


BMJ Open 'Now I can train myself to be with death': a phenomenological study with young doctors in care homes supported by a palliative care unit during the second wave of the pandemic in Italy

Matteo Moroni,¹ Matías Eduardo Díaz Crescitelli ,² Jenny Capuccini,¹ Cristina Pedroni,² Mattia Bianco,² Luigi Montanari,¹ Luca Ghirotto²

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¹S.S.D. Cure Palliative, AUSL della Romagna, Ravenna, Italy
²Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy

Correspondence to
Dr Matías Eduardo Díaz Crescitelli;
diaz.matias1986@gmail.com

ABSTRACT

Objective During the second wave of the COVID-19 pandemic, one of the organisational strategies established by the Italian National Health System was the special units for continuity of care (SUCCs). In the province of Ravenna, those units enrolled novice doctors to care for elderly patients with COVID-19 in care homes (CHs). The local palliative care (PC) unit decided to offer consultations and support to them. This study aimed to comprehend the experience of young doctors who asked for consultations when facing, during their first early years of practice, complex situations.

Design We conducted a qualitative study employing a phenomenological approach and in-depth interviews.

Participants We involved 10 young doctors who worked in Italian SUCC during the pandemic and used a PC consultation support service.

Results What describes our participants' experience is related to four main themes: (1) reducing distances, (2) perceiving medical futility and improvising, (3) being supported to learn how to be with death and (4) narrowed timing to humanise care. The pandemic was, for our participants, a moment of reflection and critique on the skills acquired during the university course. It was a strong experience of human and professional growth that helped them reshape and deepen their role and skills, incorporating the approach of PC into their professional identity.

Conclusions Integration between specialists and young doctors with an early entry into the workforce during the pandemic in CHs set out a 'shift' to a proactive and creative approach through a new awareness of professional and personal roles in doctor–patient relations. The continuity of care models should be rethought by integrating CHs and PC. Adequate PC training for young doctors (at pregraduate and postgraduate levels) can change doctors' vision and daily practice in assisting patients at the end of life.

INTRODUCTION

Since the first wave of the COVID-19 pandemic hit Italy hard from February to May 2020,¹ the Italian health system had to reorganise

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ No similar studies have investigated young doctors' experiences caring for patients with COVID-19 in care homes as their first experience after graduation, employing phenomenology.
- ⇒ Since the study setting represents an exclusively Italian organisational choice during the outbreak, the non-comparability with other settings in other countries limits the findings.
- ⇒ The final sample is relatively homogeneous, complying with phenomenological indications.

to meet the population's health needs. One of the organisational strategies established by the Italian National Health System² was implementing the special units for continuity of care (SUCCs) (see the document 'Guidelines for the Institution of Special Units for Continuity of Care', in Italian).³ SUCCs are medical teams supervising and providing care for patients with COVID-19 who do not require hospitalisation or are assisted at home or in territorial/residential health facilities, nursing homes or care homes (CHs).

SUCCs involved mainly young doctors who recently graduated due to the high demand for personnel engaged in the pandemic emergency and the shortage in staffing in primary care services.⁴

In CHs, SUCCs' doctors were asked to confront critical circumstances, often requiring palliative care (PC) competencies they did not possess. These competencies are frequently neglected in the academic and training curricula,^{5 6} although medical students and junior doctors consider them essential in caring for dying patients. This added to occupational and moral distress, depression and anxiety, and mental health

issues that both skilled healthcare professionals and young doctors experienced.^{7–10}

Due to previous observations and hard work on the frontline, during the second wave of the pandemic, the PC unit of Ravenna (Italy) offered a service of consultations (involving mainly PC specialists but also geriatricians and respiratory specialists) to support young doctors operating within SUCCs. Consultations entailed an online debriefing session for case discussion (weekly) and phone calls in case of need on working days. Consultations helped young doctors deal with symptom treatment, patient–family communication and problem-solving strategies for issues among colleagues.

Taking advantage of this service, we conducted a qualitative study to comprehend the experience of young doctors who asked for consultations and were facing, during their first early years of practice, unpredictable, extreme and complex situations such as those arising from dealing with CH residents during the pandemic. Building on the lived experiences of young doctors may inform medical educators, academic decision makers and staff managers on how to help novices process this experience sequela and consider needs and required skills arising from real emergency/pandemic situations in appropriate training programmes.

METHODS

Design

We conducted a descriptive phenomenological study to answer the following research question: ‘What is the lived experience of novice doctors who worked in a CHs during the pandemic?’ We employed Colaizzi’s descriptive phenomenological method,¹¹ which can reveal the ‘essence’ or ‘essential structure’ of a studied phenomenon.¹² As for essence, we refer to the number of unique features defining the specific phenomenon. We reported this study according to the Consolidated Criteria for Reporting Qualitative Research¹³ (online supplemental appendix 1).

Setting

During the second pandemic wave, the Italian National Health System set up the SUCCs: in the province of Ravenna, SUCCs were medical teams supervising and providing care for patients with COVID-19 living in nursing homes or CHs. Most of these professionals were young doctors at the beginning of their practice soon after graduation.

