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► To cite this version:

Andréa Tarot, Maxence Pithon, Ashley Ridley, Virginie Guastella, Morgane Plancon, et al.. Experiencing and enduring patient distress: The distress of palliative care patients and its emotional impact on physicians in training Authors. *BMC Medical Education*, 2024, 24 (1), pp.696. 10.1186/s12909-024-05668-9. hal-04652710

HAL Id: hal-04652710

<https://hal.science/hal-04652710>

Submitted on 18 Jul 2024

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1 **Experiencing and enduring patient distress: The distress of**
2 **palliative care patients and its emotional impact on physicians in**
3 **training**

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31 **Abstract**

32 **Background**

33 The extreme vulnerability experienced by patients in palliative care may result in significant
34 distress. These patients require appropriate care while not pathologizing their natural distress.
35 Given the challenges of caring for people experiencing significant distress, it is important to
36 understand what professionals in training may feel when caring for patients in palliative care.
37 Therefore, the aim of this study was to explore how professionals in training feel when
38 confronted with the distress of patients undergoing palliative care.

39 **Methods**

40 A qualitative study employing interpretative phenomenological analysis was conducted. In
41 2022, 11 physicians in training were interviewed about their experiences with distressed
42 patients due to palliative care. The interviews were conducted via video conference. The
43 students participated in the national palliative care cross-training and were in their final year
44 of residency training.

45 **Results**

46 The interviews revealed the following five themes: feelings of powerlessness, duty to act,
47 difficulty in building a relationship, feeling insecure about oneself, and creating a space for
48 listening and relating. All participants felt powerless in front of their patient's distress.
49 Numerous defense mechanisms were identified that made the relationship with the patient
50 difficult. Four participants described being able to create a space for listening and relating to
51 their patients.

52 **Conclusions**

53 A minority of students could establish a quality relationship with their distressed patients.

54 Two concepts, interprofessional education and the patient-centered approach, were identified

55 and could be developed in training.

56 **Keywords**

57 Medical Psychology, Palliative care, Psychological Distress

58

59 **Background**

60 In 1997, the National Comprehensive Cancer Network (NCCN) defined distress as a
61 “multifactorial, unpleasant experience of a psychological, social, spiritual, and/or physical
62 nature that may interfere with the ability to cope effectively with cancer, its physical
63 symptoms, and its treatment. Distress ranges along a continuum from the common normal of
64 vulnerability, sadness, and anxiety to problems that can become disabling, such as depression,
65 panic, social isolation, and existential and spiritual crisis”¹. This definition helps us avoid
66 reflexively pathologizing the distress of patients receiving palliative care and instead allows us to
67 consider their experience as a response to a situation of extreme vulnerability^{2,3}.

68 Even if this experience is not pathological, it requires specific and appropriate management.

69 In this regard, the NCCN developed recommendations for distress management in 2019⁴.

70 According to these recommendations, the management strategy for such patients is complex
71 and multidisciplinary, with no specific drug treatments. These recommendations imply that
72 the physician’s role is to diagnose and direct the management of patients in distress
73 differently from the management of patients with a psychiatric pathology. However, no
74 studies have addressed whether physicians are trained to do this. Some studies have shown
75 that the emotional experiences of physicians can influence their decision-making⁵; therefore,
76 it is important to understand what professionals in training might feel when confronted with
77 patients’ distress in palliative care.

78 If specific recurring emotions are identified among professionals in this setting, educating
79 future caregivers about them could help them integrate their experiences to inform future patient
80 management.

81

82 **Methods**

83 This was a qualitative study embedded in a constructivist paradigm. We adopted
84 phenomenological interpretive analysis, which allows us to examine how a life experience
85 was perceived and interpreted by the individual who lived it. It assumes that researchers will
86 use their own subjectivity as an investigative tool. The reality being approached is then
87 constructed by the individuals, rather than existing in a fixed form, which aligns with the
88 constructivist paradigm ^{6,7}. This study was conducted as part of the thesis project for a Master
89 of Science (MS) program in palliative medicine research. The pedagogical committee, as well
90 as the students, contributed to the study design.

