

Article

Caregivers and Family Members' Vulnerability in End-of-Life Decision-Making: An Assessment of How Vulnerability Shapes Clinical Choices and the Contribution of Clinical Ethics Consultation

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Abstract: Patient-and-family-centered care (PFCC) is critical in end-of-life (EOL) settings. PFCC serves to develop and implement patient care plans within the context of unique family situations. Key components of PFCC include collaboration and communication among patients, family members and healthcare professionals (HCP). Ethical challenges arise when the burdens (e.g., economic, psychosocial, physical) of family members and significant others do not align with patients' wishes. This study aims to describe the concept of vulnerability and the ethical challenges faced by HCPs in these circumstances. Further, it assesses the contribution of clinical ethics consultation (CEC) in assisting HCPs to face these difficult ethical conundrums. Two clinical cases are analyzed using the Circle Method of CEC. The first regards the difficulty faced by the doctor in justifying treatments previously agreed upon between the patient and his/her friends. The second regards the patient's concern about being a burden on their family. Family burdens in EOL settings challenge PFCC in that patient autonomy may be disregarded. This compromises shared decision-making between the patient, family and HCPs as a core component of PFCC. In their ability to promote a collaborative approach, CECs may assist in the successful implementation of PFCC.

Keywords: end of life; clinical ethics; vulnerability; patient-and-family-centered care; communication



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1. Introduction

Vulnerability is a critical aspect at the end of life (EOL) [1,2]. When the patient can no longer recover and the course of care is aimed only at pain and symptom control, meeting the patient's physical and emotional needs and ensuring the highest possible quality of life for the time remaining is paramount. EOL care implies making not only clinical but also existential decisions that may affect the patient and the patient's family alike. For instance, because patients are embedded in a social structure and a web of social ties, patient-and-family-centered care (PFCC) is critical at the EOL [3,4]. Shared decision-making between HCPs, patients and family members is core to the successful implementation of PFCC [5].

Based on the principle of respect for patient autonomy, the acquisition of the patient's written or verbal consent is mandatory prior to performing any medical treatment. However, the patient's right to choose regarding his/her health and care pathway may be influenced by his/her interpersonal relationships with the other individuals involved in the clinical case.

Healthcare decisions are always based on the criteria of clinical appropriateness and proportionality, requiring consideration of the existential burdens of the disease/condition experienced by patients and their families [6]. The debate on whether or not it may be justifiable for a patient to consider a treatment to be no longer subjectively bearable in

physical terms (the degree of resistance varies from person to person) remains open [7–9]. Similarly, scholarly discussions surrounding the acceptability of treatment refusal by the patient based on the burdens (again, in primarily existential terms) that his/her care entails for his/her family members are ongoing [10]. One should also note the case in which the patient is no longer competent, and caregivers put forward a request for treatment withholding/withdrawal based on the burdens implied in their actions of care [11–13].

Burdens play a role in defining treatment proportionality; however, it is necessary to examine whether and to what extent it is possible to consider such burdens in decision-making. The inadequate consideration of burdens in decision-making carries the risk of endorsing a culture that excludes vulnerability as a hindrance to a life that does not admit the burden of caring to be considered worth living [14].

In particular, in a hospice or home setting, being close to a beloved dying person entails two conditions. On the one hand, family members witness their beloved person's psychophysical deterioration and suffering caused by an illness that is taking over. On the other hand, they recognize that their beloved one's vulnerability requires "taking care", implying burdensome daily actions that are sometimes experienced as overwhelming [15].

Patients with advanced illness may experience different types of "existential challenges" [16], including the sick person's self-identification with being a burden to his/her family. A self-perceived burden is the "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feeling of responsibility, and diminished sense of self" [17].

A self-perceived burden is not without psychosocial, economic and cultural difficulties, and it leads to the identification of family members, informal caregivers and sometimes HCPs as vulnerable subjects [18–20].

Similar to the dying person, the caregivers holding responsibility for the provision of EOL care often experience negative physical, mental, emotional, social and economic consequences [17].

The patient, family members and HCPs have different and unique perceptions of the concept of quality of life. This influences each person's existential condition [21–25] and, in turn, has an influence on the criterion of treatment proportionality. Evidence shows that clinical ethics consultation (CEC) is a useful supplement for the analysis and resolution of ethical challenges and for the promotion of shared decision-making [26–28].

