

A Medicina Está a Oferecer aos Doentes em Fim de Vida Aquilo que Procuram?

Is Medicine Giving End-Of-Life Patients what they Are Looking For?

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Healthcare is being challenged by increasing care demands from an ageing population and the impact of chronic disease in our community as well as changing patient and community expectations about care delivery and outcomes. Clinicians are becoming more and more aware that concepts such as focus of patient centred care brings with it patient participation in shared decision making.¹⁻³ However, we know those issues are not always consistently prioritized and applied in our care. Not addressing these considerations can be especially challenging in the end-of-life context. Caring for people across the last year of life as well as those who are actively dying is becoming an expectation across the health system. In 2014, the World Health Assembly passed a resolution calling for member states to strengthen the field of palliative care as a component of comprehensive care across the life course. This resolution highlighted the importance of what has always acknowledged that the patient and their family caregiver are the 'unit of care' and as such encouraged shared decision making, particularly when 'goals of care' are being discussed.⁴ Despite this philosophy of care, gaps remain across acute care, primary care and, as it now appears, also in specialist palliative care. End-of-life is a time of great uncertainty for the patient and their family and for clinicians this often means they are being available across the whole of the health system including primary and community care.⁵ However, uncomfortable questions are emerging that suggest that sometimes as health professionals we do not feel comfortable or able to handle these

issues. But patients are there, every day, expecting the best care from us. Are we mindful of what they are looking for and are we equipped to meet their needs as health professionals and as a health system?

If health care systems are not meeting the needs of their population, people will find others to provide care, advocate and fill in the gaps in care. In some countries a new role in the end-of-life space is emerging: the death doula. The term "doula" is a Greek word meaning a woman caregiver.⁶ Better known in their work in birthing,⁷ this informal role has been adapted into contemporary models of care such as illness doulas,⁸ delirium doulas⁹ and cancer care doulas.¹⁰ Following this trend in changing models of care, doulas are now emerging in the end-of-life domain.

Death doulas are working with people at the end of life in varied roles that are not well understood, and can be described as similar to that of "an eldest daughter" or to a role that has similarities to specialist palliative care nurses. It includes conversation and education about disease and end-of-life, discussion of goals of care, advocating patient and family preferences and provides psychological and spiritual resources.¹¹

The death doula role was also described as a non-medical care worker that emphasizes personal happiness and satisfaction rather than an extension of life; accompaniment based on intimate human relations; integrated care that encompasses the physical, emotional, social and spiritual facets of the dying person. The aim is to give patients and families a sense of control, increasing confidence in decision-making, decreasing stress and increasing peace and tranquility.¹² It could also provide the patient and their families with more time dedicated to care and support than is able to be provided by health professionals.¹² Actually, supporting families is an important part of the doula role, as is providing them with information to help navigate the healthcare system, the disease and death itself.

The arrival of a role such as a death doula appears to have come from the need of empowerment during the dying process, giving alternatives to the current modern clinical approach, with a shift directed towards awareness and choice. It seems to have been created by the patients' need to promote balance in their dying process; preventing or stopping excessive medicalization of end-of-life care, thus

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bringing meaning and spiritual comfort. They also help to organize alternative funeral celebrations, personalizing them and giving them special significance.

The relation between death doulas and health systems are not very well established, but some authors say there is some overlap with health professionals' roles, more specifically that of specialist palliative care nurses¹³ and even specialist supportive community care workers. They are more commonly seen, however, as a supplement for the care provided by the multidisciplinary palliative care team.¹⁴

They may not see the need to work with or alongside healthcare professionals, and indeed this may not be warranted. It should also be considered that there are roles that patients, caregivers, and families do not want their health professionals to fill, or roles that they do not see as that undertaken by a health professional.