91 **Recruitment**

92 Our study focused on students in the final year of residency training and enrolled in the
93 national palliative care cross-training for 2021–2022. An invitation to participate in the study
94 was sent to the entire class via email. A second follow-up email was sent 1 month later. The
95 participants were interviewed between March and June 2022. They were offered a semi-
96 directed interview by videoconference, recorded with their consent. We stopped recruiting
97 when we determined that we had reached data saturation, as assumed and discussed among
98 the researchers ⁶.

99 **Data collection and analysis**

100 The interview guide is consistent with the interpretive phenomenological analysis and is non-
101 rigid to facilitate exchange ⁸. It was tested with one participant before beginning the
102 interviews. No modifications were made during the interviews, but the follow-up questions
103 used varied according to the participants. During the semi-structured videoconference
104 interviews, the participants were asked to describe a significant situation that they had
105 experienced with a palliative care patient in distress. Thereafter, they were asked about their
106 feelings toward the patient.

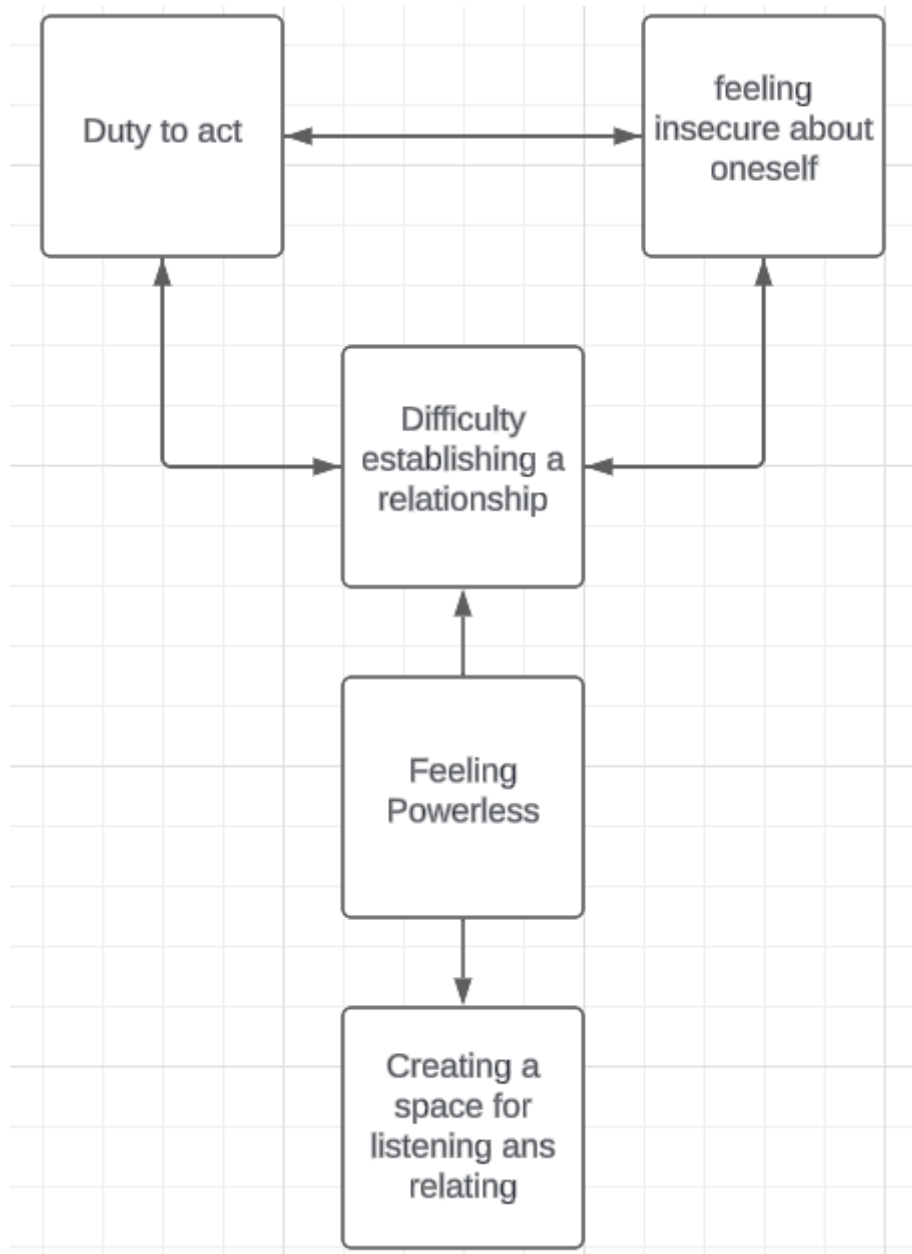
107 Out of a class of 51 students, 12 participants were included in the study. One participant
108 discontinued the national palliative care cross-training; their interview was non-contributory
109 because they did not have a situation to relate to. Eleven interviews were analyzed; the
110 participants comprised two men and nine women. Their specialties included geriatrics (n=2),
111 oncology (n=1), public health (n=1), and general practice (n=7). The interviews lasted from
112 19 minutes (shortest) to 34.20 minutes (longest).

