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Peer Reviewed

Euthanasia in Mental Illness: A Four Part Series

Part I: The Case of EF

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Abstract:

A female, known only by her initials, EF, died by euthanasia in June 2016. She is the only known case of euthanasia for mental illness in Canada. Euthanasia for mental illness has since been outlawed by Bill C-14. Part 1 of this 4 part series describes how and why this occurred, highlighting some of the major problems that arise when mental illness is used as the justification for euthanasia.

Keywords: euthanasia, mental illness, EF

Sometime in early June 2016, a female patient known only by her initials “EF” died by euthanasia somewhere in the lower mainland of British Columbia (BC). EF lived in Alberta but the euthanasia took place in BC. This to my knowledge was, and is, the first and only individual with a primary mental illness who has been euthanased in Canada.

Many jurisdictions around the world have struggled with euthanasia but only a few such as Belgium, Switzerland, and the Netherlands have allowed euthanasia where the sole medical condition is a mental illness. In the narrow window of 6 to 17 June 2016, Canada joined this group. Bill C-14 has eliminated euthanasia for mental illness for now but the debate is ongoing and the provision against euthanasia for mental illness will likely be challenged. On 13 April 2017, Adam Maier-Clayton who had Somatic Symptom Disorder against a background of depression, anxiety, tics, obsessive-compulsive disorder, and dissociative depersonalization disorder, committed suicide (Franzoi, 2017; Hughes, 2017). He had lobbied for medical assistance in dying (MAID) for individuals with mental

illness. His father plans to continue his activism and this issue has not, and will not, go away.

The Background:

In February 2015, the law in Canada against helping someone die was overturned in a Supreme Court decision known as Carter 2015. The government of Canada was given 12 months, later extended to 6 June 2016, to come up with a new law governing MAID for someone who wished to end their life. A new law governing euthanasia in Canada known as C-14 came into force 17 June 2016. Until this new law came into effect, individuals could apply to the Supreme Court of their province for an exemption to allow euthanasia to proceed.

To qualify for this exemption, the applicant had to meet all 4 of the following criteria:
(1) the patient had to be a competent adult who (2) clearly consents to the termination of life, (3) had a "grievous and irremediable medical condition (including an illness, disease or disability)" that (4) caused "enduring suffering that is intolerable to the individual in the circumstances of his or her condition".

EF, opposed by Canada and BC with Alberta in an advisory capacity, had therefore applied to the Supreme Court of Alberta (Alberta Court of Queen's Bench) to allow her to proceed with euthanasia. She was fighting a deadline as C-14 was in debate and the promulgation imminent. Bill C-14 would have and did exclude mental illness as reason for euthanasia. The province of BC was involved seemingly because no physician in Alberta was willing to provide this intervention but there was one in BC, where her euthanasia did in fact take place.

The only clinical details about EF that are in the public domain have been published in the Court of Appeal of Alberta's (CAA) Memorandum of Judgment, May 17, 2016 (Canada (Attorney General) v E.F., 2016 ABCA 155 (CanLII)) and are as follows:

> "E.F. is a 58 year old woman who endures chronic and intolerable suffering as a result of a medical condition diagnosed as "severe conversion disorder", classified as a psychogenic movement disorder. She suffers from involuntary muscle spasms that radiate from her face through the sides and top of her head and into her shoulders, causing her severe and

> constant pain and migraines. Her eyelid muscles have spasmed shut, rendering her effectively blind. Her digestive system is ineffective and she goes without eating for up to two days. She has significant trouble sleeping and, because of her digestive problems, she has lost significant weight and muscle mass. She is non-ambulatory and needs to be carried or use a wheelchair. Her quality of life is non-existent".

A truly terrible condition and present for 9 years.