In this study, we aim to assess the contribution of CEC in determining the relationship between the concept of vulnerability and the ethical challenges faced by HCPs when the wishes of patients and family members/significant others misalign. Further, we aim to determine the role of CEC in assisting HCPs to face these difficult ethical conundrums.

2. Materials and Methods

2.1. Study Setting

We analyzed two emblematic clinical cases (Case Vignette 1 and 2) that occurred in a hospice in Northern Italy. The cases were chosen for their ability to exhibit the aspects of vulnerability associated with significant others (e.g., friends) and family members, respectively. Based on the criterion of treatment proportionality, these cases show the relation between vulnerability and burdens, with the final goal of accompanying the dying patient to their *exitus* in the best possible way.

In both cases, HCPs were challenged by difficult conundrums and recognized the need for CEC to maintain a healthy relationship between the dying person, family members/friends and HCPs, allowing the successful implementation of shared decision-making as a critical aspect of PFCC.

Case Vignette 1

Does the physician always have to convince the patient's entire social context? If the patient agrees to the treatment, why is it necessary for the physician to have the approval of family members or friends?

Mr. G. was a 65-year-old physician, with a cohabitant partner and two sisters. He was admitted to the hospice with a neuroendocrine carcinoma diagnosis. He had infiltrate lung cancer and a complementary diagnosis reported atrial fibrillation, heart failure and anemia. He was hospitalized for a 39-day period prior to death.

The patient was always alone during the night. His two sisters and partner regularly came in for visits. He also had a pair of friends (husband and wife) who were medically competent (one was a dentist and the other a general practitioner) but had no experience in palliative care. For them, palliative care meant keeping the patient in the hospice, letting him do whatever he wanted, and allowing him to make decisions regarding his condition and quality of life. The two sisters and partner were never questioned by the patient's friends. They came to the hospice when the friends were not there.

The partner agreed to symptom therapy, to appease the patient, and she approved the use of morphine so that the patient could breathe easier, thus reducing dyspnea. The friends came to halt any medical procedures, and to persuade the patient to do nothing after their initial visit to the facility.

The patient was responsive to the palliative care to reduce the pain symptoms (he always accepted the treatment proposed by the doctors with an open mind and a positive attitude), but his friends persuaded him to change the therapy after every visit, with a hostile and critical attitude toward the treatment proposed by the doctors and accepted by the patient. They often said, "This treatment is no good! And you are no longer you!" For them, he was to live to the end of his life in full command of his own situation. He was completely conscious, although suffering and dyspneic, and he underestimated the symptoms, which were masked by morphine. The friends attributed his pain to a cardiological problem (cardiopathy), even though they knew that he would die from lung cancer.

The ward physician was bewildered and disappointed. Confident in the suitability of the treatments proposed and shared with the patient, he found himself in an uncomfortable situation: on the one hand, he did not want to take away the patient's ability to relate to his friends; on the other hand, he recognized the difficulty of communicating with them because of their critical and closed attitude.

Another friend, a lawyer, was favorable to the palliative care, but the other two competent friends silenced him. There was much coming and going in the room and, in general, the patient seemed to willingly accept all these visits.

A catheter was applied on day 32 after admission. On day 35, only a sister visited the patient. The patient was no longer able to stand up. For the four nights preceding his death, the patient slept in an orthostatic position, allowing him to breathe more easily. He was conscious and responsive until the evening preceding his death. As the patient was suffering intensely, during the evening of the patient's last day of life, a sleeping-aid therapy with Midazolam 5 mg was initiated. He then rested until early in the morning and died later on the same day.

Case Vignette 2

How do dying persons experience and manage the fear of being a burden on their families?

Ms. A. was a 75-year-old widow who resided alone in Southern Italy. She had a single son living in the northern part of the country, whose wife suffered from multiple sclerosis and was undergoing experimental treatment. Ms. A. was diagnosed with stomach cancer, which was initially treated with a gastric resection.

Her general condition progressively declined; a neoplastic stenosis requiring the application of a stent was detected 6 months following surgery.

