A Year in Review: The Who, When, Why and How of Requests for Medical Aid in Dying in Quebec

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Introduction

- Bill 2 (QC) - December 2015
- Bill C14 (Canada) - July 2016

  - Ineffective communication about end-of life care is well documented.
  - No consensus on when is the best time to broach end of life discussions.
  - To our knowledge, little data exists on how requests for MAiD fit into the broader context of end-of-life discussions/planning in Canada.

Objectives

This study aimed to:

1. Identify demographic info of MAiD requests in our institutions.

2. Situate requests for MAiD within the broader context of end-of-life care practices.

Methods

- Retrospective chart review of all formal MAiD requests (3 QC institutions)
- Dec 10, 2015 - June 9, 2017.
- 80 charts identified & reviewed.
- Study sites: McGill University Health Centre (25); Cité de la Santé, Laval (36); Rose de Lima (19).
- Standardized data collection forms.
- Descriptive statistics

Results

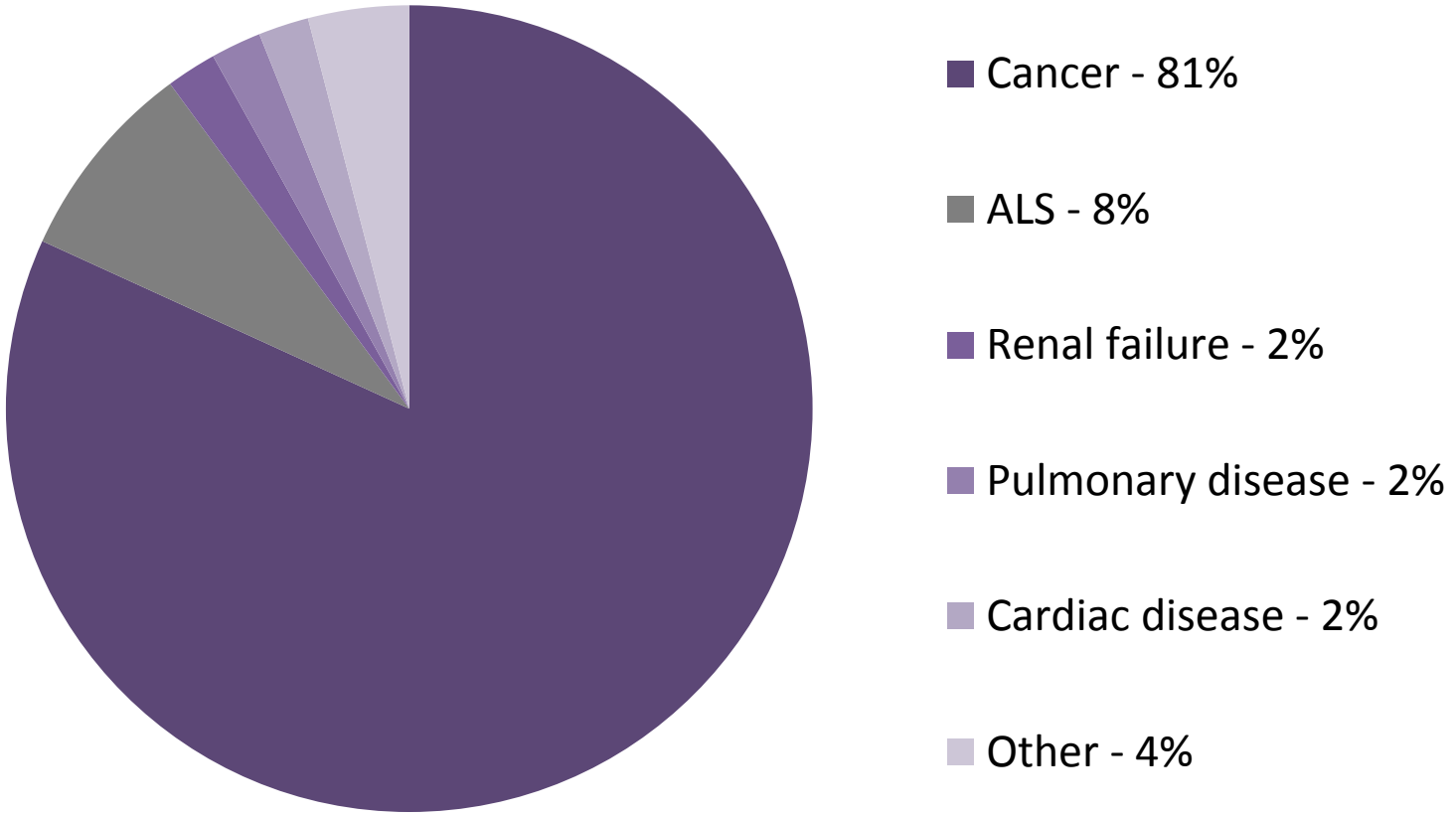
CHARACTERISTICS	%	(n)
TOTAL # MAiD REQUESTS (n=80)		
MAiD provided	54	(43)
MAiD not provided	46	(37)
AGE AT TIME OF REQUEST		
32-49	6	(5)
50-70	45	(36)
71-92	49	(39)
SEX		
Male	54	(43)
Female	46	(37)
MARITAL STATUS		
Single	55	(44)
In a relationship	45	(36)

