

Bereaved Mothers' Use of Media Advocacy in Advancing Drug Policy Reform in Canada

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Addiction and the Family
International Network (AFINet)
Webinar Series

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Presentation Outline



1. Remembering and honouring loved ones lost to failed drug policy
2. Overview of Canada's drug poisoning crisis.
3. Describe the work undertaken by Moms Stop the Harm in advocating for drug policy reform and offering mutual support.
4. Report on research project exploring the experience of media advocacy by bereaved mothers.



Danny Schulz 1989 – 2014

Substance use and overdose can affect anyone

It affects some more than others



Drug Poisoning Death in Canada

20 Canadians die every day

There was a total of **26,690 apparent opioid toxicity deaths** between January 2016 and September 2021

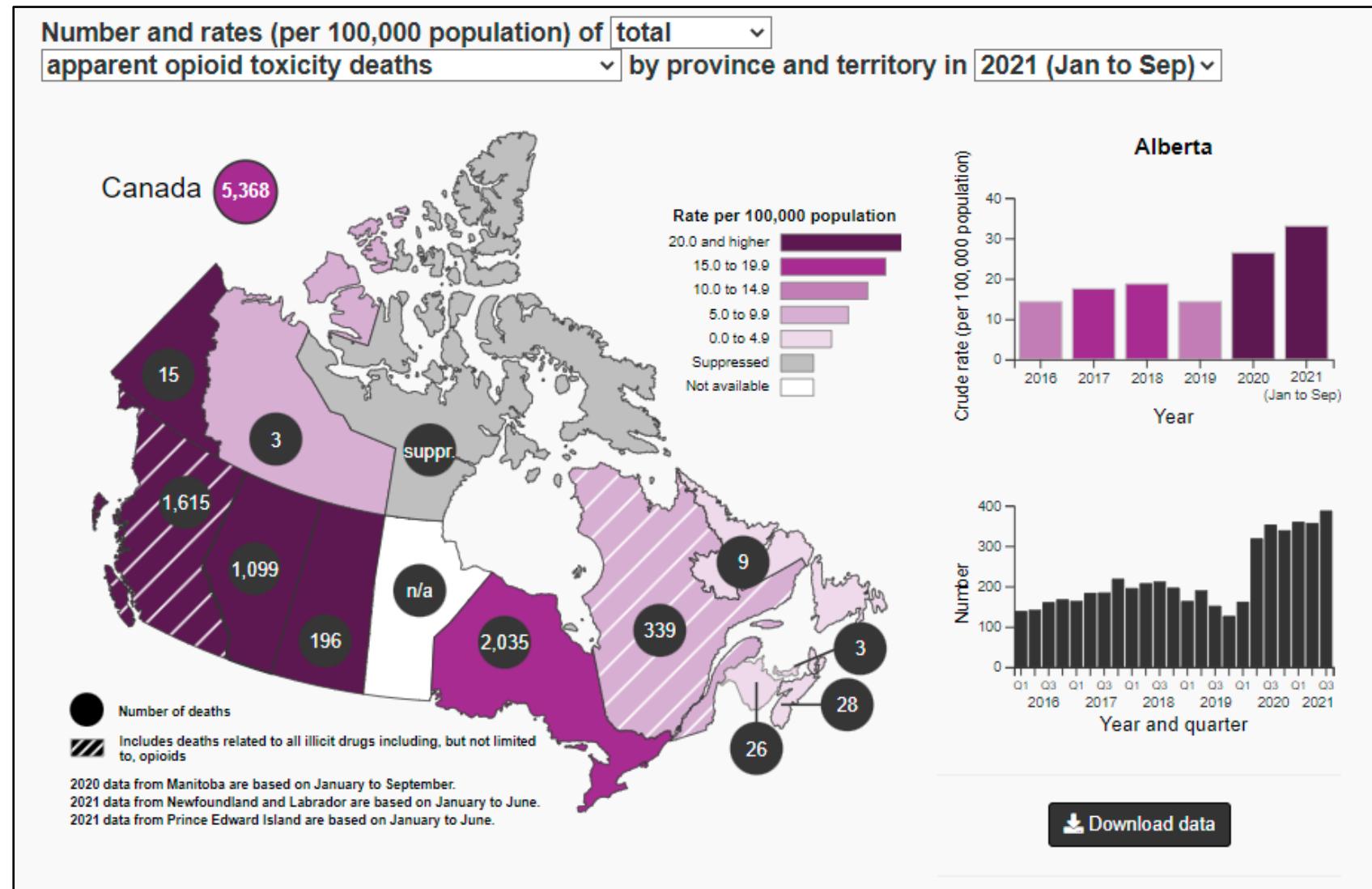
Most in British Columbia, Alberta, and Ontario; increases observed in other regions.