Sampling and participants

We performed a purposive sampling¹⁴ involving (1) young doctors (recently graduated), (2) working in the SUCCs within CHs during the second Italian wave of the COVID-19 pandemic (September–December 2020), and (3) benefited from clinical consultations with the Ravenna PC network.

MM and JC contacted participants by telephone who met the inclusion criteria for participation. They explained the study’s procedures and objectives, the approximate time it might take to complete the interview, risks and benefits, and a request for voluntary consent for participation. Once they obtained a positive answer, interviewers contacted them to organise the interviews.

Data collection

Data were collected using open-ended questions by MEDC and LG. An interview guide was developed to let participants be free to account for their experiences, with no references to literature or preconceived theories.¹⁵ Participants were asked to talk about broad topics, with exemplifying questions used as prompts based on the participants’ responses during the interviews. Due to pandemic restrictions, interviews were conducted remotely and audio recorded. Data were collected from March to June 2021. In table 1, we show the interview guide.

Data analysis

MB verbatim transcribed all the interviews. Analysis was performed according to Colaizzi’s indications,¹¹ including the following steps: (1) All authors read several times all the interviews to familiarise themselves with the data; (2) CP, JC, MB, MEDC and MM independently identified significant statements in the participant accounts; then, (3) researchers identified relevant meanings emerging from carefully considering the significant statements; (4) using NVivo V.12, MEDC, LG, MM, and MB clustered the identified meanings into common themes and subthemes, reporting a comprehensive description including all the themes; (5) next, all authors discussed the report and integrated the comprehensive description, formulating the definition of the overarching statement (ie, the summarising of the participants’ lived experience) on which all the authors agreed; lastly (6), participants were offered the opportunity of corroborating the findings.

Patient and public involvement

MM and MEDC shared the findings with participants via email for verification, asking for feedback (whether they were adequately conveying and describing their experience). No meaningful comments were received.

Reflexivity and epochè

MM, the principal investigator (male, doctor of philosophy (PhD)), JC (female, PhD) and LM (male) are PC physicians. MB (male) and CP (female, PhD student) are registered nurses (RNs). MEDC (male) is an RN with a PhD in Health Sciences and an expert in qualitative methods. LG (male, PhD) is a methodologist with a background in education and social sciences. The interviewers, MEDC and LG, had no prior knowledge or interaction with the participants before data collection. For data validity and reliability, authors bracket their presuppositions to stick closely to the phenomenon experienced

Table 1 Interview guide

Topics	Instructions/exemplifying questions
Opening	The interviewer thanks the participant and provides clarification, including reminding them that the interview will be audio-recorded and the recording will be anonymised. Thank you for being here. Do you have any questions or doubts about the purpose of the research?
Experience as SUCCs' professional	Could you tell me how you experienced this pandemic as a USCA professional? What were/are your thoughts?
Events/situations experienced during care	Could you tell me about an event that particularly impressed you? Can you think of other examples of what happened to you during the pandemic? Concerning these events, how did you feel?
Consultation service	Could you tell me how you became aware of/contacted the PC consultation service? What did you think? Did you feel the need to compare yourself with other colleagues? Could you give me an example? Regarding the consultation service, could you tell me what the consultation consisted of? Could you tell me what role it played? What were the aspects that impressed you? Could you give me an example? How would you evaluate this service? What idea did you get from this service?
Emotions	Concerning the situations you told me about, how did you feel? And now, what are your feelings while recalling them?
Evaluation of the experience as a whole: tips and suggestions for improving the service	What do you feel you have learnt from using this service? What tips/suggestions would you give to improve the service? Would you recommend it to others? To whom in particular? Concerning what?
Conclusion	The interviewer again thanks the participant and asks if the respondent has any thoughts, examples, or comments to share in closing.
USCA, Unità Speciali di Continuità Assistenziale (Special Continuity Care Units).	

by participants (epochè). 'Bracketing'¹⁶ allowed us to reach a shared view on findings, trying not to allow personal thoughts and previous experiences to operate while analysing the participants' narratives. The analytical work was conducted collaboratively: the authors shared all the steps, helping each analyst's bracketing.

RESULTS

Fifteen young doctors were contacted and expressed their willingness to participate in the study. Five declined afterwards, declaring the interview time did not fit their schedule. We then conducted 10 individual interviews (mean duration: 39 min, range 19–48 min) with six women and four men (mean age: 31 years, range 25–45). Their characteristics are summarised in [table 2](#). Six participants have recently graduated, while the remaining were attending medical specialities training (internal medicine

and geriatrics). In Italy, medical doctors receive a 6-year generalist training (master equivalent). Afterwards, they attend a specialisation programme with limited enrolment and admission exams.

