

Protocol identifier: PC-19-EU ClinicalTrials.gov: NCT05089032	Synopsis version last update: 1.3 16th March 2023	FINAL
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PEOpLE-C19-EU - Electronic survey: questionnaire

QUESTION GROUPS:

1. CHARACTERISTICS OF THE PARTICIPANT AND THE HOSPITAL
2. EXPERIENCE OF PALLIATIVE CARE BEFORE AND DURING THE COVID-19 PANDEMIC
3. DESCRIPTION OF PALLIATIVE AND END-OF-LIFE CARE AFTER THE PANDEMIC
4. TO EXPLORE THE EXPERIENCES AND POSSIBLE FACTORS LEADING TO MORAL DISTRESS

GROUP	No.	QUESTIONS	POSSIBLE ANSWERS
I. CHARACTERISTICS OF THE PARTICIPANT AND THE HOSPITAL	1.	What is your profession?	a) Nurse b) Physician c) Physiotherapist d) Dietician e) Psychologist f) Other.... (please specify)
	2.	What gender do you identify as?	a) Male b) Female c) Other d) Prefer not to say
	3.	What is your age?	... years
	4.	In which country do you work?	Drop-down list
	5.	What type of hospital are you working in?	a) Primary (regional, remote) b) Secondary (community, urban) c) Tertiary (university or teaching hospital) d) Other (please specify)

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II. EXPERIENCE OF PALLIATIVE CARE BEFORE AND DURING THE COVID-19 PANDEMIC	6.	What type of intensive care unit (ICU) do you work in?	a) Medical b) Surgical c) Mixed d) Other (please specify)
	7.	Have you taken direct care of COVID-19 patients in ICU during pandemic? (January 2020 until January 2022)	a) Yes b) No
	8.	How many years have you practiced critical care medicine/nursing? Years
	9.	Have you finished your speciality training?	Yes No
	10.	Do you have experience with delivering palliative care before the COVID-19 pandemic?	Yes No
	11.	My practice of end-of-life care changed during the COVID-19 pandemic.	a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree
	12.	If you answered that you have changed your practice, which factors could have led to this difference? (tick all that apply)	a) Staff factors (staff qualification, exhaustion or overload,...) b) Administrative factors (organisation and management in the ICU) c) Equipment limitation (drug therapy, medical devices, medical supplies) d) Different clinical characteristics and prognosis of patients with COVID-19 disease e) Overwhelmed healthcare f) Difficult communication (in health team, with hospital / department management)

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III. DESCRIPTION OF PALLIATIVE AND EOL CARE AFTER THE PANDEMIC			<ul style="list-style-type: none"> g) Process of End-of-Life-Decision making (family participation, healthcare team members participation) h) Different ethical principles (tendency to rescue as much as possible people) i) Impact of emotions in the decision making (emotional burden) j) Other (please specify) 	
	13.	During the care of COVID-19 patients in your ICU, have you ever found yourself in a situation known as resource scarcity? <i>(Resource scarcity is a situation characterised by lack of time, medication or equipment...)</i>		Yes, frequently Yes, occasionally No
	14.	Have you ever felt that limitations of resources (e.g., skilled staff, ventilators, beds) were used as an argument in end-of-life decision making?		Yes/No
	15.	If so, what was your perspective?		<ul style="list-style-type: none"> a) I was not comfortable incorporating resource scarcity into the decision-making process. b) I understand the need to incorporate resource scarcity into the decision-making process. c) Other (please specify)
	16.	Do you have a local protocol for End-of-Life-Decision making (EOLD)?		Yes No
	17.	Do you have a dedicated palliative care team in your hospital?		Yes No
	18.	Please indicate who is usually involved in the end-of-life decision-making (EOLD) (tick all that apply)		<ul style="list-style-type: none"> a) Patient b) Head of department c) Attending physician d) Nurse manager (head of the nurses, matron) e) Attending nurse

