

Palliative care in emergency care: invoking Kairos and rethinking health care systems

Cuidados paliativos na emergência: invocando Kairós e repensando os sistemas de saúde

Cuidados paliativos en la emergencia: invocando a Kairós y repensando los sistemas de salud

Diego Lima Ribeiro ¹

Marco Antonio de Carvalho Filho ²

doi: 10.1590/0102-311XEN127922

Abstract

Acute crises of decompensation of a chronic disease are, in most cases, handled in an Emergency Room setting. In these services, emergency care professionals face several challenges, such as incomplete information on the patient's disease, scarce resources, and the pressure of having to make decisions in a short time. In this context, what can be done to provide patient-centered care that is at the same time technically appropriate and aligned with their values? Understanding the patient's situation in relation to their disease; talking to the patient about their clinical condition, comprehending their values and feelings; and understanding time as Kairos – that is, the time of the consultation as an opportunity to understand the patient's needs and build a shared therapeutic plan – are possible solutions to this challenge. Proper handling of patients with severe diseases requires that all links of health care systems are functional and coordinated from primary health care to hospital and home care, starting with the education of health care professionals and the strengthening of work settings that foster the expression of Kairos. This is a long and fundamental path for health care systems such as the Brazilian Unified National Health System (SUS) and that health managers and professionals should not afford to ignore.

Palliative Care; Emergency Medical Services; Delivery of Health Care

¹ Faculdade de Ciências Médicas, Universidade Estadual de Campinas, Campinas, Brasil.

² Utrecht University, Utrecht, Netherlands.

Correspondence

D. L. Ribeiro

Rua Dr. Edilberto Luis Pereira da Silva 796, Campinas, SP
13083-190, Brasil.

lrdiego@unicamp.br



Claudio, a 70-year-old man with functional class IV chronic heart failure, systemic arterial hypertension, and stage IV chronic kidney disease was admitted to the Emergency Room (ER) because of community-acquired pneumonia. During hospitalization, the patient developed septicemia and acute renal failure. This is his third hospitalization in the last 12 months. Claudio has been losing weight progressively, and has constant edema in his legs. Claudio is a retired truck driver, has three children, and his wife has been helping to take care of him for the past year, because he feels dyspnea when bathing and dressing. What therapeutic plan best addresses Claudio's needs?

Cases such as that of Mr. Claudio are common in the daily routine of ERs around the country and the world ¹ and indicate important deficiencies in several health care systems. In Brazil, population longevity has increased exponentially along with the prevalence of chronic diseases that frequently decrease the quality of life of patients and their families ². Individuals with advanced chronic disease suffer from progressive loss of functional capacity, with successive clinical decompensations that are part of the natural history of their disease, with uncomfortable symptoms, such as pain and dyspnea, in addition to a variety of psychosocial issues, such as the fear of being a burden on their family from a physical, affective and financial point of view.

In Brazil and in several countries around the world, acute crises of decompensation of a chronic disease are, in most cases, handled in the ER ³. In these services, emergency care professionals face several challenges: they often lack electronic medical records to better understand the evolution of a disease; they often are not able to talk to physicians responsible for the longitudinal care of patients; and they are forced to make decisions under the pressure of time and, commonly, of scarcity of resources. As they do not have a longitudinal relationship with patients, they lack the intimacy necessary to deeply understand their fears, anxieties and wills, that is, they have more difficulty in understanding what makes sense or not for that person in that context. Considering this complex context, what can be done to provide patient-centered care that is at the same time technically appropriate and aligned with their values?

From a clinical point of view, the first step involves seeking to understand the patient's situation in relation to their disease, the possible causes of decompensation, and available therapeutic approaches, including their risks and potential benefits, the probable outcomes, and the possibilities of reversing the condition ⁴. This, in itself, is already quite complex, as it necessarily requires the ability to navigate the uncertainties related to the act of prognostication, which will always remain an effort to predict the future. However, in isolation, this step is often insufficient to define the best clinical conduct in the emergency care.