113 All interviews were conducted and transcribed verbatim by author AT –a physician in the
114 palliative care unit and a student in the MS program. Data coding was performed in several
115 steps and according to an interpretive phenomenological analysis of the interviews. First,
116 descriptive line-by-line coding was performed using coding software (Nvivo, RITME,
117 French) to identify the initial codes. A triangulation of the data from line-by-line coding to the
118 initial codes was performed separately for the first two interviews with physicians in the
119 palliative care unit (MP and AM). Then, the initial codes were developed into preliminary
120 themes with the study group. A final list of the themes and categories was developed by RA
121 and AM. Preunderstanding could be worked on with the multidisciplinary Master's study
122 group (physician, psychologist, nurse) to deconstruct the researcher's expectations and remain
123 open to unexpected results ⁹.

124 The study was declared to the data protection officer at the Clermont-Ferrand University
125 Hospital (French, Clermont-Ferrand). The study was conducted according to the MR004
126 reference methodology. The Clermont-Ferrand University Hospital has signed a commitment
127 to comply with this “reference methodology” dated March 29, 2022. This study was
128 registered in the establishment’s treatment register under the number M220402.

129 **Results**

130 The following five themes emerged: feeling powerless, duty to act, difficulty in establishing a
131 relationship, feeling insecure about oneself, and creating a space for listening and relating
132 (figure 1).



133

134 *Figure 1: Five emerged themes*

135

136 **Feeling powerless**

137 The participants described feeling powerless at the beginning of their interview. In most
138 cases, the powerlessness was expressed with the pronoun “we.” They describe a feeling of
139 powerlessness in the face of the specific situation of patient distress. This does not mean that
140 they are generally powerless; powerlessness is not a personality trait but a specific feeling in
141 this situation.

142 It was quite frustrating for me not to be able to help him, to feel a bit powerless.
143 Because in the end, we had reached the end of our therapeutic possibilities. (Student
144 10)

145 A powerlessness... it was the powerlessness that made us uneasy, I think. There is a
146 psychologist who told me the other day that there are two things that break down
147 people’s psyches: death and powerlessness, the fact of being incapable. It’s a bit like
148 what happens when you see a traumatic scene, you see a terrible thing and you can’t
149 do anything. And here, I think, we are a bit in it, we are in a kind of collective trauma,
150 feeling powerless before this patient. (Student 12)

151 And we...for us, the psychological suffering was at first sight, we were not able to
152 work with him in this sense, and therefore this created for us a great frustration... a
153 terrible experience of powerlessness. (Student 7)

154 When the feeling of powerlessness was evoked, it was often a question of helplessness, of
155 loneliness, and of having to do things alone:

156 The great helplessness and... I would also say loneliness too...being alone with this
157 patient. And I felt very, very helpless and very concerned about his distress. (Student
158 11)

159 With the notion of solitude, the participants used the article "we" to refer to a larger entity in
160 order to recreate reference points. The sense of powerlessness was closely related to the next
161 theme: the duty to act. The sense of powerlessness called for action. Most of the time,
162 “feeling powerless” was not expressed verbally at the moment but was articulated later in the
163 interview, using the same terms as those used to describe the feeling of powerlessness.

