

Advance Care Planning in Primary Care: A Step toward Normalizing the Conversation

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TABLE 1.
Demographic and clinical characteristics of patients who had ACP conversation(s) with their family physician and/or specialist documented in the EMR

Characteristic	Patients with documented ACP conversation(s)		
	Family physician* (n = 17/200)	Family physician triggered by COVID-19† (n = 4/17)	Specialist‡ (n = 4/200)
Age at the time of ACP conversation, [§] year, mean ± SD (range)	83.9 ± 6.5 (72–97)	88.3 ± 2.9 (86–92)	81.0 ± 11.1 (65–89)
Age group, year, number (%)			
95–99	1 (5.9)	0 (0)	0 (0)
90–94	2 (11.8)	1 (25.0)	0 (0)
85–89	6 (35.3)	3 (75.0)	2 (50.0)
80–84	3 (17.6)	0 (0)	1 (25.0)
75–79	3 (17.6)	0 (0)	0 (0)
70–74	2 (11.8)	0 (0)	0 (0)
65–69	0 (0)	0 (0)	1 (25.0)
Sex, number (%)			
Male	3 (17.6)	0 (0)	2 (50.0)
Female	14 (82.4)	4 (100)	2 (50.0)
Ethnicity, number (%)			
Black	0 (0)	0 (0)	1 (25.0)
East Asian	3 (17.6)	1 (25.0)	1 (25.0)
Latin American	1 (5.9)	0 (0)	0 (0)
White	9 (52.9)	2 (50.0)	2 (50.0)
Not available	5 (29.4)	1 (25.0)	0 (0)
Born in Canada, number (%)			
Yes	6 (35.3)	1 (25.0)	0 (0)
No	9 (52.9)	3 (75.0)	2 (50.0)
Not available	2 (11.8)	0 (0)	2 (50.0)

Characteristic	Patients with documented ACP conversation(s)		
	Family physician* (n = 17/200)	Family physician triggered by COVID-19† (n = 4/17)	Specialist‡ (n = 4/200)
ESL, number (%)			
Yes	8 (47.1)	3 (75.0)	2 (50.0)
No	9 (52.9)	1 (25.0)	2 (50.0)
Religion, number (%)			
Jewish	6 (35.3)	1 (25.0)	2 (50.0)
Christian	1 (5.9)	1 (25.0)	1 (25.0)
Not available	10 (58.8)	2 (50.0)	1 (25.0)
Living situation, number (%)			
Alone	11 (64.7)	3 (75.0)	2 (50.0)
With family	3 (17.6)	0 (0)	2 (50.0)
Retirement home	2 (11.8)	1 (25.0)	0 (0)
Long-term care home	1 (5.9)	0 (0)	0 (0)
Number of chronic conditions per patient, median (IQR)			
	3 (2 to 4)	3 (2 to 4.5)	5 (5 to 5.3)
Chronic conditions, number (%)			
Cardiac/vascular disease§	10 (58.8)	2 (50.0)	3 (75.0)
MCI/Alzheimer's/dementia	9 (52.9)	2 (50.0)	1 (25.0)
Neurological illness**	5 (29.4)	1 (25.0)	1 (25.0)
Respiratory disease††	4 (23.5)	1 (25.0)	3 (75.0)
Cancer	4 (23.5)	0 (0)	2 (50.0)
Renal disease‡‡	1 (5.9)	0 (0)	2 (50.0)
Frailty§§			
	9 (52.9)	2 (50.0)	3 (75.0)
Number of ACP conversations per patient, median (IQR)			
	1 (1 to 1)	1 (1 to 1.3)	1 (1 to 1.5)
SDM(s)/attorney(s) for personal care/family present during ACP conversation(s), number (%)			
	7 (41.2)	2 (50.0)	2 (50.0)

ACP = advance care planning; EMR = electronic medical record; ESL = English as a second language; IQR = interquartile range; MCI = mild cognitive impairment; SD = standard deviation; SDM = substitute decision maker.

* n = 1/17: Attorneys for personal care had ACP conversations with both the family physician and the specialist (palliative care).

† One family physician proactively called patients aged >80 years in April 2020.

‡ Documented in a copy of a consultation note (n = 3: geriatrics, nephrology and general surgery) or hospital discharge summary (n = 1: general internal medicine) in the EMR.

§ Age at the time of first ACP conversation if the patient had more than one ACP conversation.

¶ Cardiac/vascular disease includes congestive heart failure, myocardial infarction, coronary artery bypass graft, aortic aneurysm, peripheral vascular disease and other cardiac and vascular conditions.

** Neurological illness includes stroke, traumatic brain injury and other neurological conditions.

†† Chronic respiratory disease includes asthma, chronic obstructive pulmonary disease, bronchiectasis and other chronic respiratory conditions.

‡‡ Renal disease includes chronic kidney disease, renal failure and other renal conditions.