The second step involves talking to the patient about their clinical condition, trying to understand them as a person, their individual needs, fears, objectives, and priorities. This conversation should necessarily be based on a relationship of trust, respect and affection. Two factors often make this type of conversation difficult: *taboo* and *time*. Taboo is a word originated in Polynesia, derived from Tongan *tabu* and Maori *tapu*, which refers to the prohibition of a certain act due to superstitious belief ⁵. For example, there is a fear that conversations about the end of life may further harm a patient who is already in a vulnerable situation. However, after years of experience in cases such as that of Mr. Claudio in the emergency care ward, we believe that these conversations are liberating for patients and health professionals, due to the opportunity to share and build meaning together. Truth liberates, especially when it is shared within an environment full of affection. And this affection is possible even within the rush of the ER, provided that we are truly present in body, mind, and spirit. This kind of presence requires focusing on the other and being available for their pain, being sure that much can be done to alleviate suffering even when the cure is no longer a possibility.

In relation to time, the argument often used is that there is no time to start conversations about the end of life in the ER. The ancient Greeks had two conceptions of time: Chronos and Kairos. Chronos is quantitative and refers to the time that can be measured (seconds, minutes, hours, or days); in turn, Kairos is qualitative, a time that is not measured in seconds or minutes, a time that is perceived ⁶. Kairos is the opportune moment. In the ER, time is often measured in minutes to institute a life-sustaining therapy (orotracheal intubation, for example). However, upon diagnosing an end-of-life patient, the quality of time is imposed and it is a priority to understand the needs and expectations of the patient in that situation.

Unfortunately, Kairos is often disregarded in end-of-life situations. The case of Mr. Claudio is a good example. In each of the three previous stays in the ER, there was the opportunity (Kairos) to start this conversation, understand his needs, share his clinical situation, alleviate his suffering, and consider his therapeutic possibilities. When these opportunities are lost, health teams often make poorly reflected decisions and increase the chances of patients receiving treatments that are misaligned with their values and that worsen their suffering.

Still from a clinical point of view, the third step involves building a shared therapeutic plan taking into consideration the information obtained in the previous steps. This step requires weighing, on the one hand, the objectives and values of the patient and, on the other hand, the certainties and uncertainties about the possibility of achieving these objectives. This is a dialogical act aiming to find in conjunction with that human being what is the best path to follow considering their desires and the limits imposed by their clinical situation⁷. This requires that health professionals have a certain degree of moral flexibility to adapt their usual conduct, conditioned by their personal values, so as to be able to align the therapeutic plan with the needs and values of the patient^{8,9}. This means inviting the patient to a conversation without having a prior decision of what will be done, whether it is a decision to institute life-sustaining therapies or to immediately initiate exclusive comfort measures. Nevertheless, it is important to recognize that there are situations where certain objectives that would be important to the patient are simply not possible and, ultimately, there is an ethical imperative that no professional should implement treatments for which there is certainty that not even their physiological objectives are achievable¹⁰. In these cases, health professionals should be able to maintain empathic communication and negotiate other objectives relevant to the patient within the permitted ethical limits.

From the point of view of Public Health, the challenge consists in improving health care systems not only for the promotion of health and prevention of illness, functional loss and death, but also for the prevention and relief of suffering¹¹. This necessarily involves an effort to coordinate and strengthen palliative care at all levels of health care systems¹². This is a complex task that involves the education of health professionals in general about basic principles of palliative care and includes rethinking medical precepts and social concepts about the value of death as a process not only physiological, but relational and with deep influence on how we interact with life and with the world around us¹³.

The process of education on fundamental principles of palliative care includes training in communication skills, interdisciplinary work, care planning, shared decision-making, assessment and handling of common symptoms such as pain and dyspnea, in addition to psychosocial and spiritual needs. It should be obvious that a health care system whose professionals know and practice such skills will be more beneficial and cause less harm, even to patients who are far from the end of their lives, than health care systems in which such knowledge is unknown to most professionals.