164 So what drove us was again the frustration, the fact that we wanted to succeed, we
165 wanted to bring him well-being, whatever the form of well-being, it was so difficult
166 for us, that we were ready for many things. (Student 12)

167 All that to say, to summarize, a powerlessness..., in fact, it is the powerlessness that
168 made us so bad, I think, and that’s it. (Student 12, later in the interview).

169 **Duty to act**

170 The duty to act was expressed by the participants. They were able to verbalize the need to act
171 in response to patient distress. Action was necessary, despite the description of it as
172 ineffective. However, it was not carried out with the patient's outcome in mind.

173 The mass continued to grow and so he had intestines coming out of the stoma opening
174 into the pouch. I couldn’t tell if it was anxiety or physical pain, but sometimes seeing
175 his intestines in the pouch could cause a crying fit, screaming... distress, and at that
176 point I would feel obligated to do something, so I would bolus and the boluses
177 wouldn’t work... (Student 11)

178 The participants could perceive an “obligation to do” with several notions of “good” and
179 “bad” in the discourse to justify this transition to action. This “obligation to do” was very
180 much linked to a moral obligation. This theme was closely linked to the notion of value, with
181 an overexpression of the superego in the participants.

182 Because...on the one hand I thought it was good because I felt like I was doing the
183 right medicine, and on the other hand when I heard the request, I was a little...I
184 thought I shouldn't have... (Student 4)

185 Typically, the patient in pain in my mind is not good. And so that means that my job is
186 to make sure that he doesn't stay in pain. (Student 6)

187 I think that's a little bit my "physician" side, but it's true that I've noticed that there's
188 a lot of desire to respond... well to respond to that distress by trying to... for example, I
189 find it easier to deal with a physical symptom like pain or even anxiety or congestion...
190 because... bang, we can pull things out of the bag. (Student 8)

191 **Difficulty establishing a relationship**

192 The participants described interactions with patients as unsatisfactory or at least perceived
193 that the interactions were not optimal.

194 She was a woman that I had difficulty establishing a relationship with because she was
195 well known in the department, I'm just a trainee, just passing through, and she had
196 trouble accepting that the team was helping her, she was so nice but we felt that there
197 was still... she was quite closed off. (Student 10)

198 I felt that I was not fully in tune with my patient and that I was not listening enough.
199 (Student 7)

200 The participants felt less capable or unable to listen attentively to distressed patients. They felt
201 the exchange remained superficial, sometimes out of tune with the patient's situation.

202 I did not allow myself to break through this veneer. I knew that there were members of
203 the team, like the psychologist or certain members of the team, but there were not

204 many of them, contrary to the usual situation where the team, well... of course the first
205 place is for the family, but there is always a bit of closeness, but there I did not, I
206 really stayed on the surface. In the symptoms, "Are you relieved or not?" But I had a
207 hard time going...because there was clearly pain uh...a psychological dimension to the
208 pain as well uh...physical integration that was...so I stayed pretty much on the surface.
209 (Student 10)

210 When the professional could not describe their difficulties in the relationship, in most cases,
211 they were left with a great deal of incomprehension with respect to the patient. The
212 participants described communication with uncooperative patients as a power struggle
213 between the professionals and the distressed patient.

214 Despite the restraint, there is sometimes a bit of anger because it was like confronting
215 a wall. (Student 1)

216 There may have been a little bit of anger, we have to be a little bit honest too, but I
217 admit that at the very end it was despair, and then, the total lack of satisfaction
218 throughout the care. There was nothing satisfying, nothing at all! We tried everything,
219 there are even things we did for her that we never did for other patients, we went out
220 of our way to get her organic fruit, to squeeze her..., we never did..., she had a
221 treatment..., well in my opinion, and also in the opinion of other people, she still had a
222 preferential treatment..., we gave everything. And in fact, it took us long weeks, even
223 several months, to understand that in fact, no matter what we gave her, no matter how
224 much effort we made, never a thank you, never, never a satisfaction, nothing! (Student
225 12)

226 The participants describe numerous defense mechanisms, in particular repression and
227 projection. They were no longer "the bad doctor"; rather, the patient became the "bad patient."