Most among young- to middle-aged males

Toxicity of supply continues to be a major driver of the crisis

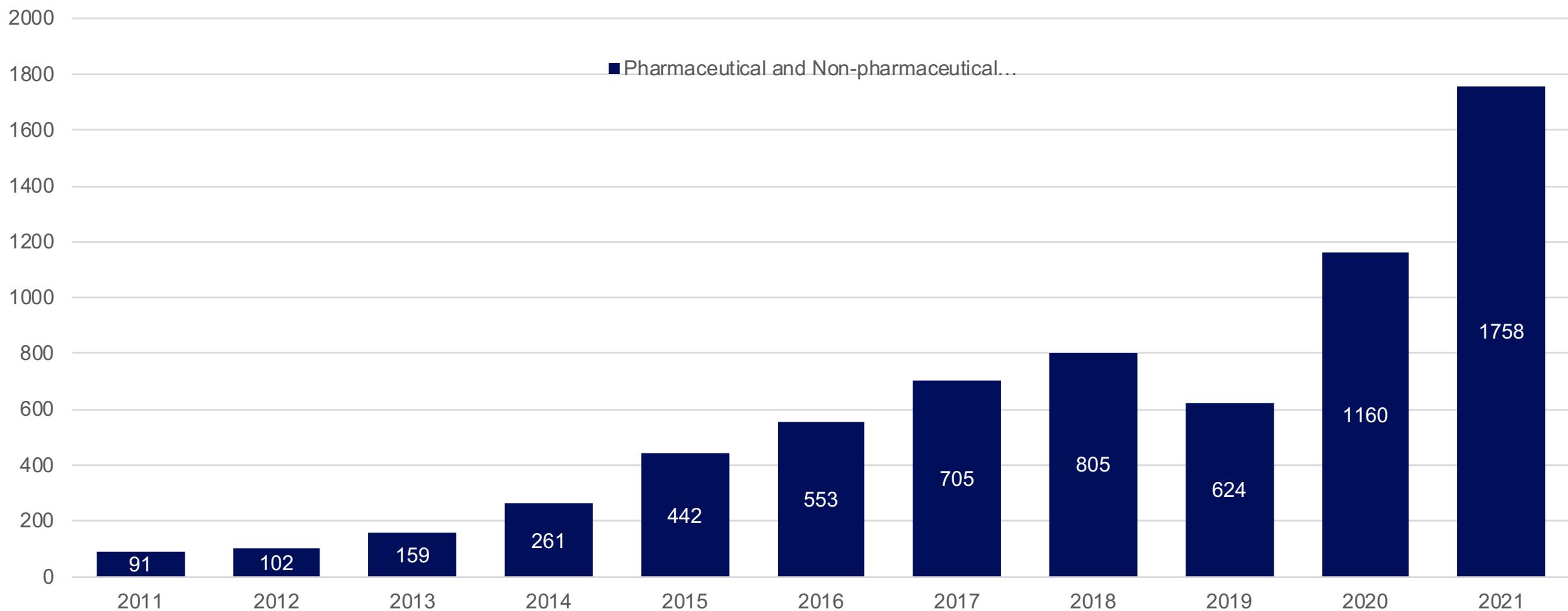
There was a total of 29,228 opioid-related and 12,977 stimulant-related poisoning **hospitalizations** from January 2016 to September 2021 in Canada (excluding Quebec)

- March 2022 <https://health-infobase.canada.ca/substance-related-harms/opioids-stimulants>



Source: Government of Canada, March 2022

Cumulative apparent accidental opioid poisoning deaths in Alberta, 2011 – 2021



NB: Data presented in this chart were compiled from multiple Alberta Health reports available here: <<https://www.alberta.ca/substance-use-surveillance-data.aspx>> and personal communications with health officials (pre-2014 data). Numbers are subject to minor fluctuations as certification of deaths can take six months or longer.



