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3 **Title:** Newspaper Portrayal of Family Veto in Organ Donation in Canada
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Introduction

Transplantation is a cost-effective, life-saving therapy for many patients with end-organ failure but transplantable organs are in short supply. Almost 4500 Canadians are currently on transplant waiting lists and as wait-lists continue to grow, patients suffer prolonged illness and some die waiting for a donor (1). Organ transplantation relies on public support and willingness to donate. The public gains much of their knowledge about health and scientific developments from the popular press (2-4). Research has shown that how an issue is framed in the media can affect public discourse, and shape public opinion and policy debates (2-10).

Canadians can communicate their wish to be an organ donor by documenting it in writing (11) and, in some provinces, by joining a donor registry (12-15). While this authorization is legally sufficient for organ procurement after death, it is common practice to seek agreement from the individual's next-of-kin before donation proceeds (16). When a family member of a person who has given legal consent to donate decides against donation, this is referred to as family veto (FV). The veto represents a conflict between respect for a deceased's previously expressed wishes and those of the family. How FV is framed in the media can impact public discourse on organ donation. The aim of our research is to investigate the portrayal of FV in organ donation in Canadian newspapers and identify the major frames surrounding FV that have featured most prominently in the print media discourse.

Materials and Methods

The Canadian Newsstand Complete database (via ProQuest web interface), which offers access to nearly 300 newspapers from Canada's leading publishers, was searched for news print

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3 articles published in English addressing FV between January 1, 2000 and December 31, 2014.

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5 The database review was guided by a search strategy that included the following terms: (famil*
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7 or wife or husband or child* or mother or father or daughter* or son*) or (next of kin) AND
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9 veto* or challenged* or overrule* or over-rule* or overturn* or over-turn* or override* or
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11 veto* or challenged* or overrule* or over-rule* or overturn* or over-turn* or override* or
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13 over-ride* or dispute* or oppose* AND (organ* NEAR/2 (donor* or donation*)) or (kidney*
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15 NEAR/2 (organ* or donation*)) or (liver* NEAR/2 (donor* or donation*)) or (heart* NEAR/2
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17 (donor* or donation*)) or (lung* NEAR/2 (donor* or donation*)). Duplicate and topically
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19 irrelevant articles, where there was no mention of FV in organ donation, were removed from
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21 the data set.
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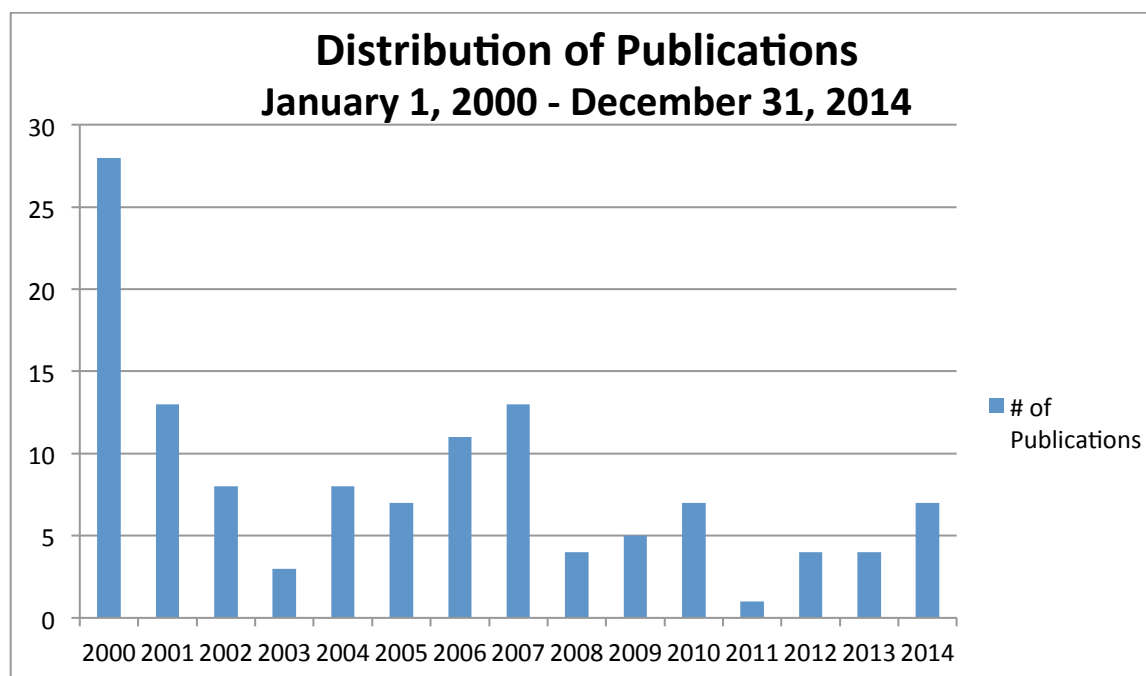
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26 A framing paradigm provides a conceptual process within which to analyze the influence of the
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28 media on public discourse. Framing theory emphasizes the selective presentation of specific
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30 topics, facts, controversies, and assertions in media coverage (10, 17-19). Guided by the
31
32 theoretical perspectives of framing of media effects, a systematic content analysis of the
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34 newspaper articles was conducted to examine how the Canadian media framed FV in organ
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36 donation. An initial in-depth analysis of the data set identified coding categories. All analytic
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38 categories were defined in a structured coding framework with the following variables: (i)
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40 frequencies of coverage by newspaper and province; (ii) publication date, article type, author or
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42 article source, and who was attributed with providing information or evidence on FV; (iii)
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44 identification of the primary framing of FV in organ donation; (iv) incidence rates of FV; (v)
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46 reasons for FV; (vi) ethical or legal concerns with FV; (vii) whether the article made
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48 recommendations, and; (vii) the overall tone (positive, neutral, and negative) of the article.
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3 Two coders analyzed the data set to ensure intercoder reliability. One coded the complete
4 dataset and the other independently coded a random selection of 61 articles (50% of the total).
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6 Inter-coder (rater) variability was measured using the Kappa statistic. The calculation of the
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8 statistic is based on the difference between how much agreement is actually present
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10 (observed) compared to how much agreement would be expected by chance alone (expected).
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12 The Kappa-scores on the coding frame categories ranged from 0.60 to 1.00, indicating
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14 moderate to excellent intercoder reliability (20). The k-score was >0.74 for 80% of the coding
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16 questions. The k-scores for the analytical categories of frame and tone were 0.76 and 0.74,
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18 respectively.
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27 **Results**