Findings

According to our analysis, what describes our participants' experience is related to four main themes: (1) reducing distances, (2) perceiving medical futility and improvising, (3) being supported to learn how to be with death and (4) narrowed timing to humanise care. The pandemic was, for our participants, a moment of reflection and critique on the skills acquired during the university course. It was also a strong experience of human and professional growth that helped them reshape and deepen their role and skills in a dramatic and rapidly changing context, incorporating the approach of PC into their professional identity.

Reducing distances

In a context where distances increased (social distancing, wearing masks) as one of the effective strategies against the pandemic, paradoxically, our participants reported that their first professional experience meant interpreting a role entailing enhancing empathy, compassion and connectedness with patients and families.

Table 2 Participants' characteristics

Gender	Female	6
	Male	4
Age range (years)	25–30	6
	>31	4

From a relational point of view, the participants perceived a reduced distance towards the patients. Gestures and attitudes became informal, helping to create a climate of closeness and coparticipation. Some then noticed that the doctor–patient encounter was the only opportunity for patients to socialise.

I saw much less formality and a much more ‘human’ relationship without the superstructures that sometimes exist in a hospital setting—calling them by name while entering the room in a much simpler way. Very often, we were the few contacts they had during the day. They opened up to us about their experiences and their history. This thing impressed me a lot... and the climate. (#04)

All participants described the close contact with patients’ daily lives and personal histories as unexpected. The fact that they were the few people with whom the patients could relate prompted the young doctors to shorten another distance imposed by the pandemic: between people in CHs and their relatives. All reported feeling unprepared for dialogue with relatives. They described how uncomfortable they felt while informing them about the patients’ health status and their rapid prognostic evolution.

It was difficult to make them understand these realities because many obviously do not expect it, in the sense that they do not know what to expect either. Not being able to see relatives for such a long time, not having any information when they get worse like that... it’s hard! Patients can’t and don’t talk on the phone, of course, so all the news is filtered between us, and even video calls become particularly difficult to do. (#05)

The distance between the participants and death (and the communication related to dying) was drastically shortened. All respondents stated that managing end-of-life care so early in their careers was not something they would have expected. The rapid and sometimes sudden worsening of patients’ health conditions gave the young doctors little time to prepare themselves and their relatives. The discomfort of communicating patients’ deteriorating health to relatives was therefore exacerbated by the frequent need to communicate bad news. For this type of communication, the participants did not feel prepared.

In this situation, participants recounted how family members were not continuously informed about the health condition of their loved ones. The bad news that the doctors had to give was abrupt for them.

Managing the end of life of people who arrived ‘healthy’ and the situation worsened... It was even more difficult because the family was not ready to hear about it. Sometimes they did not accept the situation, so end-of-life management was very complicated. (#03)

Some felt the need also to shorten communication and ‘not mince words’ when communicating bad news.

If I tell a person that their loved one is dying, it is more impactful than saying that their loved one is in a clinical condition that is worsening... rather than mincing words, I have learnt to use a few concise words (#06)

In this context, some participants described invented strategies to allow relatives to say goodbye to their loved ones before death in compliance with pandemic containment measures.

There was this insistent request from relatives to see him, to be able to say goodbye. We tried to find a middle way between the wishes of the relative and the patient, and we managed to get the relative to come. Or, since the ward is on the ground floor, where we have big windows, they could see each other through the glass. They could talk to each other, say goodbye. (#03)

For all participants, the emotional involvement was at a high level. Their first work experience included participating in the suffering of patients and their families, witnessing deaths in isolation, and giving up the ritual of mourning for family members forcibly.

Even though it was a COVID-19 nursing home, very often family members came with us, all dressed up or not. Because even the family member, after seeing the patient, then stops, asks you.... cries... I mean, from an emotional point of view, that definitely stuck with me the most. (#09)

For the interviewees, it was a time when they could not adopt an attitude of emotional detachment, both during their shifts and often outside.

Let’s say that the first five days I was working on the front line, and I was alone. I would come home, and I literally didn’t have the strength to cry. (#05)

Even the sleeping was difficult because I kept thinking about how they were... even the operators. Eventually, you would get attached. (#06)

Perceiving medical futility and improvising

If the participants’ perceived experience was that of living in close quarters with patients, family members and painful emotions, from the point of view of medical preparation and therapeutic possibilities, our participants felt almost useless.

I felt discouraged because I knew I would go there and make little difference. I would go there and prescribe therapy, but if there was nothing to do, there was nothing to do. On many days I felt almost useless. On other days I was satisfied because some people got better. (#06)

Young doctors described feeling inadequate in recognising and accommodating patients' needs in a timely manner. The feeling, for some, was that of living their professionalism in improvisation.

Let's say it caught us very... unprepared, and we went after the need. (#10)

Together, we had some good paths! Even with relatives and colleagues. But everything as if we were improvising. (#02)

Our participants told us that they felt inadequate from a clinical–therapeutic point of view, unprepared to understand patients' needs, communication and relational aspects.

I didn't feel up to it. I had no idea, within the situation, what to do. (#05)

Most charged that they had received insufficient and ineffective teaching.

I thought I would learn to be a doctor using the guidelines, learning to apply them well. But I was faced with a much bigger job. (#01).