The Power of Parent Advocacy

Moms Stop the Harm (MSTH) is a network of Canadian families impacted by substance-use related harms and deaths.

3500 families Canada wide

Mission: We advocate to end substance use related stigma, harms and death.

Provide peer support and welcome new families.

<https://youtu.be/jNWjGkHCUBs>





MSTH engages in Advocacy and Peer Support

Stronger Together Canada



Aims to build capacity and improve outcomes for individuals and families with peer lead support groups.

Healing Heart groups for families who have lost loved ones

Holding Hope Groups for families whose loved ones are using substances

- STCA is funded by the Health Canada Substance Use and Addictions Program

MSTH advocates for:

A safer regulated supply #safesupply

Decriminalization of PWUD

Harm reduction in all provinces

Evidence-based treatment

Upstream prevention

Meaningful inclusion of PWLLE and their families in all decisions that affect us!



The Knowledge Translation Project:

Seeing Beyond the Numbers: What families want you to know about opioids, stigma and harm reduction



PHIL
Phil Haug lost his son, Alex. These are the words Phil would say to him today.

KYM
Kym Porter grieves for her son, Neil. Here are her thoughts for him.

DONNA
Donna May talks to her daughter. This is what she wants her to hear.

PETRA
Petra Schulz lost her son Danny when he was just 25. This is her letter to him.

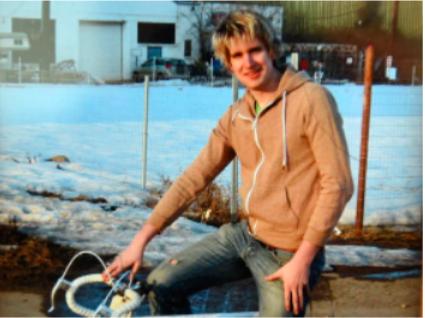
<http://www.see-beyond.ca/>

<https://www.youtube.com/watch?v=uSy9lanywQo>

Local News
‘My worst fear, here it is’: Edmonton family speaks out about son’s fentanyl overdose

Otina Ellwand

Sep 11, 2015 • September 11, 2015 • 5 minute read • □ Join the conversation



Daniel (Danny) Schulz, 25, who died on April 20, 2014, from fentanyl poisoning. PHOTO BY SUPPLIED /Edmonton Journal

Moms united in grief and new purpose: to change how addiction is treated in Canada

CARLY WEEKS > HEALTH REPORTER
PUBLISHED NOVEMBER 18, 2018

This article was published more than 3 years ago. Some information may no longer be current.



Moms Stop the Harm co-founders Lorna Thomas, left, and Petra Schulz, near a bench dedicated to Lorna's



Local News
Toxi-City: Deadly drugs in Edmonton – Overdoses are happening across all neighbourhoods and families are bearing the brunt of the crisis

Between January and October of 2021, 1,372 Albertans died of drug poisoning, marking it as the deadliest year on record. But behind every number was a person, someone's loved one. And left to pick up the pieces are family members who wonder what more could have been done

Anna Junker
Mar 18, 2022 • March 31, 2022 • 13 minute read • □ 84 Comments



Stories from people who have lost loved ones to opioids

Geordon Omand, THE CANADIAN PRESS



Mother fighting back against fentanyl 1 year after son's tragic overdose death

Ryan Pinneo's overdose death inspired his mother to take action

By Courtney Dickson, CBC News Posted: Jan 20, 2017 2:56 PM PT | Last Updated: Jan 20, 2017 2:56 PM PT

Former Sault Ste. Marie resident relates her daughter's tragic opioid addiction and painful last days; Donna May now determined to spread awareness around the planet



By Jeffrey Ougler, Sault Star
Tuesday, February 7, 2017 10:13:34 EST PM

Grieving mom hopes good can come after tragic death

BEVERLEY WARE SOUTH SHORE BUREAU

Published October 3, 2014 - 8:11am

Last Updated October 5, 2014 - 11:40am

Federal response to fentanyl crisis 'dismal,' says mother of victim

CTV NEWSGO



CTV News Channel: 'There is no quick fix':

CTV News Channel: 'There is no quick fix':

BCPHA Vice President Alex Dar Santos says the fact that the PM acknowledges this is a long-term problem and short-term funding won't help.