Steinhauser *et al* studied the factors deemed to be important by patients as to what supports a good death.¹⁵ Patients identified the need to have physicians who are comfortable talking about death and dying and who are someone with whom a patient can express their own personal fears. While physical care is crucial and ranked as important by patients, they view their end-of-life with broader psychosocial and spiritual meaning. In order to prevent unmet needs in their illness experience, they require supportive health care professionals who can communicate openly and who can focus on the broader psychosocial issues.¹⁶

The emerging role of the death doula appears to reflect a desire for different approaches and ways of caring at the end-of-life.¹⁷ Such new roles remind us as health professionals that our practice needs to reflect the patients' needs and desires, including their psychosocial and spiritual dimensions. In a time of increasing care demands, this new role may help health systems to better support dying people and their families. ■

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REFERÊNCIAS

- Pieterse AH, Stiggelbout AM, Montori VM. Shared Decision Making and the Importance of Time. *JAMA*. 2019;322:25-6. doi: 10.1001/jama.2019.3785.
- Rotenstein LS, Huckman RS, Wagle NW. Making Patients and Doctors Happier — The Potential of Patient-Reported Outcomes. *N Engl J Med*. 2017;377:1309-12. doi:10.1056/NEJMp1707537.
- Barry MJ, Edgman-Levitan S. Shared Decision Making — The Pinnacle of Patient-Centered Care. *N Engl J Med*. 2012;366:780-1. doi:10.1056/NEJMp1109283.
- Moulds R. Therapeutic Guidelines: Palliative Care. Version 4. Melbourne: Therapeutic Guidelines Limited; 2016. [accessed Jan 2020] Available from: <http://www.tg.org.au>.
- WHO. Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course. *J Pain Palliat Care Pharmacother*. 2014;28:130-4. doi:10.3109/15360288.2014.911801.
- Campbell DA, Lake MF, Falk M, Backstrand JR. A randomized control trial of continuous support in labor by a lay doula. *J Obstet Gynecol Neonatal Nurs*. 2006;35:456-64.
- Sosa R, Kennell J, Klaus M, Robertson S, Urrutia J. The effect of a supportive companion on perinatal problems, length of labor, and mother-infant interaction. *N Engl J Med*. 1980;303:597-600.
- Robinson A, Spencer D, Lewis B. Illness Doula: Adding a New Role to Healthcare Practice. *J Med Humanit*. 2017;1-12.
- Balas MC, Gale M, Kagan SH. Delirium doulas an innovative approach to enhance care for critically ill older adults. *Crit Care Nurse*. 2004;24:36-46.
- Rocque GB, Dionne-Odom JN, Huang CS, Niranjana SJ, Williams CP, Jackson BE, et al. Implementation and impact of patient lay navigator-led advance care planning conversations. *J Pain Symptom Manage*. 2017;53:682-92.
- Fukuzawa RK, Kondo KT. A holistic view from birth to the end of life: end-of-life doulas and new developments in end-of-life care in the West. *Int J Palliat Nurs*. 2017;23:612-9. doi:10.12968/ijpn.2017.23.12.612
- Lentz JC. Palliative care doula: an innovative model. *J Christ Nurs*. 2014;31:240-5.
- Howell D, Hardy B, Boyd C, Ward C, Roman E, Johnson M. Community palliative care clinical nurse specialists: a descriptive study of nurse-patient interactions. *Int J Palliat Nurs*. 2014;20:246-53. doi:10.12968/ijpn.2014.20.5.246.
- Poulos RG, Harkin D, Poulos CJ, Cole A, MacLeod R. Can specially trained community care workers effectively support patients and their families in the home setting at the end of life? *Health Soc Care Community*. 2018;26:e270-9. doi: 10.1111/hsc.12515.
- Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000;132:825-32. doi:10.7326/0003-4819-132-10-200005160-00011.
- Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284:2476-82. doi:10.1001/jama.284.19.2476.
- Rawlings D, Tieman J, Lewis LM, Swetenham K. What role do Death Doulas play in end-of-life care? A systematic review. *Health Soc Care Community*. 2018;27:e82-e94. doi:10.1111/hsc.12660.