In particular, the most critical training gap the young doctors pointed out concerned the end-of-life care of patients and the PC approach. This knowledge would, according to some, have lightened the burden of a complex first work experience.

The most difficult thing was experiencing the end of life, which was present in the CHs on many occasions. One criticism I raised was about palliative care. End-of-life care was never discussed at university. (#02)

Being supported to learn how to be with death

Realising that they had had this significant educational lack during their medical school years (which, had it not been there, some participants felt would have given them essential tools to cope better) provoked emotions of anger and disillusionment. However, at the same time, some realised, with pleasure, that possible approaches to treatment had not been exhausted during formal academic training.

From this experience, I realised that I must study all the time. These are things I never saw during my six years in medicine. I still have to build on it, and this work made me realise that I must constantly update myself. (#06)

In this context, the participants greatly appreciated the counselling and support they received.

Having someone to talk to about all these things was fundamental for me. Then we also did it among ourselves, but someone had experience here. On a psychological level, it was fundamental. (#07)

Even more, they appreciated the opportunity to implement PC under supervision. Our participants stated that

this possibility was very educational: they learnt that PC could become a fundamental way to respond to patients' needs and professionally connect with end-of-life care.

Now I can train myself to be with death. I trained this because I was in it... and the palliative care service helped us with this. (#02)

As to experiential learning gains, the participants reported that providing PC triggered a mindset change in thinking about clinical situations: biomedical skills faced 'real life', and care relationships met the urgency of creating human connections with a high grade of compassion in a short time.

I experienced it on my own skin.... is that the people I dealt with were 'people'. The patient is not an abstract thing. They are real people... asking you questions. They ask you: 'What's wrong? What therapy do you want to give me? What is wrong with me?' It is a question I have often been asked, and many times I have been unable to answer. Another lesson I learned is that their relatives are people too... I used to treat them as learning objects. (#06)

The participants realised the importance of the 'how' of care.

They remained as a final prognosis the same, but how one arrived at this end changed. This is something that I would like to remain in the work that I will do. (#01)

These perceived learning outputs also included improved self-efficacy in dealing with communication and relational aspects.

Finally, participants described their gladness with acquiring 'technical' skills.

We learnt so much, even from a technical point of view... using opioids I had no idea how to use. (#01)

Narrowed timing to humanise care

The reduction of distances, the commitment to create relationship opportunities for patients and family members, and the learning and trying out, in reality, a new approach to care, which filled the training gap that our participants perceived, are experiences that helped to humanise the relationship. This journey had to happen very quickly.

I was always thinking about what needed to be done and doing it quickly. Because then there is worsening anyway. From one moment to the next, we have seen it in so many patients who were fine, and after six hours, they died. (#06)

From being objects of study, patients became flesh-and-blood human beings to be treated, cared for and sometimes accompanied to death. At times, entering into a caring relationship meant that participants had to do

things beyond their responsibility and how they interpreted their professional role.

There was a role reversal ... We found ourselves doing things that were not strictly related to our role, like giving drinks during shifts [...] We also had to go to the pharmacy to look for morphine with our prescriptions because either it was Sunday or there was no health worker who could go there. I remember we had a patient who was starting to get sick. Not to wait until Monday to try to intervene early because we could see that he was sick. (#07)

Being immersed in an unusual and emotionally demanding dimension of care changed their view of their patients. Social distancing from families and caregivers, patients' loneliness with high symptom burden and short life expectancy narrowed the time span to come closer to the patients compared with other clinical situations or settings before the pandemic.

Overarching statement

PC provided these young physicians with a dramatically creative stimulus, a 'virtuous forcing' to overcome perceived training deficiencies never experienced before. These were particularly evident in the context of end-of-life care and the care of CH patients. Shortcomings were described in the technical (lack of PC knowledge and skills), relational (participants reported feeling uncomfortable relating to patients and relatives) and personal (participants felt unprepared to handle the emotional burden) domains.

The clinicians understood the importance of the PC approach in an emergency and dramatic context. At the same time, they were able to find ways to manage the reduced distances (emotional, relational and symbolic, with distances that reduce death) to react to educational gaps. Finally, participants had to learn and put new knowledge and competencies into practice in a narrow and short time to connect with people (patients and family members were no longer abstractions but in the flesh) as early as possible.

DISCUSSION

This qualitative study confirms what has been repeatedly stated in the literature regarding the need to ensure adequate 'basic' PC training before and after graduation.¹⁷ This training can provide the essential skills for strictly clinical management of patients in CHs and improve professionals' skills in assuming an appropriate care relationship. In this perspective, the support that a PC team can provide in highly complex situations (the pandemic), also by ensuring the integration between services in terms of the continuity of care (in a setting with high needs such as CHs), is palpable.¹⁸ Outside the pandemic scenario, it's well known that transitioning from graduating to independent practice is challenging for young doctors to build a professional identity.^{19 20}

Developing technical and relational skills could lead to issues of unpreparedness with emotional reactions, and managing such issues and lived experiences could help a better transition to professional independence.²¹

Consequently, the general feeling of being unprepared for young doctors became a feature of the pandemic due to academic-training pitfalls and the rapid and tragic evolving situation.²²

Participants frequently reported being 'forced' to reduce the relational and professional distance from patients and family members. To reduce the risk of losing a real human connection, our participants implemented creative approaches, similar to what Mitchinson *et al*²³ and colleagues reported: the restrictions of traditional care were meant as a threat to good standard care, a lonely death and the risk of burnout led healthcare workers to create new ways to deliver compassion and connection.