228 **Feeling insecure about oneself**

229 The participants described feeling a sense of danger towards the end of the interview. This
230 danger was not explicitly identified but was often described as a feeling of insecurity about
231 oneself. The description of the danger itself by the participants was highly fantasized and
232 never precisely described. Paradoxically, death was absent from the participants' discourse.

233 I had a kind of dissociation in front of me and myself during the interview I found
234 myself a little bit torn between “listen to him, be the most...you are asked to be the
235 most...you have to remain reassuring for this patient” and at the same time telling
236 myself “don’t be too much of a pushover either...”, I felt torn, I really felt it at one
237 point during the week when it went to a crescendo. I didn’t feel very stable in
238 interviews. I didn’t feel safe myself in my relationship, in my therapeutic relationship.

239 (Student 7)

240 I have the impression sometimes that it also allows me to protect myself in a certain
241 way because in fact when you start to... it’s a degree of suffering that is so great that if
242 you get too close to it, you suffer too. I have the impression that, in general, these are
243 situations that often take a lot of energy, that require a lot of...well, we often discuss it
244 again afterward among ourselves or in the staff because we can’t handle it alone.

245 (Student 8)

246 I didn’t know to what extent I could be affected, and so I wasn’t able to keep the
247 necessary distance... the small distance that is necessary. I think I put up the barrier
248 and I kept it up until the end because... yes, I was afraid of myself at that point, of my
249 reaction. (Student 11)

250 This feeling was intensely expressed using strong words: “I had to, completely, too much...”.
251 The danger was also described as intruding at the psychic level, making it difficult to maintain
252 boundaries between the private and professional spheres.

253 I brought it back a little bit in the private sphere, my companion who is not a physician
254 at all, not at all... Normally I compartmentalize the work quite a bit, personally, but
255 there I admit that it is something that I was not able to leave at work. (Student 12)

256 Let’s say that it was a case that was of concern beyond the patient’s room. It was
257 something that occupied the mental space, a little bit beyond what it was confined to.
258 (Student 3)

259 **Creating a space for listening and relating**

260 Four out of the 11 participants described a shift in their interactions with the patient, marked
261 by a transition to active listening that facilitated new insights during the interview. These
262 moments of interaction fostered a unique relationship between the patient and the
263 professional, providing space for both parties to communicate, thereby advancing patient
264 understanding and management through a collaborative process.

265 So, I think both because we allowed him, well the way we allowed him to build that
266 relationship, because we actually asked him questions that were also personal. We also
267 tried to understand a lot of things. It’s also our attitude to have been available, to have
268 spent time, and in most cases it’s a little bit the framework that is given in the sense
269 that we have this time that we don’t usually have in the specialized services. And so, I
270 think it’s a little bit on both sides, he invested a lot of time because that’s why it left an
271 impression on me, but it’s us who gave him that time and that way of investing it, so
272 he just occupied the space that we had given him. (Student 3)

273 Little by little, this is a lady that I saw several times, in different contexts, sometimes
274 in a consultation, in the emergency room during one of the shifts, in a certain context,
275 and then over time went by she became a lady, we got attached to her, there are
276 always patients that we get attached to more or less, and she was a lady that we had
277 more or less... yes, she was a lady that was pleasant. We made a commitment to
278 follow her from the beginning, we said “well listen to us as soon as you come, we’ll
279 be there to see you if you feel like it” and then she said yes to us, so somewhere along
280 the line we weren’t at a dead end because I think this lady was being helped. (Student
281 9)

282 These participants could describe a very special relationship with distressed patients,
283 highlighting a relational space that emerged during the exchange, enabling the patient to
284 invest in the relationship. The interviews revealed few misunderstandings, and the
285 participants perceived the exchanges as high quality. Detailed information about the patients,
286 including their history and the content of the interviews, was provided by all of these four
287 participants, each expressing satisfaction with the care provided to these patients.