Results

CHARACTERISTICS	%	(n)
COUNTRY OF ORIGIN		
Canada	77	(62)
MATERNAL LANGUAGE		
French	81	(65)
English	9	(7)
Other	5	(4)
Not available	5	(4)
RELIGION		
Not documented	63	(50)
Christian	35	(28)
Jewish	1	(1)
Other	1	(1)

Results

Requests by diagnosis



REASONS FOR MAiD REQUEST (n=80)	%	(n)
1. Suffering	**91**	(73)*
a. Physical (pain, dyspnea, nausea)	*38*	*(30)*
b. Existential/loss of meaning	*24*	*(19)*
c. Psychological	*20*	*(16)*
d. "Exhaustion"	*5*	*(4)*
2. Control	**75**	(60)
a. Control timing/manner of death	*34*	*(27)*
b. Avoid future suffering	*18*	*(14)*
c. Avoid loss of dignity	*12*	*(10)*
d. Avoid a "bad death"	*6*	*(5)*
e. Avoid loss of capacity	*5*	*(4)*
3. Loss of Future	**25**	(20)
a. Condition is evolving, no Rx	*16*	*(13)*
b. Loss of hope	*5*	*(4)*
c. Tired of fighting/suffering	*4*	*(3)*
4. Decreased Quality of Life	**24**	(19)
5. Minimize impact on others	**20**	(16)
6. Loss of autonomy	**19**	(15)
7. No articulation of the reason	**12**	(10)

Results

REASONS MAiD NOT PROVIDED (n=37)	%	(n)
Lost capacity during the process	35	(13)
Did not meet Eligibility criteria	22	(8)
Incapable	*11*	*(4)*
Not at end of life	*5*	*(2)*
No advanced decline	*3*	*(1)*
No persistent suffering	*3*	*(1)*
Died suddenly of natural causes	19	(7)
Changed their mind	14	(5)
No reason documented	5	(2)
Symptoms required sedation	5	(2)

Received palliative sedation instead 19% (7)

Results

Cases counted after introduction of Bill C14 in July 2016 (n=38)		
	%	(n)
MAiD provided <10 days	60	(23)
Reason why		
Fear of loss of capacity	30	(7)
No reason documented	26	(6)
Worsening symptoms (imminent death)	22	(5)
To avoid provider based delays	13	(3)
Patient demand	9	(2)

Results

FAMILY INVOLVEMENT	%	(n)
Family aware of request (n= 80)		
Family aware	95	(76)
Requested family not be informed	5	(4)
Family present for MAiD (n=43)		
Family/friends present	81	(35)
Family/friends not present	7	(3)
Data not available	12	(5)

Results

CHARACTERISTICS	%	(n)
PALLIATIVE CARE		
Involved prior to MAiD request	68	(54)
Involved the day of or after their request	18	(15)
Not involved	14	(11)
LEVEL OF INTERVENTION		
Had an LOI of 1* or 2	20	(16)
Receiving LST at time of request	19	(15)

- 10% (8) had no LOI form at time of request so treated as a “1”
- 5% (4) never had an LOI form completed