Our study adds the description of the role played by the PC team in implementing and improving this 'creative approach' of participants. Those reduced distances can bring doctors closer to burnout, as widely underlined in the literature.²⁴

Caring for patients within CHs changed the features of bereavement management due to the harsh complexity of the pandemic scenario. Wallace and colleagues²⁵ described how PC providers could be a vital resource for other colleagues in understanding and managing this 'new kind of grief'.

The gap between the situations the participants faced daily and the skills acquired during academic courses caused distress to our participants, connecting with a study by Spiers and colleagues,²⁶ where together with high risks of personal and organisational crisis due to pandemic issues, a positive impact raised from mutual support needed among healthcare workers in hard times of working practice.

The young doctors we interviewed felt lonely and inadequate during the pandemic. According to Montagna and colleagues,²² this feeling may result from the rapid transition to professional activity: our participants confirmed through interviews that a fast entry into the workforce in such difficult times triggered a crisis in self-confidence in skills and professional role.

In this context, being supported was pivotal. Participants reported they could overcome difficulties through consultations with PC specialists, enabling them to 'be with death'. The literature about the benefits of PC training for medical students and novices highlights a training gap to solve and the feeling of unpreparedness to manage.¹¹ This can be even truer given the pandemic, where PC consultations proved fundamental in providing 'new answers for new emerging needs'.²⁷ Our data support the call of Bharmal and colleagues⁶ for a breakthrough in medical education about palliative and end-of-life care. Learning 'how to be with death' for medical students invokes a reflection on how death as a topic is covered during academic training. Generally, medical students are trained within a bioscientific-medical model,²⁸

making the academic training of physicians focus mainly on diagnosing and treating diseases. So, the topic of death cannot always be comprehensively covered during the academic training of physicians due to several factors, including the taboo of death and the fear of death itself.²⁹ Despite this, our participants learnt that it was necessary to openly address this topic and manage it with patients and their families.

This experience may have helped young doctors to understand that the PC approach applies to many patients and is part of any doctor's role, regardless of specialty, as many studies demonstrate and advocate for.^{29–33}

Strengths and limitations

There are no similar studies that have specifically investigated the experiences of young doctors caring for patients with COVID-19 regarding their professional knowledge and subsequent changes when integrating with PC. This study provided an in-depth insight into a defined and experimental professional and care scenario within the pandemic phenomenon. The SUCCs represent an exclusively Italian organisational choice during the outbreak. The non-comparability with other care realities in other countries is a findings limitation.

Implications

Our findings emphasise that the PC approach can be a tool to facilitate dealing with the complexity of the pandemic scenario, connecting with several other studies.^{27,34} Moreover, additional relevant elements can be drawn from our data.

- ▶ Young doctors have a potential risk of severe burnout at the beginning of their professional experience.³⁵ Dealing with the weight of first-care activities in an emergency/pandemic situation can generate creative responses to plan complex personalised interventions. Nonetheless, medical educators, academic decision makers and staff managers should help young doctors capitalise on the acquired skills and process the possible psychological, ethical and emotional sequela.
- ▶ The PC approach helped young doctors go 'beyond' the biomedical dimension, integrating it with the relational one.³⁶ Appropriate academic programmes are compelling because employing graduating doctors with poor expertise in care, dignity and respect for the patient's quality of life is no more acceptable.
- ▶ In this situation, PC service could link different services, concurring with the continuity of care, as elsewhere outlined.³⁷ Although expressing a specific context in Northern Italy, this research wanted to capture young doctors' expertise in reformulating organisational strategies once their experience is heard. Even after the pandemic, the PC team may favour a greater integration between professionals, especially in elderly patients within CHs.³⁸

CONCLUSIONS

The pandemic built a scenario where young doctors had an early and prompt entry into the workforce, facing high-complexity patients, many deaths in a short time, and personal, professional and organisational issues in the relationship of care.

The gap between skills acquired during university and actual needs of end-of-life care and human relationship of frail elderly patients (along with restrictions and isolation from families) was the leading cause of a profound reflection on professional role and risk of burnout syndrome, as frequently stated in literature and confirmed in our study.