§§ Frailty was defined as per Clegg et al. (2013) and Engelhart et al. (2022). According to Engelhart et al. (2022: E51), "Frailty is a syndrome characterized by reduced physiologic reserve that renders an individual more susceptible to adverse outcomes in response to stressors. Frailty is an underrecognized clinical entity that is distinct from normal aging. In frailty, an accelerated decline results from an accumulation of health deficits, leading to dysregulation of multiple systems over time. Many interrelated biological (e.g., genetics), clinical (e.g., underlying comorbidities) and socioeconomic (e.g., social isolation) factors contribute to this accelerated decline, with frailty being a final common pathway."

TABLE 2.
Themes, subthemes and representative quotations from documented ACP conversations

Theme	Subtheme	n*	Representative quotations
Understanding	Cognitive/memory issues	≤5	“[S]omething hit me over the holidays, I feel old and slow, [find it] hard to walk, [I am] not myself, cannot write ...”
	Frailty [†] /loss of functional abilities	≤5	“[The patient expressed concerns of] memory loss, [it] bothers them. [The patient stated], ‘I feel incapable, cannot get back to myself. I forget names of people. I have been attending the memory clinic. [However, currently], I am walking and talking and making my decisions.’”
	Disease (e.g., cardiac, renal)	≤5	“[The patient and family] all understand that [the patient] could pass away from their illness even within the next few months.”
Information	Disease (e.g., cancer, cardiac, respiratory)	6	“[The patient] asks about why this is happening. [I] explained their illness is multifactorial, they will always have some illness, [and it] will need to be managed.”
	Frailty [†]	≤5	“[I] discussed [the] diagnosis; [the patient is] aware and understands. [The patient is] willing to do treatment if I recommend it. [I] reviewed that it is worthwhile to do when early in illness, can prevent long-term sequelae. [The patient] agrees. I will relate that to [the] specialist.”
	Cognitive/memory issues	≤5	
	COVID-19 [‡]	9	“[I] discussed their illness. [It] can [be] managed [but] not cured.”
	Within ACP conversations	≤5	“I spoke to [the patient’s family] about the nature of end-stage illness and what happens to the body during this time, and how it includes loss of oral intake and increased fatigue.”
	Outside ACP conversations	≤5	“[I] discussed symptoms of COVID-19, typical and atypical. [I] discussed treatments if ill: fluids, Tylenol, rest and call[ing] for help [if needed]. [I] discussed at >80 [years old], if [the patient] got ill, [they] may need admission if [they experience] SOB. [There is a] chance of needing ventilation, if needed then only [a] very small chance (2 to 3%) that [they] would be in health after. [They] would need 14 or more days on vent[ilation].”
Values, beliefs, life goals and quality of life§	Values	7	“[F]ear loss of dignity and independence more than death.”
	Independence	≤5	“[F]ear degradation and indignity far more than death.”
	Dignity	≤5	
	Loved ones		“They have had to use a walker, and their [family member] has moved in with them to help [with] their loss of independence.”
	Family	25	
	Friends	≤5	“[The patient] cannot drive anymore, hates to depend on others. [The patient currently lives in a retirement home, but] will move into a home of one of their kids with [a] caregiver. [A]fter that they feel MAiD is [the] ‘right thing to do.’ [The patient is] mindful and independent.”
	Pets	10	
	Spirituality [¶]	21	
	Cultural background ^{**}	37	“[The patient] would like to go to [another country] to live with their [family member]. [I] discussed [that the] patient is at high risk [of COVID-19] and [the other country poses] higher risk than here. [The patient] will have to be more cautious, [the patient is] aware. [The patient] has [a] compromised immune system.”
	Previous/current career ^{**}	104	
Activities/hobbies (e.g., sports, arts, music, reading, knitting, gardening, etc.)	75		
Travelling	72	“[A]llow me to die with dignity.”	