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29 The search of the Canadian Newsstand Complete database conducted on April 3, 2015 yielded
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31 642 articles. After excluding duplicates and topically irrelevant articles, the final data set
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33 contained 123 newspaper articles. The majority of these articles (72%) were published in
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35 Ontario. Table 1 shows the distribution of publications between January 1, 2000 and December
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37 31, 2014. The highest number of articles was published in the Ottawa Citizen (n=21; 17%),
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39 followed by the Toronto Star (n=10; 8%) and the Hamilton Spectator (n=8; 7%). A further 26
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41 newspapers each published only one article.
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47 Table 1
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Two major frames in the portrayal of FV in Canadian media were identified. Family veto was predominantly framed as “something that should not be allowed to occur” in 80 (65%) of the articles. The concept of a family overriding a deceased’s expressed wish to donate was characterized as “terribly wrong”, “a shame”, and “tragic”. Table 2 highlights the primary framing of FV, by bringing salience to the issue of prohibiting FV.

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Table 2 – Quotes Illustrating Primary Frame

Frame	Quotes
Family veto should not be allowed	“a family shouldn’t be able to override a person’s decision to donate organs at the time of death if they signed a card. That is like saying a dead person’s will is not valid and a family can disperse belongings as they wish”
	“loved ones should not be able to overrule signed intentions to donate”
	“Something is terribly wrong when the wishes of the deceased are respected in disposing of their possessions but are ignored when their bodies are the issue”
	“When you just have one person who didn’t have his wishes come true, that’s one person too many”
	“the family should not have a veto vote on this informed decision”
	“Family should not be able to overrule organ donations...Individual donors, not

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3	their family members, should have the final say on organ donation”
4	“...the law, public opinion and ethics all support an individual’s right to have
5	their decision honoured.”
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7	“Opinion polls show that better than 90 percent of Canadians don’t want family views
8	to outweigh their own.”
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10	“We have a tradition to respecting people’s last will and testament...why do we so
11	easily deny them their last will about what happens to their body parts after they die
12	– what could be more personal?”
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14	“While their (family) reluctance is understandable, organ donation is not and should
15	not be their decision to make. A signed donor card or its electronic equivalent should
16	be treated as a sacrosanct commitment made by one who has died so that one may
17	live.”
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19	“Opting to keep or donate organs should be a decision that cannot be overturned by
20	family.”