The patient was told that, prior to chemotherapy initiation, the positioning of the stent would be essential to improve her appetite and stabilize her general condition. She requested hospice admission to accelerate recovery. Throughout their lives, there had been a good relationship between mother and son, based on mutual trust. However, given the lack of discussion surrounding the existential difficulties implied in an inauspicious prognosis, the relationship between the two was progressively deteriorating. The son had been informed of his mother's condition, but she did not know that he was fully aware of the situation.

Ms. A. was aware of the diagnosis but expected to recover physically and to be able to undergo chemotherapy; therefore, she withheld information from her son. The son had been informed that chemotherapy would not be feasible, but did not disclose this information to his mother.

During hospitalization, the contradiction between the lack of total honesty regarding her condition among family members and her frustration at not being able to live up to her son's expectations emerged. There was often silence in the room. The son and mother would not speak, except about superficial things, leaving out the topics that would be meaningful for their future. This silence confused the patient and embarrassed the son. The patient felt frustrated, and the son felt guilty about failing to tell his mother the truth.

The son shared his discomfort with the healthcare team. Together, they decided to progressively inform the patient about her prognosis, thereby creating a truthful climate in which, by acknowledging the expectations and goals of care, mother and son could have a more meaningful and truthful relationship.

As a result, she was gradually helped to become aware of the severity of the situation and seemed to accept her condition.

She also desired to be less of a burden to her son and daughter-in-law, given that the latter also suffered from a chronic pathology. This led to a state of discomfort and suffering.

Throughout the following weeks, the progressive and delicate communication to the patient of her real condition, and therefore of the unlikelihood of further specific therapies (chemotherapy), allowed her to accept her condition and led to a clear reduction in her existential suffering.

This led to a terminal phase during which the patient, the son and the daughter-in-law were able to share frank communication and a sincere relationship.

The patient became less and less independent, and her son and his wife welcomed her to their home after hospice discharge.

2.2. Definition of the Key Terms

Vulnerability: Etymologically, vulnerability is the predisposition to be easily attacked, offended or at risk [29–31]. In healthcare, vulnerability should not be confused with “susceptibility” and “frailty”. “Susceptibility” refers to an individual's biological predisposition to manifest a particular phenotype based on his/her genetic heritage; “frailty” outlines a psycho-physical weakness and the consequent likelihood of aggravating one's health condition [32].

The concept of vulnerability can also be a consequence of one's own or others' frailty that causes pain, fear and disorientation as one becomes aware of the severity of the situation. Thus understood, vulnerability has a direct impact on the existential factors (especially burdens) that directly affect the quality of life of both the patient and the people involved.

Proportionality: The determination of treatment proportionality is based upon a thorough evaluation of the clinical features, objective state of health, life circumstances, personal history, needs, psychological resources and personal values of individual patients. These must be acquired through careful listening and an open dialogue and over a sufficient

period of time. Therefore, it is within the relational process between a patient and the responsible clinician(s) that the ethical significance and acceptability of decisions can be established. Further, in palliative care and in the event of terminal illness, the proportionality criterion considers both terminality and existential burdens, respectively, for two reasons. At the EOL, the terminality criterion is predominant in the analysis of the course of treatment; “terminal” is similar to a diagnosis, offering some guarantees when affirming whether a specific treatment, in addition to being clinically appropriate, may also be considered proportionate. However, to avoid the violation of the patient’s right to autonomy, a terminality diagnosis, per se, should not be considered conclusive [33].

The existential burdens that regard both the patient and family members associated with a specific treatment play an important role in defining the criterion of proportionality during the course of care for terminally ill patients, because they have a direct influence on the subjective interpretation of quality of life.

2.3. Study Instrument

We used the Circle Method to analyze the two clinical cases. The Circle Method is a novel approach to the analysis and resolution of the ethics dilemmas arising in daily clinical practice (see Appendix A, Table A1).

The Circle Method consists of four circular sectors that make up the image of a circle. It is structured into four macro-sections responding to the following questions: Who needs the CEC? Who is involved? Why does this problem exist? How can we offer a solution? Each section addresses specific questions that continuously examine the relationship between the people involved and the current ethical dilemma [34].

This method presupposes both the analysis of the clinical–ethical aspects presented in the specific case (phenomenological aspects) and a dialogue between the speakers (hermeneutical aspects), and it highlights the relationship between practical experience and the resulting hermeneutical reflection.