The Memorandum of Judgment (Canada (Attorney General) v E.F., 2016 ABCA 155 (CanLII)) adds: "While her condition is diagnosed as a psychiatric one, her capacity and her cognitive ability to make informed decisions, including providing consent to terminating her life, are unimpaired. She deposes that she is not depressed or suicidal, but "simply exhausted after years of suffering indescribable pain". Medical opinion evidence confirms that the applicant is not suffering from depression and is able to and is voluntarily consenting. Her mental competence is not in dispute. We also note that the applicant's husband and adult children are supportive of her decision"

In the Queens Bench's hearing, concerns were raised about the sufficiency of the evidence before the court, particularly the sufficiency of the psychiatric evidence. Canada also took the position that the applicant did not come within the criteria set out in Carter 2015 for two reasons: (1) the applicant's illness, however severe, is not regarded as terminal, and (2) the applicant's illness has at its root a psychiatric condition.

The evidence proffered, however, allowed the Queens Bench's judge to conclude that EF met the Carter criteria, overruled all other objections, and sanctioned the use of euthanasia. This judgment was issued on 5 May 2016.

The state represented by the Attorneys General of Canada and BC appealed the decision to the CAA essentially on the same grounds as those raised before the Queens Bench. The appeal to the CAA was heard by 3 judges. The role of the CAA is not to retry the case but in error detection and correction (Canada (Attorney General) v E.F., 2016 ABCA 155 (CanLII)). The Queens Bench's judgment has not been released. All we know of the evidence before the Queens Bench is that

contained in CAA's published judgment. No other details are known and there is an ongoing ban on publishing information that may identify the names and any other information involved in this matter.

In the Queens Bench hearing, the state seemingly had not provided their own medical experts and neither Canada nor BC took issue with EF's competency nor her ability to consent to the termination of her life.

The CAA denied the appeal and euthanasia was allowed to proceed.

The Problems:

Problem #1 - diagnostic uncertainty

Conversion disorder belongs to a category of psychiatric conditions called somatic symptom disorders (previously called somatoform disorders), where mental illness causing emotional turmoil manifests atypically as a disturbance in bodily function. Almost any bodily function may be involved. Pain is often associated or may be the primary and only symptom. Conversion disorder is a specific type of somatic symptom disorder where the symptoms are confined to the voluntary nervous system presenting, for example, as paralysis, movement disorders, or episodic attacks that look like epilepsy.

Conversion refers to the mental process whereby emotional turmoil (mostly depression and anxiety) associated with a destabilized mind is "converted" into neurological symptoms and signs. Psychic pain becomes physical pain and is reported as such (Hurwitz, 2004). Confusingly, similar symptoms may occur in individuals with identifiable neurologic damage. In conversion disorder, no such damage can be identified despite all investigations and critically, the pattern of symptoms does not, on careful scrutiny, match the pattern that accompanies identifiable neural tissue injury or malfunction. So caused symptoms and signs are identified by the qualifier psychogenic. Psychogenic signifies that the problem is due to a psychiatric illness.

Mild forms are common. Very severe forms occur less frequently, but when present, can cause profound distress accompanied by a major disruption in the patient's psychosocial functioning and

quality of life. The diagnosis is made only after a thorough assessment to exclude medically identifiable causes, calling upon the expertise of neurologists (especially those who have sub-specialized in the area of neurology relevant to the patient's presenting problem), and making use of the full battery of neurodiagnostic investigations such as MRI and EEG. However, many neurological conditions are not textbook presentations and some such as movement disorders do not have objectively identifiable neurodiagnostic markers. These "neurological" presentations remain dependent upon clinical judgment. For pure conversion disorders, there is a 4% chance that the diagnosis can be wrong. This is the updated rate of misdiagnosis in patients initially diagnosed with conversion disorder that over time, then turns out to have a neurological condition (Stone et al., 2005). In the past, this error occurred in 33% (Slater, 1965) to 15% (Mace & Trimble, 1996) of patients. A correctly diagnosed neurological condition may dramatically change the patient's available treatment options and hence prognosis and quality of life. Such may have been the case with EF. She presented with a severe movement disorder. Movement disorders in particular can be very bizarre and even amongst movement disorder specialists, the inter-rater agreement about diagnosis is only moderate (Morgante et al., 2013; van der Salm et al., 2013).