Theme	Subtheme	n*	Representative quotations
Trade-offs	Physical or cognitive abilities	≤5	"[F]unction is very important; [the patient] does not want to be in a wheelchair."
	Values	≤5	"[They] do not wish to remain alive if they cannot participate in life and enjoy life."
	COVID-19	≤5	
	Enjoying food	≤5	"[The patient and family] have relaxed [the patient's] dietary restrictions somewhat to allow for more quality of life, especially as their electrolytes are within acceptable limits." "[I] discussed risks/benefits of having [grandchildren] over – in their case, they feel the benefits of socialization and preventing depression outweigh the risk of COVID." "If [I] got COVID-19, [I] would want to stay at home, and be treated at home, not go on a ventilator, even if it meant that I would not survive."
Worries and fears	Loss of independence	≤5	"[The patient is] worried about memory, forgets conversations or events, remembers things from years ago."
	Loss of dignity	≤5	
	Loss of capacity	≤5	"[T]hey feel like they cannot do anything. [A family member] is there doing everything for them. The RN is coming still, twice per week. They feel like a burden to their family."
	Being a burden on others	≤5	
	Being in pain	≤5	"[The patient has a] fear of the future and dying."
	Loss of health	≤5	"[They] fear they will die at home alone."
	Financial issues	≤5	
Sources of strength	Spirituality	≤5	"[T]hey pray and like to go to church when [the church is] empty."
	Loved ones	≤5	
Near the end	Preferred location at EOL	≤5	"[I] would want to stay at home."
Future care wishes	Legal documents (e.g., will, POA/SDM/NOK, advance wish), funeral planning	24	"[I] also recommend review[ing] POA medicine and POA finances [to] ensure that they are in place." "They have a living will in place, and both of their [children] have shared power of attorney over their finances and personal care."
	Code status/GOC (e.g., life-sustaining treatments, DNR, palliative care, etc.)	21	"[The patient indicated] full code." "[The patient indicated] DNR, no mechanical ventilation but would want cardioversion for their illness." "Effectively, most of the children are still in favour of life-prolonging measures, including treatment in hospital with IV antibiotics." "[The patient] has consistently expressed their wish to not try dialysis, to both their [family] and to our clinic team. [However,] they wish to be [provided with other] medical [treatments if indicated]. We have talked about a palliative care referral down the road, and will initiate this when it is needed." "[I] discussed [a] palliative care referral – [the] family would like active treatment of conditions that are reversible but [have decided on] DNR. [The family] prefers that I do not expedite palliative care visit due to current treatment for illness." "[The patient's family] are clear they do not want CPR, intubation, tube feeding or transfer to ER." "Goals of care: DNR; comfort is important; [they] don't want to prolong life but also do not want to hasten it. No [gastric tube]. No hospitals. [The family] would like [the patient] to stay in their retirement home."

Theme	Subtheme	n*	Representative quotations
Future care wishes (continued)	EOL planning/ACP (e.g., future living arrangements, assistance with ADLs/IADLs, safety, etc.)	14	<p>"[I] discussed POA, MedicAlert, private cleaner, living will."</p> <p>"[I discussed] advance care planning – [the patient and their spouse] have POA [documents] for each other. [They] would consider [their] children [as POAs]. [They are] living in a house with everything on one level; across the street is an assisted living location [they] are talking [about]. Living will [has been] given."</p>
	Discussed with family	≤5	<p>"[I] discussed advance planning – residence has [a] pendant [for the patient] to wear, supervision for emergencies. [The patient] has [their] will done, [has made] funeral arrangements and [completed a] power of attorney [document]. I have [telephone] numbers for [POA and family]. [I] discussed finding a place where cooking is not necessary [for the patient to] consider two years hence."</p>
	Directed ACP conversations: COVID-19 (e.g., POA/SDM/ NOK; code status/GOC, e.g., intubation, mechanical ventilation, DNR, palliative care, etc.; preferred location at EOL; provided a link to the "Speak Up Ontario" website (HPCO n.d.b.)	≤5	<p>"[They have] advance care plans. DNR [is] in place. [T]hey will send me a copy, do not want any heroic measures. [I] discussed what could happen if they got infected. [I] discussed many survive, death is not certain, many are sick for two weeks [with] cough, fever, SOB [or] may not get fever. Home care, via CCAC and MDs; perhaps me if near otherwise through CCAC. [Family member] is POA for both personal care and for finances. [I]n the case that they get ill the [patient] will go to their [family member's home]. [I] advised [the patient to] check websites, send me [the] POA [document] and [a] copy of their My Wishes: Covid19toronto.ca makingmywishesknown.ca."</p> <p>"[I] discussed symptoms of COVID-19 [and treatment], if ill. [The patient] would want to stay at home, would not want ventilation, would call Lifeline. Patient cannot access internet, I will call their [family member] to discuss makingmywishesknown.ca."</p>

ACP = advance care planning; ADLs = activities of daily living; CCAC = Community Care Access Centre; CPR = cardiopulmonary resuscitation; DNR = do not resuscitate; EOL = end of life; ER = emergency room; GOC = goals of care; IADLs = instrumental activities of daily living; IV = intravenous; MAiD = medical assistance in dying; NOK = next of kin; POA = power of attorney (for personal care); SDM = substitute decision maker; SOB = shortness of breath.

* Counts less than or equal to five are not displayed to protect patient privacy.

† Frailty was defined as per Clegg et al. (2013) and Engelhart et al. (2022).

‡ COVID-19 information provided by the physician within ACP conversations included the patient's risk due to age and/or underlying health condition(s) and what could happen if the patient were to become infected with COVID-19 (e.g., symptoms, treatment options, possible outcomes). In contrast, COVID-19 information provided by the physician outside ACP conversations included risk of transmission, risk of travel, compromised immune system, vaccines, public health guidelines, etc.

§ Values were often revealed in trade-offs or worries/fears.

¶ Spirituality was often noted to be an important factor guiding healthcare decision making.

** Social history source.