288 That’s also what’s interesting because I think that’s what... that’s the space where
289 most of the stuff happens. And in some ways, it’s almost the most interesting care
290 because there’s a lot of personal stuff going on, a lot of what’s being delivered and
291 their experiences. Ultimately, there is something that comes out of these treatments
292 that is extremely rich. And it doesn’t happen very often, and when it does, we’re
293 happy that it can happen, it means that we’ve done what was possible. There is also
294 this idea that it is almost a success to have been there for these patients in distress.
295 (Student 3)

296 We can see here that the participants were aware of what they had been able to put in place to
297 ensure that the relationship was of high quality, and this was rewarding for them.

298 **Discussion**

299 The participants in our study revealed that they experience difficulties in their relationships
300 with distressed patients in the vast majority of cases. They all felt a sense of powerlessness,
301 which led them to use some defense mechanisms to protect themselves from this feeling ¹⁰.
302 Their initial training did not prepare them to understand these feelings of powerlessness.

303 The North American Nursing Diagnosis Association defines helplessness as “Pa feeling that
304 one’s actions will have no effect, a feeling of being helpless in the face of a current situation
305 or immediate event” ¹¹. This definition highlights the connection between feelings of
306 powerlessness and action. It also qualifies that this feeling is an impression, as in Miller’s
307 definition of powerlessness ¹². Its description refers to the feeling experienced by a person in
308 relation to the circumstances of the moment or generated by the given situation itself.

309 Therefore, powerlessness does not imply a stable personality trait. In this sense, powerlessness
310 is an existential construct conditioned by a specific situation with which the person is
311 confronted. Professionals who can create a space for listening and relating to the patient
312 understand this nuance and can perceive the effectiveness of their care. By contrast, those
313 who cannot understand this nuance or perceive the effectiveness of their care may become
314 victims of the feeling of powerlessness. They describe a strong sense of helplessness with a
315 loss of direction and a feeling of loneliness. In these situations, the pronoun “we” suggests
316 unity. In addition, to alleviate this experience, the participants felt the need to act, even if it
317 was considered useless. This is confirmed by Simon’s work in the 1950s, highlighting the
318 limits of the rational decision-making approach¹³.

319 Only four participants could create a space for listening and relating that was comparable to
320 the patient-centered approach described by Roger ^{14, 15}. These participants felt less
321 powerlessness than the other participants did and created a special space with the patient. This
322 space seems to be beneficial for both the patient and the professional. Compared with the
323 other professionals, these professionals appear to be in less pain, satisfied with the care given,
324 and feel valued. This space allows co-construction; the professional strives to “understand”
325 the patient and who they are entirely. Finally, focusing on understanding the patient and
326 establishing a caregiver–patient relationship helps professionals shift from their own
327 experience to that of the patient. This space for dialogue becomes a useful therapeutic tool for
328 the healthcare professional.

329 Creating a space for listening and relating to the patient seems necessary to successfully
330 support distressed patients in palliative care. We propose two concepts to help professionals
331 create this space: interprofessional education (IPE) and the patient-centered approach.

332 **Interprofessional education**

333 The evolution of medicine today leads to increasingly complex situations; this partly explains
334 the need to involve several professions in the management of patients ¹⁶. The IPE is a very
335 interesting concept to help professionals work together ¹⁷, especially in the palliative context
336 ¹⁸. The World Health Organization defines IPE as “when two or more professions learn about,
337 from and with each other to enable effective collaboration and improve health outcomes” ¹⁹.

338 In the specific situation of a distressed patient in palliative care, interdisciplinarity would offer
339 a physician in training an analysis of their subjectivity through a joint interview with the
340 psychologist of their team to elaborate on the feeling of powerlessness as a mirror of the
341 patient’s distress. Psychologists in palliative care have already described this role in France
342 since 2016 ^{20, 21}. Interdisciplinarity would also help address the second concept, the patient-

343 centered approach. The patient needs a physician working as part of a team to be understood
344 as a whole. Each brings a unique viewpoint, allowing for a global patient understanding.