When compared with the four principles approach and the casuistic method [35,36], the Circle Method has some major strengths. First, it enables consideration of the ethical dilemma at stake and, at the same time, of the person(s) asking for CEC (e.g., different persons may offer different solutions to an ethical dilemma). By doing so, the Circle Method identifies the objectivity of a story through the subjectivity of the storyteller. Further, it highlights the relationship between the practical experience and the theoretical reflection deriving from individual clinical cases. Finally, it stresses that phenomenological aspects develop from both the patient’s clinical condition and the ethical dilemma(s) of the subject(s) who request CEC.

3. Results

Analyses performed by the Circle Method reveal an interconnection existing between vulnerability and the existential burdens of the persons involved, as it is based upon the experiences of all parties involved in each case.

This relationship has the potential to strike a balance between care, the feeling of inadequacy and not knowing how to behave throughout the EOL journey, especially among family members and significant others. Further, it enables the clarification of the related existential burdens arising chiefly when the dying person’s wishes and the needs and possibilities of those providing care and assistance misalign.

3.1. Vulnerability and Ethical Challenges

The first case involved friends that the patient trusted completely. Because the friends defended an abstract, untrue idea of hospice and palliative care, this undermined the shared decision-making between the patient and the physician team.

In this case, the patient’s decision-making autonomy was significantly affected by his interpersonal relationships with his significant others. For instance, the patient was strongly influenced by the medically competent but non-specialist judgments of his friends; there-

fore, he did not de facto self-determine decisions regarding his treatments [27]. Given the patient's vulnerability, ensuring the patient's decisional autonomy about his care pathway required the attending palliative care physician to intervene with the patient's friends.

Despite the underlying good intentions and willingness to respond to the patient's needs, the behavior of the patient's friends came across as hostile to the care team and ultimately undermined the quality of the palliative care course.

The second case analyzed the dying person's fear of being a burden on her family (especially her son). In this case, the task of the HCP team was to carefully evaluate the objective aspects of the patient's condition (refractoriness and persistently viable therapies) and the subjective aspects of the relationship between the patient and her son. This engendered a means of communication that could make the patient fully aware of her prognosis and therefore recalibrate her expectations of care and establish a more truthful relationship with her son.

The role of the son was significant; together with the HCPs, he was able to allow the mother to recognize the unstoppable progress of the disease, the inability to restore her desired state of health and her limited life expectancy.

3.2. Contribution of Clinical Ethics Consultation

In the first case, regarding the doctor's request to obtain consent from the patient's friends, the request for CEC was made by the attending clinician. The doubt concerned the actual role of the patient's friends and their negative influence on the patient's willingness to pursue the course of treatment agreed upon with the HCP team earlier in the process. The main ethical challenge consisted in identifying ways to accept their criticisms, while, at the same time, exploring ways to explain the valid reasons for the specific care pathway proposed.

The doctor immediately grasped the seriousness of the situation, as the friends daily undermined the doctor-patient relationship by alarming the patient and suggesting the possibility of other types of care within the hospice. In this case, the irrational rejection of sedation in the management of refractory symptoms occurred when other treatment options were preferred but did not provide adequate relief. This strategy of avoidance also involves not wanting to deal with all the difficult discussions about sedation and the treatment of EOL issues, resulting in increased anxiety and excessive preoccupation regarding the death event.

The greatest difficulty consisted in recognizing the need to start a series of personal consultations with the parties to underscore the valid reasons for the treatment path chosen by the doctor.

The need to communicate with the patient's friends regarding treatment choices was shared with the attending physician. A series of 20 meetings was organized with the attending physician so that the friends could better understand the appropriateness of the methods and the objectives of treatment.

In the second case, CEC was requested by the medical and nursing teams. CEC was carried out within 24 h of the request, in the presence of the entire treating team. The doubt was about how to create a "truthful environment" in order to allow the patient to recalibrate her treatment goals and have a truthful relationship with her son.

The patient wanted to live up to her son's expectations despite the poor prognosis. The son and his wife, who suffered from multiple sclerosis, wanted to have a truthful relationship with the patient.

As a result of moving and profound meetings between the patient, the HCPs and the son, a more intimate and truthful relationship was created during the last few days of the patient's life. The patient peacefully lived her last days completely aware that her clinical condition would not negatively affect her relationship with her son.

