North America portray overdose death in ways that exclude racialized and marginalized people and families. Specifically, there have been several examinations of the representation of race in media coverage pertaining to the overdose epidemic (James & Jordan, 2018; Johnston, 2019; McLean, 2017; Mendoza et al., 2018; Netherland & Hansen, 2016; Webster et al., 2020). Many have argued that the news media has focused most of its attention on white opioid users, portraying them as 'innocent victims,' while ignoring or stigmatizing the stories of Indigenous or Black people who use opioids and their families. McLean (2017) for example contends that as rates of heroin use have risen amongst white Americans, so has a more sympathetic response by news media where "... stories increasingly [are] centered around 'unexpected' opioid users, whose habits are made legible through biomedical discourses of addiction" (p.411). As nearly all of our participants identified as 'white' and 'middle' or 'upper' class, we acknowledge that most enjoyed some degree of social privilege, which likely helped them garner media attention and made journalists more inclined to report their messages uncritically. While race, class, and gender privilege undeniably play a role in shaping 'whose story gets told', the absence of news stories from Black and Indigenous families on this issue may also be tied to the lack of safety that these communities have in sharing their stories in mainstream media.

In this particular cultural moment where we are experiencing a long overdue reckoning with previously denied or minimized accounts of racism, violence, and exclusion experienced in institutions, it would be naive to believe that journalism and the news media are somehow immune from bias and systemic racism in reporting on drug use issues. In fact, a recently published study by Rohlinger et al. (2020) found that news coverage is indeed diminished for women, older activists and activists of color "... by underrepresenting them, presenting opponents' claims at higher rates, and reinforcing dominant cultural narratives about political authority" (p.1). This was apparent early in Canada's overdose crisis, when in 2015, media coverage reporting on the high number of deaths in Kainai First Nation (CTV News.ca Staff, 2015), failed to galvanize the immediate political and public support needed to address the crisis within this community.

While considering how reporting on overdose may reinforce narratives imbued with white privilege, any media analysis on drug policy should also be concerned with whether or not stories from white, middle-class families are subjected to the 'sensationalism' our participants described (i.e. when stories frame overdose deaths as especially 'shocking' or 'tragic' because they occurred in so-called 'normal families' from privileged contexts). Journalists are encouraged to examine their own implicit biases and provide more fair and equitable portrayals of people who use substances across class and race (Netherland & Hansen, 2016). It is clear that in media storytelling, research, and policy, the meaningful representation of Black and Indigenous people, and other people of color who use drugs or who have lived experience of family drug use and overdose death should not only be amplified but shared in a way that allows journalists to reveal the political and structural forces which shape substance use in structurally vulnerable communities.

Academics working in substance use and drug policy have also used research, sometimes in collaboration with journalists, to advocate for changes to how drug use and drug policies are reported on, and to challenge drug stigma and advance evidence-based perspectives in reporting. For example, there are guidelines for avoiding myths about drug use (Changing the Narrative, 2020) and journalists are encouraged to be inclusive of voices of people who use drugs while using person-first, non-stigmatizing language (INPUD & ANPUD, 2020). In Canada, there are also best practice guidelines on how to report on addiction and mental health (The Canadian Journalism Forum on Violence and Trauma, 2017) as well as trauma-informed approaches to reporting (CBC radio, 2019). Advocates themselves are directed towards specific strategies when working with the media such as articulating policy 'asks',

pivoting to key messages, utilizing research evidence, and using speaking notes to help feel comfortable which are further described by the Canadian Drug Policy Coalition (2021) and in the MSTH Advocates Handbook (Moms Stop the Harm, 2017). Finally, members of the government have a responsibility to ensure that information presented about people who use substances in press releases, media interviews, and online reports is both non-stigmatizing and rooted in evidence (Lancaster et al., 2017).

While our study brings many strengths and is among the first to center the experiences of mothers who use media to advance drug policy reform, there are limitations to acknowledge. At the time of these interviews, there was a significant amount of media coverage in Canada featuring bereaved mothers with respect to the overdose crisis. The experience of media advocacy is likely to vary with shifts in public and political discourse about drug use and the importance of supporting (versus punishing) people who use drugs. Similarly, while the majority of the mothers we spoke to have lost a child to drug poisoning/overdose (primarily related to opioid use), family members whose child died from other substance-related causes such as alcohol and/or stimulant use may call for different policy responses and engage in different approaches in their media advocacy work. Finally, we did not address the experience of other family members (fathers, spouses, children, or siblings) which is an important consideration for future studies.

In conclusion, our findings illustrate a significant yet complex relationship between journalists who aim to share the stories and messages of bereaved mothers and the mothers themselves who are working to frame these messages in ways that will bring about significant and long-term changes in Canada's drug policy landscape. While journalists are perceived as important allies in advocacy, working with the media poses several risks that bereaved mothers might well encounter when engaging with the news media. We trust that the experiences described herein may be used to inform media advocacy undertaken not only by parent advocates, but by all groups who are actively working to advance drug policy reform in Canada and around the world.

#### Ethical statement

Our study protocol was approved by the human research ethics boards at the University of Calgary, the University of British Columbia and the University of Alberta.

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#### **Declaration of competing interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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