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22 Family veto was also framed as “a reality” that is “little understood outside of the transplant

23 community”. Articles conveyed the perspective that Canadians may think that by signing an

24 organ donor card or expressing their wishes through an on-line registry, their intentions would

25 be honored. However, when made aware of the issue of FV through newspaper publications,

26 the responses conveyed in the editorials, opinion pieces and letters were of “dismay”,

27 “surprise”, “bitterness” and “anger”. Articles contained storylines of “shock” to the reality of

28 FV – “what a shock to read that anyone – even if it is my next-of-kin – has the power to veto my

29 wishes to donate organ after my death” and “frustration” that it’s simply not enough to sign an

30 organ donor card or register your wishes – “I carry an organ donor card, but it’s absolutely no

31 use”. A common theme across the newspaper articles (n=43; 35%) was the need to bring

32 attention to the “reality” of FV.

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51 Thirteen (11%) of the articles referenced the incidence rate of FV. Amongst these articles there

52 was wide variance in the cited occurrence of FV across the newspaper publications, ranging

53 from 5 to 70 per cent – “Families are allowed to counter their loved one’s decisions in

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3 approximately 5% of cases” to “About 70 per cent of those who sign donation cards have their
4 wishes vetoed at the hospital, because family members refuse to donate organs.” Information
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6 about incidence rates of FV was primarily attributed to quotes from family members and/or
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8 patients, patient advocates, and health professionals.
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14 Thirty-eight (31%) of the articles addressed reasons for FV, with the deceased not having
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16 previously discussed their decision with their family as the predominant reason (n=28) – “so
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18 many people don’t realize their family members’ wishes” or “If you sign your organ donor card
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20 and your family is unaware of your wishes, they may reverse that decision”. Other reasons
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22 highlighted in the articles included: (i) “custom” and “culture” of the hospital - “It’s custom –
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24 not the law, not ethics and not public opinion – to ask the family” and “Asking the family is part
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26 of the folklore, part of the culture of the intensive care unit”; ii) family is approached at a
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28 difficult time – “We’re approaching the family at a weak moment” or “They’re in shock and not
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30 able to make decisions”; (iii) healthcare workers are afraid of being sued – “Doctors are afraid if
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32 they remove organs without the family’s consent they will be sued; and (iv) hospital staff not
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34 wishing to further harm the family – “No hospital staff would agree to operate on a patient if
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36 they knew the family did not consent” or “We really don’t want to agitate people” and wish to
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38 “avoid the awkward issue altogether.”
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48 Eleven (9%) of the articles questioned who is responsible for the occurrence of FV. The
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50 publications were divided between placing responsibility on physicians (n=5) - “Doctors are
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52 driving down the donor rate by not agreeing to a donor’s wishes”; and families (n=5) “the
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3 family can overrule...which is an act of extreme selfishness". One letter to the editor implied
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5 that the responsibility should be directed to the government.
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9 A quarter of the articles (n=32; 26%) highlighted ethical issues associated with FV. These
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11 concerns were centered on the ethical principles of autonomy and justice. Ethical issues
12
13 surrounding FV were framed as "infringing" or "violating" individual rights, patient values, and
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15 personal autonomy. These articles emphasized that one's personal choice in matters of organ
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17 donation should be "respected" and "honoured".
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21 A large proportion of the articles (n=80; 65%) erroneously stated or implied that existing
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23 legislation permits FV. Whereas only a handful of articles (n=13; 11%) suggested that FV is not
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25 permitted by existing legislation (Table 3).
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31 Table 3 – Representations of Legislation
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34 Legislation permits family veto	"Under Ontario law, even if a donation card has been signed, family members could over-rule the donor's wishes when death occurs."
	"The government needs to change a legislative provision that allows family members to overturn permission to harvest organs. That can occur despite the fact that an individual has signed the necessary documents."
	"In Ontario, it is the law that we approach the family and obtain consent."
	"Without regulations prohibiting families from stepping in and halting the organ-donation process, all health authorities can do is watch helplessly as another person's chance at life might be abruptly ended."
	"Officials...still require permission from the deceased next-of-kin."
	"The legislation will fall short because it continues to allow the family to overrule the desire of a relative to donate."
	"Right now in every province, officials must approach families to make the final decision on organ and tissue donations."
35 Legislation prohibits family veto	"Seeking the family's agreement violates the Human Tissue Gift Act in each province"
	"Signing an organ donor card means you've given 'full and binding