Diagnostic uncertainty may lead to a premature psychiatric diagnosis with major and, in EF's case, fatal consequences. EF may have had what is known as primary or secondary generalized dystonia and as such, may have benefitted from neurological therapies that include the possibility of deep brain stimulation. At the very minimum, her problem with blindness from blepharospasm could have been addressed and managed by using the simple intervention of botulinum toxin into her peri-orbital muscles.

I do not have access to her medical records and cannot pass an opinion on whether EF did or did not have a psychogenic movement disorder, but this would be the very first matter to address in anyone who presented as she did. She should have been seen at an academic center by a neurologist with tertiary level expertise in movement disorders, supported by a second opinion, and these opinions provided to the court.

The medical evidence submitted are sealed and we will never know. The diagnosis of conversion disorder can only be made by a neurologist after which care is transferred to a psychiatrist. None of

the medical opinions offered to the court were provided by appropriately skilled neurologists. The opining physicians upon whom the court relied would not have made the diagnosis themselves. These physicians would have had to accept the diagnosis made by others as a given, relying only on her paper record.

Here, the stakes for the patient could not be higher. As such, EF should have been seen and assessed in person by a psychiatrist who has sub-specialized in this area of psychiatry and who is familiar with somatic symptom disorders and the steps needed for diagnosis and the options for treatment. This sub-specialty is known as neuropsychiatry. I believe that in Canada, the neuropsychiatry group in western Canada (BC and Alberta) collectively represents the best experts in Canada on conversion disorder. There are 14 of us who have special training in this field or make this their chief area of psychiatric practice. I contacted them all, and none of us were consulted.

At the University of British Columbia (UBC) Hospital, there is a specialized neuropsychiatry inpatient unit where such patients with severe conversion disorder are treated. Calgary has neuropsychiatrists but not a dedicated inpatient unit, but could have arranged for an admission supported by their specialized input. We cannot, nor do not, claim to cure patients but we can and do make a difference. Even prior to the request for euthanasia, EF was never referred to this program or to the neuropsychiatrists in Calgary, and none of us were contacted to provide advice.

Problem #2 - suffering not dying

Somatic symptom disorders are mental illnesses and as with all mental illnesses, the patients are suffering not dying. Death in mental illness comes only from suicide or from the progression of an underlying brain disease that is causing the mental illness, such as Huntington's disease.

The suffering in mentally ill patients is complex and represents a combination of the mental illness itself combined with complex psychosocial factors where all and every contributor can be mitigated in some way. Euthanasia in this setting is highly problematic and morally taxing. Euthanasia for mental illness has to be clearly contrasted with euthanasia for individuals who are terminally ill from a medical condition and are obviously dying; death is imminent and unpreventable and the patient's suffering palpable and obvious. In such circumstances, it is very hard for any compassionate

physician not to do something to alleviate such terrible distress, knowing that medicine cannot prevent nature and disease from taking its final course. Euthanasia here is one such treatment option for those physicians where such a medical act does not contravene their own ethical and Hippocratic imperatives.

Problem #3 - the request for euthanasia in mental illness

In psychiatry, we diagnose someone who wants to die and has a lethal plan as having "active suicidal ideation" and mentally ill. The mental illness in question is almost always a severe depression. We need to be very clear here: the patient is suffering, not dying. Euthanasia in these patients is a request to assist with suicide: Medical Assistance in Suicide (MAIS), not Medical Assistance in Dying (MAID). The patient, in making this request, has a very clear suicidal plan – a lethal cocktail of medications to be administered by you. Such a request is never contemplated in an acute setting. To the contrary, psychiatry worldwide is entrusted by society to prevent such acts from taking place. This, after all, is the rationale for all mental health acts to allow a psychiatrist to involuntarily commit a suicidal patient to hospital and accept treatment against her or his will.

What happened?

Here is what we know:

Physician A was the applicant's attending physician who had been treating her for 28 years. That physician's affidavit stated "that EF was diagnosed with severe conversion disorder nine years ago. She has been seen by several psychiatrists and at least one neurologist, and has tried several treatments, none of which has succeeded in mitigating her symptoms. Her condition has remained largely unchanged for the last four years".