Although the starting point of this text was an emergency care service, the proper handling of patients with severe diseases requires that all links in health care systems are functional and coordinated from primary health care to hospital and home care. Health care systems need not only more palliative care specialists, but also generalists and specialists from other areas with basic knowledge of palliative medicine being part of the different levels of care and being able to work collaboratively¹⁴. For example, at the outpatient level, both in primary health care and in reference outpatient clinics, physicians should be able to diagnose patients for whom the occurrence of death within a year would not be unexpected, so they can be invited to reflect on what makes sense from their point of view in the case of acute complications. This means including in the consultation, in addition to specific therapies (such as furosemide and captopril), a conversation with the patient about the prognosis of their disease and about their needs and interests, in the present and in the future. Unfortunately, in the Brazilian context, it is still extremely common that patients with severe diseases only know about the terminal characteristic of their clinical conditions during emergency care. In terms of the population, wasting these opportunities contributes to health care that adds little value to the lives of thousands of patients and their loved ones. Paradoxically, health managers who are only devoted to Chronos and its metrics often witness their failure as they repress the expression of kairos as a productive opportunity for communication and bonding.

In conclusion, in order to preserve and ensure the dignity of patients such as Mr. Claudio and provide end-of-life care with high value to the population, it is necessary to coordinate clinical and Public Health approaches in a complementary manner. From a clinical point of view, emergency care physicians should be able to make accurate diagnoses, define an opinion relative to the patient's prognosis, recognizing the different degrees of uncertainty involved, and need to embrace *kairos*, leveraging the opportunity of the consultation in the emergency care ward to bond with end-of-life patients, and, with affection and care, share the decision-making process concerning the therapeutic plan to be implemented. From the point of view of Public Health, palliative care should be coordinated with the different levels of care based on the education of health professionals and the strengthening of work settings that foster the expression of *kairos*. This is a fundamental and long path for health care systems such as Brazilian Unified National Health System (SUS) and that health managers and professionals should not afford to ignore.

Contributors

D. L. Ribeiro contributed to the writing, editing, and bibliographic references. M. A. Carvalho Filho contributed to the grammatical and semantic revision and the development of essential concepts that underlie the text.

Additional informations

ORCID: Diego Lima Ribeiro (0000-0003-0731-9308); Marco Antonio de Carvalho Filho (0000-0001-7008-4092).

Acknowledgments

The authors thank Edison Iglesias de Oliveira Vidal for the valuable insights, the rich discussions and the careful review of the text.

References

1. Morrison SR, Meier DE. Palliative care. *N Engl J Med* 2004; 350:2582-90.
2. Szwarcwald CL, Stopa SR, Malta DC. Status of the main noncommunicable diseases and lifestyles in the Brazilian population: *Brazilian National Health Survey*, 2013 and 2019. *Cad Saúde Pública* 2022; 38 Suppl 1:e00276021.
3. Pickett G. The future of public health by the Institute of Medicine. *J Public Health Policy* 1989; 10:397-401.
4. Schumann JS, Alfandre D. Clinical ethical decision making: the four topics approach. *Semin Med Pract* 2008; 11:36-42.
5. Sílvia AP, Michaelis H. *Michaelis: moderno dicionário da língua portuguesa*. São Paulo: Editora Melhoramentos; 1998.
6. Kumagai AK, Naidu T. On time and tea bags: *chronos*, *kairos*, and teaching for humanistic practice. *Acad Med* 2020; 95:512-7.