		<ul style="list-style-type: none">f) Family (relatives) of patientg) Palliative care physicianh) Consultant physiciani) Primary (family) physicianOther (please specify)
19.	How do you normally conduct EOLD discussions with family?	<ul style="list-style-type: none">a) Face-to-face in a separate roomb) Face-to-face at the bedsidec) By telephoned) Video conferencee) The family has not been contactedf) Other (please specify)
20.	What is the usual involvement of family in the decision to transition the patient to a comfort care approach? (tick all that apply)	<ul style="list-style-type: none">a) Family fully decides on the EOLD, the responsibility for the final decision is delegated fully to themb) Family is part of the team and participates in decision-making (shared decision making)c) Family is only informed of the EOLD made solely by the medical team; the EOLD is carried out, unless the patient's relatives disagree with the decisiond) Family is only informed of the EOLD made solely by the medical team; the EOLD is carried out, even if the patient's relatives disagreement with the decisione) Family is not informed at all about the EOLDf) I cannot comment, I did not participate in these discussions.g) Other (please specify)
21.	Have you experienced a situation where you perceived a patient's care as inappropriate? (tick all that apply)	<ul style="list-style-type: none">a) Yes, life support was administered for too longb) Yes, life support was too intensivec) Yes, life support was administered for too shortd) Yes, life support was not intensive enough

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		e) No, I have not experienced this situation f) Other (please specify)
	22. If you selected a), b), c), or d) in question 21, did you express your opinion about inappropriate care?	Yes No
	23. If you selected YES in question 22, was your opinion respected?	Yes No
	24. Do you agree with the statement: The COVID-19 pandemic has changed the provision of palliative care in your ICU	Yes No
	25. If you selected YES in question 26: which particular area of palliative care has changed? (tick all that apply)	a) Processes b) Human factors c) Communication d) Ethical principles e) Education f) Other (please specify)
IV. CHARACTERISTICS OF MORAL DISTRESS AND POSSIBLE FACTORS	26. In your opinion, moral distress is a feature after the COVID-19 pandemic?	a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree
	27. If You answered a) or b) to question 26 - was the level of moral distress you felt after the COVID-19 pandemic comparable to levels experienced before the pandemic?	a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree

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	28. If you experienced moral distress after the COVID-19 pandemic, what were the possible sources of this distress? (tick all that apply)	<ul style="list-style-type: none"> a) Organisational / institutional (e.g. you did a job for which you have no training, insufficient information...) b) Interpersonal relationships (1. gender perception/ 2. collective mood/ 3. public attitude towards health workers during the COVID-19 pandemic) c) Difficulty of the work (1. physical strain/ 2. psychological strain/ 3. risk of infection of the worker) d) The need to make decisions in a situation of resource scarcity - care prioritisation e) Changes in standards of care (positioning the patient at different intervals, more difficult communication with the patient's relatives, ...) f) Administration of experimental drugs or non-indicated drugs outside studies (clinical trials) g) Other (please specify)
	29. Do you agree that currently patients die with dignity in your ICU?	<ul style="list-style-type: none"> a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree
	30. If you did not answer a) to question 29, please define those factors that contribute to the lack of dignity at the end of life? - more than one answer possible	<ul style="list-style-type: none"> a) Inadequate control of the patient's symptoms (e.g. pain, dyspnoea) b) Inadequate communication within the team c) Organizational issues (e.g. isolation and therefore entering the patient's room possible only at certain intervals)

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		<ul style="list-style-type: none"> d) Lack of understanding of the principles of comfort care e) Resource scarcity (e.g. sedatives, analgesics...) f) Inconsistency of physicians' views on palliative care g) Inconsistency of nurses' views on comfort care h) Other.... (please specify)
31.	Are the goals of treatment in EOL always clearly set and explained to the team?	<ul style="list-style-type: none"> a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree
32.	Do you know where to ask for help if you, or a team member, are experiencing distress or emotional overload?	<ul style="list-style-type: none"> a) I strongly agree b) I somewhat agree c) I do not know d) I somewhat disagree e) I strongly disagree
33.	Please use this space to write any experience or comment you would like to share with us	Free answers.