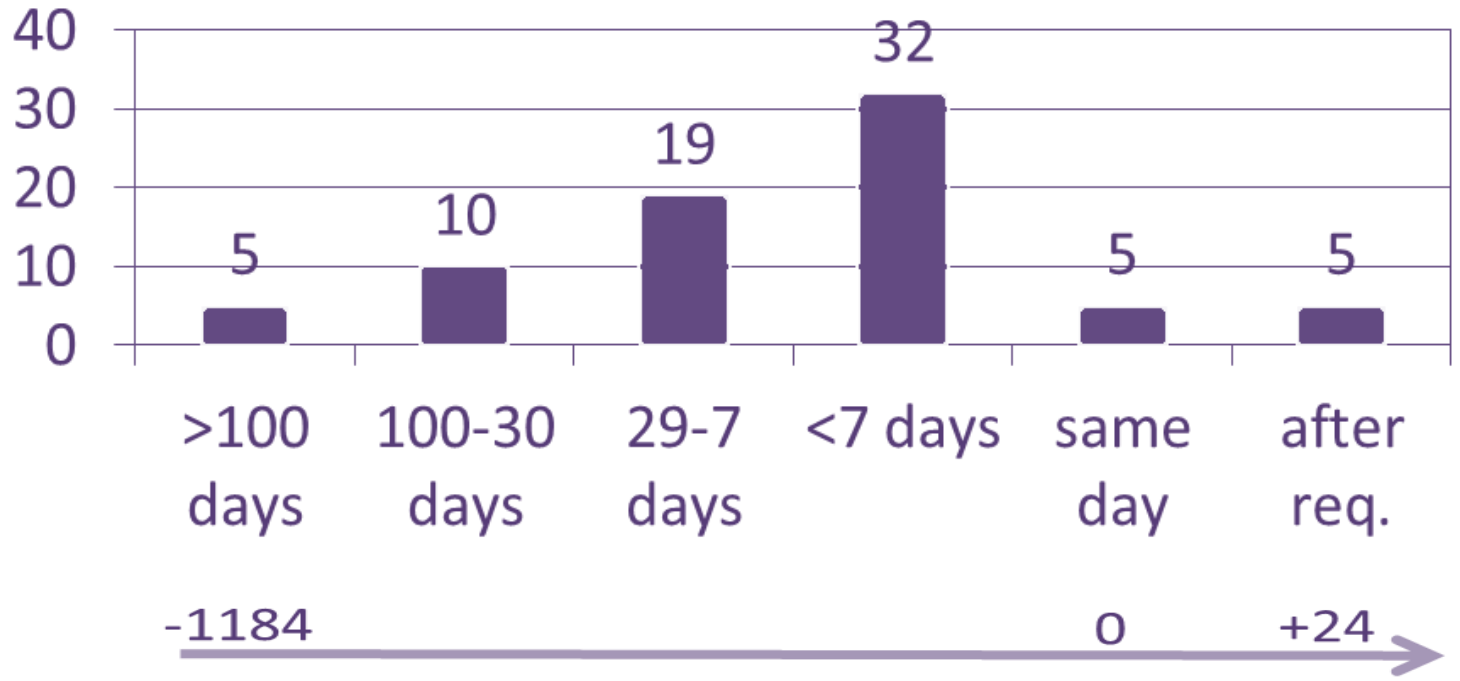
Results

CHARACTERISTICS	Median (days)	Total (n) of cases
TIMING **Median # of days between:**		
MAiD request : death (all)*	6	(43)
MAiD request : death (after 10 day rule) *	7	(37)
MAiD request : LOI form	6	(76)
MAiD request : Palliative Care involvement	5	(65)**

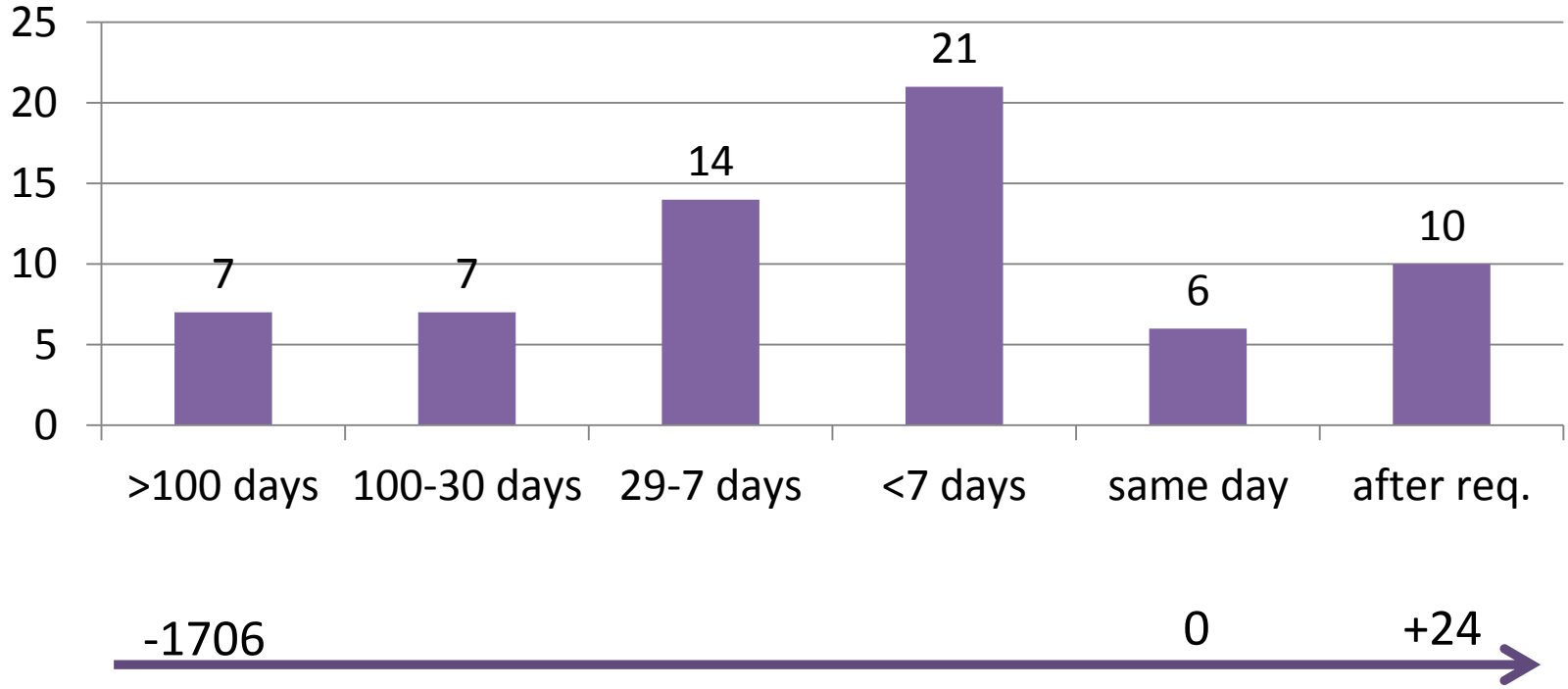
*Cases counted only if they received MAiD
** 65 cases where exact date was identified (69)