7. Schofield P, Carey M, Love A, Nehill C, Wein S. "Would you like to talk about your future treatment options?". Discussing the transition from curative cancer treatment to palliative care. *Palliat Med* 2006; 20:397-406.
8. Haidt J. The emotional dog does learn new tricks: a reply to Pizarro and Bloom (2003). *Psychol Rev* 2003; 110:197-8.
9. Haidt J. Morality. *Perspect Psychol Sci* 2008; 3:65-72.
10. Bosslet GT, Pope TM, Rubenfeld GD, Lo B, Truog RD, Rushton CH, et al. An official ATS/AACN/ACCP/ESICM/SCCM policy statement: responding to requests for potentially inappropriate treatments in intensive care units. *Am J Respir Crit Care Med* 2015; 191:1318-30.
11. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, et al. Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage: the Lancet Commission report. *Lancet* 2018; 391:1391-454.
12. World Health Organization. Strengthening of palliative care as a component of comprehensive care throughout the life course. Sixty-seventh World Health Assembly. <https://apps.who.int/iris/handle/10665/162863> (accessed on 11/Jul/2022).
13. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, et al. Report of the Lancet Commission on the value of death: bringing death back into life. *Lancet* 2022; 399:837-84.
14. Quill TE, Abernethy AP. Generalist plus specialist palliative care: creating a more sustainable model. *N Engl J Med* 2013; 368:1173-5.

Resumo

As crises agudas de descompensação de uma doença crônica são, na maioria das vezes, manejadas em ambiente de pronto-socorro. Nesses serviços, os profissionais emergencistas enfrentam vários desafios, como falta de informação completa sobre a doença do paciente, escassez de recursos e a pressão de ter que tomar decisões em pouco tempo. Nesse contexto, o que pode ser feito para prestar um cuidado centrado no paciente, que seja, ao mesmo tempo, tecnicamente adequado e alinhado a seus valores? Compreender a situação do paciente em relação a sua doença; conversar com o paciente sobre sua condição clínica, compreendendo seus valores e sentimentos; entender o tempo como Kairós, ou seja, o tempo da consulta como uma oportunidade de entender as necessidades do paciente, e construir um plano terapêutico compartilhado são possíveis soluções para esse desafio. O manejo adequado de pacientes portadores de doenças graves demanda que todos os elos dos sistemas de saúde estejam em funcionamento e integrados desde a atenção primária à saúde até a assistência hospitalar e a atenção domiciliar, tendo como ponto de partida a educação dos profissionais de saúde e o fortalecimento de ambientes de trabalho que favoreçam a expressão de Kairós. Trata-se de um caminho longo e fundamental para sistemas de saúde como o Sistema Único de Saúde (SUS) e que gestores e profissionais de saúde não deveriam se dar ao luxo de ignorar.

Cuidados Paliativos; Serviços Médicos de Emergência; Atenção à Saúde

Resumen

Las crisis agudas de descompensación de una enfermedad crónica se manejan con mayor frecuencia en un entorno de Urgencias. En estos servicios, los profesionales de urgencias se enfrentan a varios desafíos como la falta de información completa sobre la enfermedad del paciente, la escasez de recursos y la presión de tener que tomar decisiones en poco tiempo. En ese contexto, ¿qué se puede hacer para proporcionar un cuidado centrado en el paciente, que sea al mismo tiempo técnicamente adecuado y alineado a sus valores? Comprender la situación del paciente con respecto a su enfermedad; hablar con el paciente sobre su condición clínica, comprender sus valores y sentimientos; comprender el tiempo como Kairós, es decir, el tiempo de consulta como una oportunidad para comprender las necesidades del paciente y construir un plan terapéutico compartido, son posibles soluciones a este desafío. El manejo adecuado de los pacientes con enfermedades graves requiere que todos los eslabones de los sistemas de salud funcionen y se integren desde la atención primaria a la salud hasta la asistencia hospitalaria y la atención domiciliar; teniendo como punto de partida la educación de los profesionales de salud y el fortalecimiento de ambientes de trabajo que favorezcan la expresión de los Kairós. Se trata de un camino largo y fundamental para los sistemas de salud como el Sistema Único de Salud brasileño (SUS) y que los gestores y profesionales de salud no deberían darse el lujo de ignorar.

Cuidados Paliativos; Servicios Médicos de Urgencia; Atención a la Salud

Submitted on 11/Jul/2022

Approved on 18/Jul/2022