The solution shared with all parties was to make the patient aware of the severity of her situation and to never leave her alone during or after the process of sharing the severity of the prognosis with her.

4. Discussion

This study shows that CEC allows a phenomenological and hermeneutical analysis of the peculiarities and difficulties related to the various aspects of the vulnerability of the actors involved in an EOL setting.

Further, our findings show the ability of CEC to promote a collaborative approach and to assist HCPs in the successful implementation of PFCC and improved shared decision-making.

From a phenomenological point of view, the first case illustrates the vulnerability of the patient's friends, in whom the patient placed the utmost trust. Subsequently, the hermeneutical analysis was useful to formulate a "good" solution. In line with prior studies [37–39], the literature on the caregiver at the EOL does not usually identify friends as caregivers. In this case, although the friends did not play this role, they undermined the shared decision-making between the patient and the HCP team by defending an abstract, distorted idea of palliative care. Despite their medical backgrounds, they were unable to ensure a positive caring relationship. This attitude weakened the shared decision-making and obliged the treating physician to deal with this extra existential burden. As Sossauer et al. [40] highlight, regarding the discrepancy between a patient's interests and the care provided, the burden of helping the friends to understand the situation more clearly, taken on by the treating physician, was interpreted (and thus chosen) as an aid to be offered to the patient, to best continue the relationships that would ensure the highest possible quality of life during the patient's final days of life. The care team was then told that they needed to perform an extra task in addition to their normal daily activities.

The clinical and ethical resolution was to share, especially with the friends, the idea of ensuring the patient the highest quality of life for the time that they had left to live, while limiting as much as possible the major symptomatology that would make the patient increasingly vulnerable. This sharing was achieved thanks to the daily willingness on the part of nurses and doctors to engage in conversations regarding the excellence of the treatments in the patient's course of care.

In the second case, CEC allowed an initial phenomenological analysis, which served to examine the patient's objective (e.g., refractoriness and proportionate therapies) and subjective (e.g., request to be informed about the prognosis, strengthening the bond with her son, relying on him) features. The consequent hermeneutic reflection allowed us to analyze the theme of vulnerability experienced by both mother and son. The patient's son played a relevant role. As Zaninetta et al. suggested, there is often difficulty among relatives to talk about death and EOL, most often creating a "communicative desert" in which silence fills the moments lived together [41].

The mutual recognition of each other's vulnerability caused an initial relational detachment between mother and son. Sharing her poor prognosis with her son enabled a relationship in which the patient was able to live out the last chapter of her life more truthfully, by sharing the experience with her loved ones and by relying on them.

5. Conclusions

Burdens play a role in creating conditions of vulnerability. Family burdens in EOL settings challenge PFCC in that patient autonomy may be disregarded. This compromises the shared decision-making between the patient, family and HCPs as a core component of PFCC. Burdens must be considered when utilizing the proportionality criterion, especially when there is intrinsic ambiguity regarding the risk of endorsing a culture that is oriented toward not taking care of the most vulnerable. CEC creates the conditions for this ambiguity to be ultimately cleared up. By doing so, vulnerability and its associated burdens may not be considered as valid reasons to abandon those in need. In contrast, CEC enables the identification of vulnerability as a limitation inherent to the human condition, which, as such, should be dealt with and shared within the context of human relationships.

CEC is an effective means of accompanying different parties toward a good choice. CEC promotes the therapeutic relationship and contributes to improving the quality of patient care by deepening the ethical awareness of all parties involved. Hence, the importance

of both family and friendships and professional relationships is highlighted; a network of people who can offer effective presence and services has the task of alleviating the burden of the single caregiver, whose presence is nonetheless obligatory. In its ability to promote a collaborative approach, CEC may assist in the successful implementation of PFCC.

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Informed Consent Statement: Patients provided a general written informed consent to processing personal data as part of the standard hospital procedures. The Circle Method was retrospectively applied by clinical ethics experts. Data were anonymized, and patients’ names were altered. Therefore, the subjects may not be identified and, according to Italian legal regulations (D.L. 196/2003, art. 110-24 July 2008, art. 13), the study did not require authorization from the local Ethical Review Board. The study was carried out in compliance with the ethical principles of the Declaration of Helsinki (with amendments) and Good Clinical Practice. All the data regarding the patients included in the study were treated and analyzed in compliance with the European General Data Protection Regulation (EU GDPR).