	consent' to donating parts of your body, and a doctor who asks your family for permission is breaking the law”
	“It is only a matter of time before an institution is sued (by someone awaiting a transplant) for failing to follow the relevant laws”
	“Family members cannot legally defy a loved one’s willingness to donate unless they have good reason. Organ donors’ wishes must be legally honoured after death, except when a family can prove the donor changed his or her mind after signing up.”
	“People have suggested we should change the law, but the law we have would work very well if we used it. We should not be asking the next-of-kin when we have a fully binding law right now.”
	“Ontario legislation states clearly that you have every right to specify whether your organs can be donated after your death. You – no one else – have the final say.”

Many of the articles (n=101; 82%) expressed concerns about the present organ donation system and offered recommendations to address the issue of FV. Articles included quotes reflecting this sentiment such as “the organ donation system as it exists is seriously flawed”, “much can be done to improve the system” and FV was viewed as “an all too frequent reality that medical authorities would love to see changed”. Popular recommendations cited in the articles included: 1) the need for individuals to talk to family members and make their wishes known (n=53; 43%); 2) the need for organ donation awareness campaigns (n=21; 17%); 3) proposals for an ‘opt-out’ or ‘presumed consent’ system (n=18; 15%); and 4) legislative changes to ensure donors’ decisions be respected (n=15; 12%). Individuals cited in support of recommendations to address FV include family members and/or patients (n=19; 15%), patient advocates (n=15; 12%), academic or scientific experts (n=14; 11%), and health professionals (n=10; 8%).

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3 Finally, the overall tone of the portrayal of FV in Canadian media was assessed. News coverage
4 was primarily negative, with 82 (67%) articles opposing FV. Forty-two (34%) articles framed FV
5 in a neutral manner, including 38 articles providing descriptive coverage and four presenting
6 both positive and negative and / or multiple perspectives. None of the articles portrayed FV in
7 a primarily supportive or positive manner.
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16 Interpretation

17 Family veto in organ donation was predominantly portrayed in a negative manner in the
18 Canadian English language newsprint media considered in this study. Not one article framed FV
19 in a positive manner. It was predominantly framed as something “that should not be allowed”
20 in 80 (65%) of the articles, as well as a “reality” that is “little understood outside of the
21 transplant community” (n=43; 35%). Among articles that referenced the incidence rate of FV
22 there was wide variance in the cited prevalence, ranging from 5 – 70%. According to Trillium
23 Gift of Life Network, Ontario’s Organ and Tissue Donation agency, the annual incidence rates
24 for FV within Ontario range between 15 – 22% between 2012-2015 (Table 4).
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42 Table 4 - Incidence Rates

	Reporting Period		
	<i>Apr 1, 2012 – Mar 31, 2013</i>	<i>Apr 2, 201 – Mar 31, 2014</i>	<i>Apr 1, 2014 – Mar 31, 2015</i>
<i>Number of Registered Donor Family Declines</i>	31	26	39
<i>% of Registered Donor Family Declines</i>	22%	15%	18%