Integration of these doctors with PC specialists to provide symptom treatment, patient–family communication and staffing skills promoted in their daily practice and personal life a 'shift' to a proactive and creative approach based on a more profound and compassionate awareness of care relationships.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the ethical committee of AUSL Romagna (in-house prot. n. 2397/2021 I.5/55) on 13 March 2021. All the participants signed an informed consent containing transparent and standardised information about the study aims and procedures. Before proceeding to the interview, interviewers asked each participant if any further clarification was necessary regarding the study's objective and how the data would be collected. All methods were carried out following the Declaration of Helsinki.

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ORCID iD

Matias Eduardo Díaz Crescitelli <http://orcid.org/0000-0001-5635-720X>

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TITOLO

Studio prospettico qualitativo di valutazione del servizio di consulenza di Cure Palliative e dei vissuti correlati dei medici USCA del territorio di Ravenna

Principal Investigator

Matteo Moroni, Struttura Semplice Dipartimentale di Cure Palliative – AUSL Romagna, sede di Ravenna

Gruppo di ricerca

Jenny Capuccini, Struttura Semplice Dipartimentale di Cure Palliative – AUSL Romagna, sede di Ravenna

Cristina Pedroni, Direzione delle Professioni Sanitarie, Azienda AUSL – IRCCS di Reggio Emilia

Collaboratori Istituzionali

Struttura Semplice Dipartimentale di Cure Palliative di Ravenna

Supervisione scientifica

Luca Ghirotto, Unità di Ricerca Qualitativa, Direzione Scientifica, Azienda AUSL – IRCCS di Reggio Emilia

Matias Eduardo Diaz Crescitelli, Unità di Ricerca Qualitativa, Azienda AUSL – IRCCS di Reggio Emilia

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1. RAZIONALE

Introduzione

Tra le molteplici risposte territoriali messe in atto per il contrasto alla pandemia da COVID-19 e al rischio di collasso del Sistema Sanitario Nazionale vi è l'istituzione delle Unità Speciali di Continuità Assistenziale (USCA, cfr. documento “*Linee di indirizzo per l'istituzione delle Unità Speciali di Continuità Assistenziale*”)^(1,2) : team medici che garantiscono l'assistenza dei pazienti affetti da COVID-19 che non necessitano di ricovero ospedaliero e che vivono a domicilio o in strutture residenziali sanitarie territoriali.

Il contesto epidemiologico delle persone colpite da Covid-19 conferma che nella popolazione suddetta il maggior impatto di morbilità e mortalità riguarda soprattutto le persone anziane: i tassi di letalità sono inferiori all'1% per le persone di età sotto ai 50 anni e fino al 25% per le persone di età superiore agli 80 anni; inoltre, il rischio di mortalità nelle persone infette è apparso proporzionale al numero di malattie croniche concomitanti (2-7).

In merito all'ambito in cui è nato il progetto di questo studio è cruciale sottolineare che la “seconda ondata” della pandemia nel territorio di Ravenna è stata caratterizzata da una drammatica recrudescenza di focolai e numerosi decessi nelle CRA.

Il nostro Servizio, ravvisando un potenziale bisogno di Cure Palliative in questa popolazione di pazienti e valutando la giovane età anagrafica e professionale della maggior parte dei medici componenti il team ha proposto ed implementato una procedura di servizio di consulenza da parte della Rete di Cure Palliative di Ravenna^(8,9,10) ai medici USCA.

In particolare il servizio prevede:

- *Consulenza sulla terapia farmacologica e non farmacologica dei sintomi*, promuovendo la pratica della prescrizione anticipata a seguito di consulenza specialistica e confronto fra i medici ed altri operatori sanitari⁽¹¹⁾
- *Counselling informativo e comunicativo* ai professionisti dell'USCA nella relazione con pazienti, famiglie e operatori delle strutture protette. La rimodulazione forzata delle relazioni tra malati e famigliari, il distanziamento sociale e l'utilizzo di tecniche di comunicazione basata su Internet nello scenario della pandemia ha evidenziato drammaticamente quanto sia necessario migliorare le competenze per evitare la “morte solitaria”.^(12,13,14)
- *Supporto nella rimodulazione e ri-definizione del PAI nel corso della assistenza* quando è ritenuto necessario. La complessità dei bisogni, le caratteristiche profondamente evolutive e mutevoli del corteo sintomatologico, e la possibilità che

pazienti e/o tutori legali possano esprimere desideri e volontà in merito agli aspetti terapeutico-assistenziali per pianificare gli stessi rappresentano elementi di forte necessità di continua rimodulazione del piano assistenziale individualizzato^(15,16,17)

- *Partecipazione al briefing settimanale USCA on line*: La proposta di un incontro periodico e strutturato tra i consulenti ed i medici operativi sul territorio nasce anche dalla necessità di approfondire e condividere gli elementi costitutivi utili ad implementare un intervento complesso e non solo una prescrizione di una terapia sintomatologica⁽⁹⁾. In particolare, appaiono temi di doveroso approfondimento la comunicazione di cattive notizie, la gestione del fine vita in un contesto di tempi rapidamente evolutivi nella cura e la relazione con le famiglie.

Obiettivo

L'obiettivo primario è quello di accogliere la prospettiva dei fruitori sul servizio di consulenza implementato.