Days b/w LOI form and MAiD request

n=76



Days b/w PC involvement & MAiD request



*n=65: 4 other cases had PC involved but we could not identify the specific date (likely to be early)

Discussion

1. Demographics consistent with what has been reported in the literature.
2. The “10 day rule” and the emerging phenomenon of “emergency MAiD”
3. Situating MAiD in the broader context of end-of-life care

Discussion:

10 day rule…

- Bill C 14 Section 3(g) (Safeguards)
  - If 2 evaluators agree that death or loss of capacity is imminent, evaluators can jointly decide on a shorter time period appropriate to the circumstances.

The 10 day safeguard

- There were 38 cases bound by the 10 day rule.
- 60% (23) of these cases, MAiD provided <10 days (0-9 days)
- 30% (7) C-14 compliant: fear of loss of capacity
- 22% (5) C-14 compliant?: “worsening symptoms”
  - *Most cases involving worsening symptoms were referred to in chart as “emergency MAiD”*

The 10 day safeguard

- 3 of 5 requesters with worsening symptoms refused medication due to fear of loss of capacity and thus access to MAiD.
- Does # of “emergency MAiD” cases indicate that end of life criteria too stringent and/or patients are waiting very late in the process to make requests?

The 10 day safeguard

- Issue has received little discussion to date…but our data suggests this is something to consider.
- “We have now taken the position in our MAiD program that it is neither desirable nor practically feasible for MAiD to be delivered on an emergency basis at the very end of life.”(Li et al, 2017)

Discussion:

3 Key Questions…

1. Is the 10 day rule a reasonable safeguard?
2. Are worsening symptoms and/or patient demand ethically justifiable reasons to waive the 10 day rule?
3. Are there situations in which MAiD should be provided urgently?

Discussion:
Situating MAiD: Key Questions…

1. How are requests for MAiD situated?
2. Does our data imply anything with regards to the timing of end of life discussion?

1. How are Requests for MAiD situated?

- Similar to other literature on end-of-life discussion and decision making (relatively late); (median 6 days prior to death).
- The majority of MAiD requests came within 7 days of palliative care involvement or LOI form completion.
- Requests for MAiD may actually be “prompting” end-of-life discussions.
  - In 31% of cases MAiD was requested before palliative care was involved (14% never involved),
  - In 13% of cases LOI forms were completed following the request.
  - In 20% of cases LOI was a 1 or 2 at the time of request.

Limitations

- Retrospective chart review is reliant upon quality of documentation and does not comprehensively represent the experience of patients at the end of life.
  - Proxy measure E.g. documentation of “reasons” for MAiD request, physician’s summary of patient’s reasons.
  - Chronological order e.g. LOI may have been discussed weeks prior to the form being filled out.
  - Community care vs hospital records
- Only patients who completed a formal request form were studied; numbers relatively small.
- Only 3 sites in context of documented geographic differences

Conclusion

- MAiD patterns in Quebec - consistent with what is known in the literature.
- “Emergency MAiD” is an emerging phenomenon.
- The current exceptions (death & capacity) to the 10 day rule may be too narrow; worsening symptoms is a prevalent reason for non-compliance.
- Access to PC does not necessarily prevent requests for MAiD.
- Chart review likely not the best way to capture MAiD in context of end-of-life care. Future studies planned.

THANK YOU!

QUESTIONS/COMMENTS?