345 **Patient-centered approach**

346 The theme of “creating a space for listening and relating” echoes Roger’s concept of the
347 patient-centered approach ¹⁵. Interestingly, this theme can be related to a known concept that
348 can be taught and explained. Several studies show the importance of a patient-centered
349 approach in general practice ²² and palliative care situations ²³. A 2017 study showed good
350 results regarding the effect of a patient-centered communication intervention on oncologist–
351 patient communication and quality of life ²⁴. In this study, a brief combined intervention for
352 physicians and patients with advanced cancer promoted patient-centered communication in
353 the short term, with clinically significant increases in patient engagement in emotional
354 response and discussions about prognosis and treatment choices. This approach would
355 improve the quality of professional relationships with distressed patients in palliative care.

356 It would be interesting to continue this work by studying the effect of introducing these two
357 concepts to students dealing with patient distress.

358 **Strengths and limitations**

359 One of the limitations of this study lies in the inclusion of the principal investigator in the
360 analysis; the investigator is a palliative care physician who is in daily contact with distressed
361 patients in palliative care. Their involvement in daily patient care might have introduced bias
362 in data analysis.

363 Another limitation is the short duration of the training program for the interviewees (i.e., 1
364 year). Furthermore, the study population was predominantly female.

365 Regarding the study's strengths, the study population is geographically distributed throughout
366 France; therefore, it is representative of all palliative care services in the nation. The
367 interviews provided substantial data, allowing for a rich analysis of the participant's
368 experiences and related feelings. Finally, the study's subject was of interest to the
369 participants: all could relate with interest to a situation they had experienced during their
370 journey. Thus, students in palliative care medicine may find the subject of this study
371 interesting.

372

373 **Conclusions**

374 Even though this is a small-scale study, its findings demonstrate that residents may establish a
375 quality relationship with their distressed patients, although some residents were capable of
376 this. Therefore, factors that can help professionals establish quality relationships with their
377 patients must be identified. Two potential leads may be the existing concepts of IPE and the
378 patient-centered approach, which could help students confront patient distress. Furthermore,
379 with this study, we hope to raise awareness of the participants' observed defense mechanisms
380 to enable students to move from defense to coping mechanisms, in order to support their own
381 well-being and improve the quality of their patient care.

382 **List of abbreviations**

383 IPE: interprofessional education

384 NCCN: National Comprehensive Cancer Network

385 MS: Master of Science

386

387 **Declarations**

388 **Ethics approval and consent to participate**

389 The study was declared to the Data Protection Officer at the Clermont-Ferrand University
390 Hospital. The promoter undertook to conduct the study according to the reference methodology
391 MR004. The Clermont-Ferrand University Hospital has signed a commitment to comply with
392 this “Reference Methodology” dated March 29, 2022. This study was recorded in the institute’s
393 register of treatments under the number M220402. The study was approved by the local Ethics
394 Committee (IRB00013412, “CHU de Clermont Ferrand IRB #1”, IRB number 2023-CF120)
395 with compliance to the French policy of individual data protection. Three participants were
396 offered a semi-directed interview by videoconference, recorded with their informed consent.
397 They were given a study information sheet and a no-objection form.

398 **Consent for publication**

399 Informed consent

400 **Availability of data and materials**

401 The datasets used and/or analyzed during the current study are available from the
402 corresponding author on reasonable request.

403

404 **Competing interests**

405 The authors declare that they have no competing interests

406

407 **Funding**

408 None

409

410 **Authors' contributions**

411 AT: analyzed and interpreted the data and wrote the manuscript

412 MP: major contributor in writing the manuscript

413 AR: analyzed and interpreted the data; major contributor in writing the manuscript

414 VG: contributor in writing the manuscript

415 MPlancon: analyzed and interpreted the data; contributor in writing the manuscript

416 RA: analyzed and interpreted the data; contributor in writing the manuscript

417 HVR: contributor in writing the manuscript

418 AM: analyzed and interpreted the data; major contributor in writing the manuscript

419 All authors: read and approved the final manuscript.

420

421 **Acknowledgements**

422 The authors acknowledge the participants for sharing their experiences in difficult situations

423 of patient distress for this research. The authors also acknowledge the entire Master's team for

424 having participated in the construction and reflection of this research project

425

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