Fight against fentanyl goes high-tech at UVic

Experts at UVic are creating a new handheld device that could gauge the amount of fentanyl in drugs, potentially saving lives.

CTVNews.ca: Frontlines of opioid crisis

Sarah Blyth of Vancouver's Overdose Prevention Society talks about working on the frontlines of the opioid crisis.

1 2 3

'My worst fear, here it is': Edmonton family speaks out about son's fentanyl overdose

HEALTH

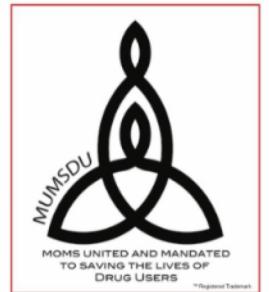
March 15, 2018 12:37 pm

'I want us to save lives': \$1.4M Edmonton suicide prevention plan aims to help desperate citizens



By Karen Bartko

Online Journalist Global News



Dr. Rebecca Haines-Saah



Dr. Emily Jenkins



Dr. Elaine Hyshka
Heather Morris RN MN
PhD Candidate

Literature Review

Research and policy work -
Inclusion of people who use
drugs - VANDU (Kerr et al.,
2006; Jozaghi, 2014)

Research: Family Advocacy and
Mental Health (Briggs, 1996;
Evans & McGaha, 1998; Olin et
al., 2010; Hoagwood et al.,
2018)

Grandmothers raising children
during crack cocaine epidemic
1990's (Roe et al., 1995) in
Oakland, CA

Mothers Advocacy In Other
areas

- Disability field
- Childhood cancer
- HIV/AIDS
- LGBTQ rights (PFLAG)
- MADD

Grieving Families
(Feigelman et al., 2020;
Templeton et al., 2016;
Titlestad et al., 2019)

Message Framing Experiments
Featuring a Mother Whose
Child Died of Substance Use
(Bachhuber et al., 2015;
Sumnall et al., 2020)

Mother's Stories of Advocacy Following Their Child's Substance Passing

Research Objectives:

1. Advance academic knowledge on parents as advocates for drug policy reform.
2. Help build parent advocates capacity to achieve evidence-based policy responses in Canada.

Research Methods

- Ethics approval : UofA, UofC, UBC
- Community-Based research drawing on narrative approaches to examining mother's stories
- Data collection between June and November 2017
 - 43 Semi-structured qualitative interviews using narrative approach
 - Length 26 -135 minutes; 7 Phone and 36 Home Visits/Public place/work/university
 - Recorded and transcribed verbatim; Honorarium provided
 - Questions: Actions, messages, purpose and motivating factors, facilitators and barriers, impact of advocacy work
- Data analysis:
 - Thematic Analysis (Braun & Clarke, 2006)
 - NVIVO 12

Research Question:

How do mothers who have lost a child to substance use describe their experience of media advocacy to advance harm reduction and other drug policy reforms?

SSM - Qualitative Research in Health 1 (2021) 100011

Contents lists available at ScienceDirect

SSM - Qualitative Research in Health

journal homepage: www.journals.elsevier.com/ssm-qualitative-research-in-health

Check for updates

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

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Sample:

- 75% of those reporting their age between 45-64
- 51% married; 7% common-law; 23% separated/divorced; 9% single or widowed; 9% multiple responses
- 30.2% 6-11 months; 25.6% 1-2 years; 25.6% 2+ years; 18.6% unclear
- 35 males and 10 females (2 mothers lost 2 children)
- Children ranged in age from 17-43 when they died; most in their 20s
- Majority of mothers (39) identified that their child died of drug overdose or poisoning, many saying fentanyl was cause of overdose death