Data Availability Statement: The original contributions presented in the study are included in the article, further inquiries can be directed to the corresponding author.

Conflicts of Interest: The authors declare no conflicts of interest.

Appendix A

Table A1. Case analyses by use of the Circle Method.

| | <i>A</i> Case 1 | <i>B</i> Case 2 |
|--|---|--|
| (1) Who needs the CEC? | The physician | Medical and nursing staff |
| Why is it required? What is/are the issue(s) at stake? | To understand the necessity for HCPs to obtain treatment agreement by friends. | To understand how best to manage the patient’s fear of being a burden to her son. |
| How urgent is it? | The request was not urgent, but CEC was performed within 3 h of the request. | The request was not urgent, but CEC was performed within 24 h of the request with the entire HCP team. |
| Is/are there any doubts? | The doubt was about the actual role of friends and their negative influence on the patient to the detriment of the HCP team. The dilemma was between pushing them away to the detriment of the patient’s willingness to see them and accommodating their doubts by creating a pathway to explain/define the valid reasons for the specific course of treatment. | The question was how to create a “truthful environment” so that the patient could recalibrate her treatment goals and have a truthful relationship with her son. |
| Is/are there any other actors who share the same doubts? | The nursing staff | No |

Table A1. *Cont.*

| | <i>A</i> <i>Case 1</i> | <i>B</i> <i>Case 2</i> |
|---|---|---|
| (2) Who is involved? | Patient’s friends, family members and HCPs, EC | Patient, patient’s son, HCPs, EC |
| What is the patient’s history, diagnosis and prognosis? | 65 yo, m, neuroendocrine carcinoma, infiltrate lung cancer and complementary diagnosis reported atrial fibrillation, heart failure, and anemia, terminal prognosis. | 75 yo, f, stomach cancer with neoplastic stenosis, irreversible prognosis. |
| What are the patient’s preferences? | Preserve relationships with significant others and share decisions regarding the care pathway. | To live up to her son’s expectations (e.g., to be able to act autonomously and recover physically before undergoing chemotherapy). |
| Are there any other actors involved in this case? | Yes, family members. | Yes, the son’s wife, who had multiple sclerosis. |
| What are their respective roles and ideas? | His friends criticized the palliative care pathway. | The son’s wife wished to have a truthful relationship with her mother-in-law. |
| Have they also expressed a similar doubt? | No | Yes |
| (3) Why does this problem exist? | Friends questioned the patient–physician relationship. | Accepting that the patient could live her last days peacefully and aware of her medical condition (e.g., to ensure that the patient’s clinical condition would not adversely affect the mother–son relationship). |
| What are the difficulties? | To start a series of dialogues to make the valid reasons for the care pathway explicit. | To communicate and recognize the severity of the prognosis. |
| What are the proportionated options? | Maintaining the relationship with friends with the help of HCPs and agree upon the most appropriate course of care to alleviate suffering. | To create a truthful climate. |
| What are the principles/values that need to be balanced? | Patient’s autonomy, beneficence, non-maleficence | Patient’s autonomy, beneficence and trust |
| Are there any similar cases reported in the literature? | No | Yes |
| What are the positions of other people involved? | The two sisters and partner were never questioned by the patient’s friends. They came in for visits when friends were not there. | No |
| (4) How to offer a solution? | Guaranteeing that friends can discuss and be informed about the appropriateness of current treatments. | Making the patient aware of the seriousness of her situation. |
| What are the possible solutions including pros and cons? | A series of meetings with the attending physician. Pro: maintaining the relationship. Con: extra work for the physician. | Not leaving the patient alone during and after sharing with her the severity of the prognosis. |
| Have these been discussed throughout an appropriate number of encounters to persistently enable the relational dimension? | Yes (20 encounters since hospitalization) | Yes (5 encounters since hospitalization) |
| Have all the options been understood by decision-makers? | Yes | Yes |
| Is the final decision respectful of the patient’s good and his/her own history? | Yes | Yes |

CEC, Clinical Ethics Consultation; EC, Ethics Consultant; F, Female; HCP, Healthcare Professional; YO, Years Old.

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