Physician B, a medical doctor with 40 years' experience and competent to provide physician assistance in dying but seemingly without any specialization, deposed that in her opinion, there are no further treatment options for the applicant that would offer any hope of improvement in her condition, or meaningful reductions in her symptoms. She stated: "Given the length of time the symptoms have been present, the treatment history and her lack of response, I considered her condition to be irremediable."

Physician C was the only psychiatrist. He was a psychiatrist with expertise in the applicant's condition, who reviewed EF's medical file, although he did not examine her. Physician C did not suggest that EF should try any particular further treatment. His opinion clearly stated: "that the applicant is suffering intolerable pain and physical discomfort, that her symptoms are irremediable and that she is capable of consent". He explained that, although some patients with conversion disorder can be successfully treated, there are other patients who "do not respond to treatment and develop a chronic unremitting course without resolution of symptoms. The longer the symptoms persist the worse is the prognosis. This is the case with the applicant".

The CAA's published judgment states "There is no reason to think that this experienced specialist would have rendered that opinion if he were not satisfied with the medical information he was provided, or if there was a treatment option that could or should be tried by the applicant. The motions judge (i.e. the Queens Bench judge) was entitled to accept the opinion of Physician C on this point, as she did".

But clearly this is the wrong advice to the courts. EF should first have been fully evaluated by movement disorder neurology specialists working in academic centers to ensure that her condition was psychiatric, not neurologic. I hope that she was, but there is no way of knowing other than that there was at least a 4% chance that her psychiatric diagnosis of conversion disorder was wrong even in experienced hands. And if she had a primary psychiatric illness, then she and the courts should have been made aware of the specialized inpatient program at UBC that treats just such complex and severe conversion disorder patients or the availability of neuropsychiatrists in Calgary who could have arranged for a local admission with their input. Ignorance is not an explanation nor exculpation. The UBC Neuropsychiatry Program is well known in BC and has been in existence since 2000, and a Google search will show our brochure "Somatoform Disorders BC" on the first page.

How does a physician make a diagnosis outside of their expertise that carries such a grave and irreversible consequence and at a distance, by examining the paper record and not the patient herself? How would you know if the patient was or was not depressed? But the medical evidence given to the courts as per the Memorandum of Judgment was that EF was not depressed – a

conclusion apparently made by reading her medical records.

The state opposed the initial application to the Queens Bench of Alberta and again at appeal to the CAA about the sufficiency of the evidence before the courts and in particular, the sufficiency of the psychiatric evidence. BC held that “in a case that involves a relatively poorly understood psychiatric condition for which treatment results can vary, there should be an evidentiary requirement to provide the court with direct evidence from a psychiatrist with expertise in the condition who has seen the applicant”.

But where are the state’s medical expert opinions, and why did the Queens Bench not want to hear from opposing medical experts and in particular from experts who had in fact examined EF in person? This is a fundamental principle in medicine. How much more so, when the treatment prescribed, whether administered personally or by a third party, will result in the worst imaginable adverse effect: a guaranteed death.

The courts were misled and the judicial and medical systems failed. The judges may have come to a different conclusion.

The case of EF provides a sobering account of how a well intended societal initiative to allow suffering and dying patients to seek assistance in dying more peacefully can be appropriated to apply to mentally ill patients who are suffering but not dying. The medically ill patient does not wish to die. Their choice is whether to linger and suffer until they die or to die sooner and more peacefully. The mentally ill patient is suffering not dying. The mentally ill patient wishes to die but this wish is a symptom of a disordered mind in which suicidality is an inextricable part of their mental illness.

There are clear differences between terminally ill patients who ask for help in dying and mentally ill patients who are suicidal. The rest of this series tries to come to grips with these differences. Part II addresses the reasons why mentally ill patients are suicidal and why this is so important to understand. Part III addresses the issue of capacity to consent in mental illness. Finally, Part IV speaks to the ethical framework that can be usefully applied by physicians and other health

professionals when asked by a mentally ill patient to assist them to die.

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