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52 The ethical issues associated with FV highlighted in the articles were framed around the
53 principle of autonomy. A quarter of the articles (n=32; 26%) stressed the importance of respect
54 for the autonomous wishes of the deceased, supporting the argument that we have a duty to
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3 enable the wishes of a deceased person who has taken the time to register their desire to be an
4 organ donor. Such compliance to the deceased's wishes is in keeping with the administration of
5 a will for material goods, which does not consider the family's agreement or dissent with the
6 choices made but rests on the last known capable, legally registered wishes of the deceased.
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11 Family veto was represented as a 'stumbling block' in our present organ donation system, with
12 the majority of publications calling for change. It is striking that 65% of the articles in the data
13 set stated or implied that FV is permitted under the law, as this is incorrect with regard to every
14 province and territory in Canada (16). Consent for organ and tissue donation is governed by
15 provincial and territorial legislation, and in Quebec, by the Civil Code. Each of these pieces of
16 legislation stipulates how individual consent for deceased donation can be given, and the
17 circumstances in which an individual's next of kin can consent on his or her behalf. Members of
18 a potential donor's next of kin are only legally entitled to provide (or withhold) consent in
19 situations where the potential donor has not already provided his or her own consent (16).
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37 When an individual has provided his or her own consent to become a deceased donor, in most
38 Canadian provinces and territories this consent is binding and provides the complete legal
39 authority necessary for organ donation to proceed (11, 16).
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45 The 12% of articles that recommended legislative change to address FV further reflect this
46 misunderstanding about the law. As legislation does not permit FV unless there is a belief that
47 the deceased's donation intentions had changed, and as individual consent is binding
48 throughout most of Canada providing full authority for donation, legislative change is
49 unnecessary. A culture change in organ donation and an approach to families that adheres to
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3 the current law is needed to overcome the gap between law and practice. While thirty-eight
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5 (31%) of the articles addressed reasons for the occurrence of FV, research with families who
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7 have vetoed a deceased's registered wish to donate may enhance our understanding of the
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9 reasons for FV and how to overcome them. Similarly, we need to engage with the donation and
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11 critical care communities and pursue research examining their underlying concerns surrounding
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13 FV, as well as their understanding of the law when it comes to enforcing the deceased's
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15 consent. It is only when the underlying causes of this practice are understood that we can
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17 implement effective solutions.
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24 References

- 26 1) Canadian Institute for Health Information. Canadian Organ Replacement Registry - CORR
27 Annual Report. Ottawa, On (2011)
- 28 2) Garrett JM, Bird SJ. Ethical issues in communicating science. *Sci Eng Ethics* 2000; 6:435-
29 442
- 30 3) Holliman R. Media coverage of cloning: a study of media content, production and
31 reception. *Public Underst Sci* 2004; 13:107-130
- 32 4) Nelkin D Selling Science: How the press covers science and technology (revised edition).
33 New York: W.H. Freeman 1995
- 34 5) Seale C. Health and the media: an overview. *Sociol Health Ill* 2003; 25(6): 513-531
- 35 6) Bubela et al. Science communication reconsidered. *Nature Biotechnol* 2009; 27: 514-518
- 36 7) Nisbet MC, Mooney C. Framing science. *Science* 2007; 316(5821): 56
- 37 8) Mazur A. Media coverage and public opinion on scientific controversies. *J Commun*
38 1981; 31:106-115
- 39 9) Callaghan K,& Schnell F. *Polit Commun* 2001; 18(2), 183-213
- 40 10) Scheufele D. Framing as a theory of media effects. *J Commun* 1999; 49:103-122
- 41 11) Downie J, Shea A, Rajotte C. Family override of valid donor consent to postmortem
42 donation: issues in law and practice. *Transplant P* 2008; 40: 1255-1263
- 43 12) Alberta Government, "Alberta Organ and Tissue Donation Registry",
44 <https://myhealth.alberta.ca/Pages/OTDRHome.aspx>
- 45 13) BC Transplant, "Register Your Decision!" <https://register.transplant.bc.ca/>
- 46 14) Legacy of Life, Nova Scotia Organ and Tissue Donation Program,
47 <http://www.legacyoflife.ns.ca/>

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 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
- 15) Trillium Gift of Life Network, Ontario's Organ and Tissue Donation Agency,
<https://beadonor.ca>
- 16) Toews M, Caulfield T. Evaluating the "family veto" of consent for organ donation. *CMAJ* 2016; doi:10.1503/cmaj.160752
- 17) Entman R. Framing: Toward a clarification of a fractured paradigm. *J Commun* 1993 43, 51-58
- 18) Scheufele D, Tewksbury D Framing, agenda setting, and priming: The evolution of three media effects models. *J Commun* 2007; 57:9-20
- 19) Gamson WA, Modigliani A. Media discourse and public opinion on nuclear power: A constructivist approach. *Am J Sociol* 1989; 95: 1-37
- 20) Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977; 33(1): 159-174

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