Obiettivo secondario della ricerca è quello di comprendere i vissuti (emozioni, percezioni) dei medici afferenti alle USCA in relazione alla loro esperienza di gestione di pazienti con bisogni di cure palliative durante la seconda/terza ondata pandemica.

Implicazioni pratiche

I risultati della ricerca potranno, attraverso l'analisi delle criticità emerse e dei possibili punti di forza evidenziati, permettere di fornire elementi utili a:

- Individuare possibili aree di miglioramento nella formazione pre-laurea ed immediatamente post-laurea per i medici nelle aree della terapia, assistenza e comunicazione nel fine vita e nel processo di elaborazione e trasmissione di decisioni "difficili"⁽¹⁷⁻²⁰⁾
- Elaborare ed implementare percorsi di adeguata continuità assistenziale nelle strutture sanitarie territoriali, allo scopo di garantire una adeguata valutazione e presa in carico dei pazienti anziani poli-patologici ad alta e media complessità (compresa la presa in carico a cura di un team specialistico di Cure Palliative)⁽⁷⁾.

Domanda di ricerca

Le domande di ricerca sono le seguenti:

1. Come i medici afferenti alle USCA valutano il servizio di consulenza?
2. Qual è il vissuto della gestione dei pazienti in fine vita?
3. Come si sono gestite le "scelte difficili" (per esempio: scelta di ricovero, comunicazione con i pazienti e con i famigliari, eventi legati al fine-vita)?

2. DISEGNO DELLO STUDIO

Studio qualitativo prospettico

La ricerca qualitativa investiga "l'intera persona" in modo olistico all'interno dell'ambiente naturale di quella persona, un approccio pienamente contestualizzato⁽²¹⁾. I punti di forza dell'approccio qualitativo includono: (a) la capacità di generare resoconti dettagliati di esperienze umane (emozioni, credenze e comportamenti) e (b) resoconti narrativi che vengono esaminati nel contesto originale in cui si verificano le osservazioni⁽²²⁾. Inoltre, l'approccio qualitativo offre un'analisi approfondita della complessità dell'essere umano, dei sistemi professionali e delle esperienze culturali in un modo che non può essere completamente catturato con scale di misurazione⁽²³⁾.

Metodo

Campione e setting

L'Unità di Analisi, che rappresenta il nucleo centrale dal quale partire per definire il/i partecipanti di una ricerca e cui riferirsi per l'analisi dei dati, è: medici afferenti alle USCA che hanno partecipato ai meeting/al servizio di consulenza per almeno 3 incontri o che ne conoscono le attività, professionisti sanitari coinvolti nel coordinamento del servizio.

L'unità operativa all'interno della quale verranno reclutati i partecipanti è la Struttura Semplice Dipartimentale di Cure Palliative – AUSL Romagna, sede di Ravenna.

Il numero massimo di partecipanti sarà di massimo 30 soggetti. Il campionamento è di tipo finalizzato.

Criteri di inclusione ed esclusione del campione finalizzato (ricerca qualitativa)

- Aver utilizzato e conoscere il servizio di consulenza in qualità di medico USCA durante la pandemia o in qualità di professionista sanitario della AUSL Romagna;
- Buona comprensione e produzione della lingua italiana;
- Aver sottoscritto il consenso alla partecipazione.

Modalità di reclutamento del campione

Il campione finalizzato prevede il contatto da parte del PI che spiegherà ai possibili partecipanti le procedure di ricerca e gli obiettivi. Saranno contattati tramite e-mail, telefono o contatti personali del PI. Sarà fornita la nota informativa in anticipo. Successivamente, i possibili partecipanti saranno

ricontattati dall'intervistatore per rispondere a eventuali domande/dubbi e chiedere la disponibilità a partecipare allo studio. In caso affermativo, l'intervistatore concorderà data e luogo per la conduzione della raccolta dati.

Strumenti di raccolta dati

I dati qualitativi raccolti provenienti da interviste semi-strutturate per ciascun partecipante dell'unità di analisi. Saranno inoltre raccolti dati demografici del partecipante (Specificati nell'Allegato).

L'intervista semi-strutturata

L'intervista è una conversazione finalizzata a uno scopo che consente un'esplorazione in profondità di un certo tema e fa emergere il modo attraverso cui un partecipante dà senso alla propria esperienza. L'intervista è diretta a esplorare l'esperienza dei partecipanti che hanno utilizzato il servizio di consulenza per raccogliere sia una loro valutazione in merito sia narrazioni della loro esperienza assistenziale durante la pandemia.

Lo scopo è, quindi, quello di stimolare la riflessione dei partecipanti a partire da esperienze personali e non da dichiarazioni teoriche o ideologiche.

L'intervista semi-strutturata comprende una serie di aree tematiche che devono essere esplorate per tutti gli intervistati attraverso domande costruite *ad hoc*, senza la necessità che queste vengano proposte con un ordine prestabilito e lasciando spazio a eventuali approfondimenti.