Findings: News media as allies



*"... it's important that they are on our team and that they don't become jaded." (*Freya)*

"... 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... they believe in what we do, and they do an important job informing the public" (Hope)

"... they have the power to change ... public opinion, to change the language, to reduce stigma through their lens of ... what happens" (Olivia)

* Names presented on all slides are pseudonyms

Findings: Rationale for Engaging with the News Media



"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." (Hope)

Rationale for engaging with news media

“... 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]”. (Sophie)

“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”. (Evelyn)

Findings: Challenges & Personal Costs of Engaging with the News Media

“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 people that use drugs by choice. They should just stop.’” (Edith)

“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” (Mandy)

“… she [journalist] told me that I think it’s an epidemic because it happened to me” (Isla)

“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”. (Cindy)

Strategies for Engagement with News Media

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)
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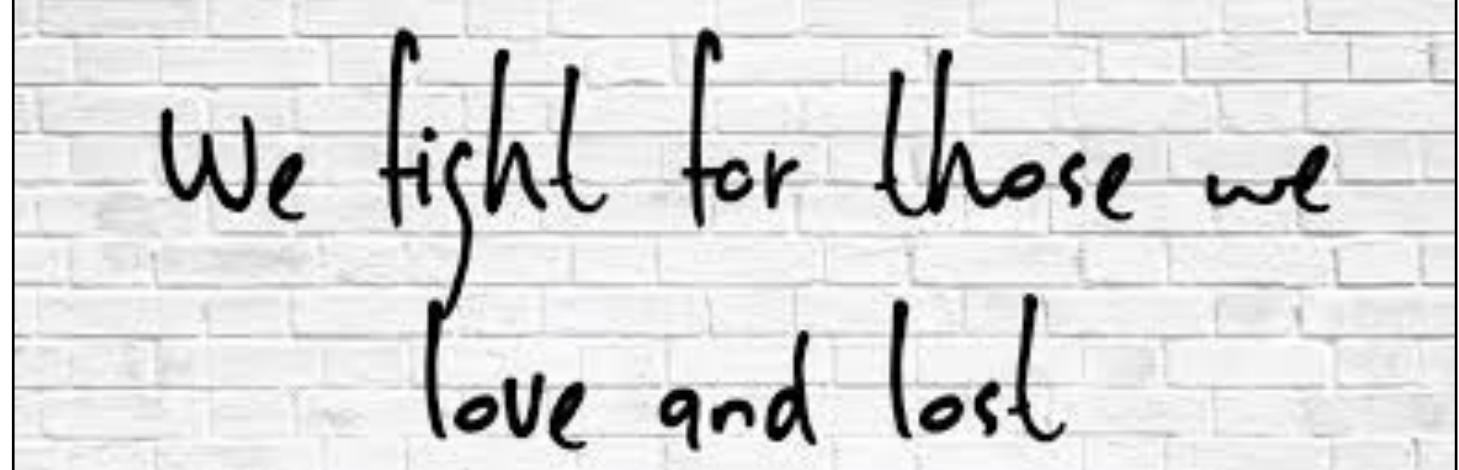
* Morris et al. (2021). “I’m not your reality show:’ Perspectives of bereaved mothers’ engagement with the news media to advance drug policy reform. Social Science & Medicine – Qualitative Research in Health.

Discussion & Recommendations



- News media seen as allies but challenges and personal costs exist when engaging with news media
- Representation of Black and Indigenous families and individuals in the media
- Recommendations for journalists and advocacy organizations
- Limitations of our study

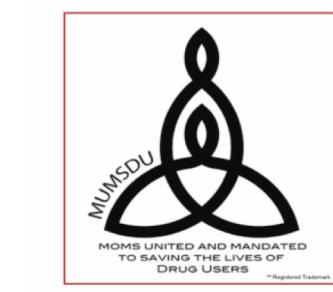
Conclusion



UNIVERSITY OF CALGARY
O'Brien Institute for Public Health



THE UNIVERSITY OF BRITISH COLUMBIA
School of Nursing



women & children's
health research institute



AWHF
alberta women's health foundation