Ai fini del buon andamento dell'intervista, sarà premura dell'intervistatore creare un clima basato sull'ascolto non giudicante e sulla fiducia reciproca. Pertanto, le interviste saranno condotte da membri del comitato guida o del gruppo di supervisione metodologica, che hanno ricevuto un'apposita formazione al riguardo, e il luogo dell'intervista sarà scelto dai partecipanti. In rispetto alle norme di contenimento della pandemia di SARS-CoV-2, l'intervista potrà essere condotta in maniera telematica. Come dichiarato successivamente, le interviste saranno registrate: nel caso di una conduzione telematica, non saranno fatte video-registrazioni. I partecipanti avranno la possibilità di essere accompagnati da persone di loro fiducia.

Il metodo può prevedere la presenza di un intervistatore e di un osservatore.

Nell'ambito del presente studio:

- L'intervista avrà una durata compresa tra 30 e 60 minuti e verrà audio-registrata;
- La registrazione audio verrà trascritta parola per parola da un membro del team di ricerca;
- A tutti gli intervistati verrà chiesta la possibilità di un secondo incontro.

Ai partecipanti verrà chiesta la possibilità di un secondo momento di incontro per eventuali chiarimenti rispetto all'intervista e/o discussione dei risultati dell'analisi.

La registrazione sarà distrutta dopo la sua trascrizione e anonimizzazione, previo consenso dei partecipanti.

L'intervista semi-strutturata alle figure identificate rifletterà sui seguenti temi:

1. L'esperienza assistenziale in USCA durante la pandemia;
2. Gli eventi/le situazioni esperite durante l'assistenza;
3. La formazione ricevuta in dialogo con le dinamiche assistenziale collegabili alle cure palliative/ai pazienti con bisogni di cure palliative;
4. I percepiti in termini di utilità, beneficio del servizio di consulenza;
5. Le richieste al servizio di consulenza e le aspettative;
6. Le emozioni;
7. Valutazione dell'esperienza nel suo insieme: consigli, suggerimenti per migliorare il servizio.

In una intervista semi-strutturata l'ordine reale dei temi è negoziato con il partecipante durante l'interazione. Ogni tema prevede più domande-stimolo che potranno essere presentate durante l'intervista, ma cui i ricercatori faranno riferimento. La traccia dell'intervista, comprensiva delle indicazioni operative per l'intervistatore, è riportata in Allegato 1.

Analisi dei dati

Le interviste saranno registrate digitalmente e trascritte verbatim insieme alle eventuali annotazioni osservative. I dati saranno analizzati secondo il metodo dell'analisi tematica descritto da Braun & Clark⁽²⁴⁾

1. Trascrizione delle registrazioni *verbatim* e lettura integrale;
2. suddivisione in sequenze di conversazione e definizione delle etichette iniziali;
3. le etichette saranno combinate per identificare i temi e i sotto-temi principali;
4. commento dell'elenco dei temi identificati per assicurare la coerenza interna;
5. descrizione dei temi principali;
6. scrittura del primo report dei risultati.

Al punto 5 del metodo di analisi, saranno fatti emergere i temi collegabili all'obiettivo primario e all'obiettivo secondario del presente studio.

3. CONSIDERAZIONI ETICHE

Sarà conseguito il parere positivo del comitato etico di CEROM che visionerà il protocollo di ricerca integrale e gli strumenti d'indagine. I dati raccolti durante lo studio saranno gestiti secondo quanto previsto dall'etica della ricerca e dal diritto alla privacy, assicurando l'anonimato e la confidenzialità delle risposte fornite. Inoltre, questo studio verrà condotto in conformità con i principi della Dichiarazione di Helsinki, così come le leggi e le norme di riferimento italiane ed europee.

Saranno prodotti e consegnati ai partecipanti schede informative, moduli di Consenso Informato e moduli di consenso al trattamento dei dati, ecc., come previsto dalle attuali disposizioni in essere.

Tutti i membri del team di ricerca hanno ricevuto una formazione metodologica specifica in merito alla messa a punto e alla conduzione dell'intervista semi-strutturata, con particolare riferimento all'approccio relazionale e alle tecniche comunicative più appropriate per esplorare contenuti che afferiscono alla sfera soggettiva, potenzialmente densi di implicazioni emotive.

L'andamento delle interviste di volta in volta condotte sarà discusso nell'ambito di incontri di supervisione, con un'attenzione particolare alla misura in cui l'intervistatore ha saputo instaurare e mantenere con l'intervistato un clima di fiducia e ha saputo gestire le emozioni elicitate nei partecipanti dai temi esplorati nell'intervista.

I dati saranno conservati per almeno 10 anni presso la Struttura Semplice Dipartimentale di Cure Palliative – AUSL Romagna, sede di Ravenna.

L'attivazione dello studio è subordinata al parere del Comitato Etico di AUSL Romagna

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5. Allegati

1. Intervista semi-strutturata al partecipante
2. Nota informativa _ Consenso informato _ Consenso al trattamento dei dati