

Brazil: time for palliative care in the community!

Brazil has a tremendous opportunity to integrate palliative care into its community healthcare services.

Santiago Rodríguez Corrêa, Carla Mazuko, Mayara Floss, Geoffrey Mitchell and Scott A Murray describe the rationale behind, and opportunities for, developing primary palliative care in the country

Global estimates show that for every one million inhabitants, 1,000 people require palliative care every year. In Brazil, this means that around 180,000 people could benefit from palliative care annually; however, most people do not currently get any such support at the end of life.¹

Brazil has an extensive network of multidisciplinary teams working in primary care; this infrastructure could be used to establish good-quality palliative care service provision in the community. However, this would require all primary care staff to be trained so that they are able to recognise when a patient will benefit from holistic end-of-life care, and to subsequently introduce a palliative care approach. Hence there is a pressing need to generate a primary palliative care strategy with the aims of increasing awareness of palliative care among healthcare professionals and improving their training.

This article highlights the potential of Brazilian primary care services to play a significant role in providing effective palliative care, and describes a recent initiative, the project 'Estar ao seu lado' (which translates roughly as 'We are by your side').

Key points

- In Brazil, around 180,000 people could benefit from palliative care annually, but most people do not currently get any such support.
- Brazil has an extensive network of multidisciplinary primary care teams working in the community as part of the national 'family health strategy'; this infrastructure could be used to establish good-quality palliative care service provision in the community.
- In Rio Grande do Sul, the project 'Estar ao seu lado' ('We are by your side') aims to make palliative care available in the community.
- Integrating palliative care in primary care will require enhanced medical training, awareness, policy and service organisation.

The case for primary palliative care

In recent years, the potential of palliative care in primary care to improve the quality of life of all people with life-threatening illnesses has been increasingly recognised. In 2014, the World Health Assembly passed a resolution recommending that all member countries should integrate palliative care in all healthcare settings, especially in the community.² We believe that a palliative care approach, and the appropriate relevant services, should be offered as early as possible in the course of all potentially fatal chronic conditions, and that palliative care should, therefore, be provided within primary care.¹ A palliative care approach, dispensed by professionals who will have been given basic training in palliative care, is essential, and primary care is in an excellent position to apply it to all patients nearing the end of life, whether they are dying with cancer, organ failure, frailty or dementia.^{3,4}

Even though the number of professionals specialising in palliative care is growing, only a small proportion of those who need palliative care have, or will ever have, access to specialist care.⁵ Some end-of-life care is already being delivered through primary care, but often it is not recognised for what it is. The palliative approach needs to be recognised as an essential component of care, and requires investment to ensure it is delivered as effectively as possible.

In Brazil, palliative care started appearing in the late 1990s, but the focus was on secondary and tertiary levels of care. Today, palliative care is not sufficiently promoted as a public policy, which negatively affects patients and families from diagnosis to bereavement,⁶ and results in a poorer quality of death.⁷ The lack of promotion and co-ordination of palliative

care is most evident in primary care. The integration of palliative care in primary care is increasingly discussed, but palliative care is not yet recognised as integral to primary care.¹

A network of teams on the ground

Primary care in Brazil is largely provided through the country's national health system, known as the Sistema Único de Saúde (SUS). This is a publicly funded and rights-based health system founded on the principles of universality and social control.⁸ About 20 years ago, primary care was 'fast-tracked' with the implementation of a 'strategy for family health', the Estratégia de Saúde da Família (ESF), which was presented as a new way of providing holistic care for individuals, their families and communities.⁹

Ideally, the ESF works with specialists in family medicine or public health, with teams composed of GPs or family health specialists, general nurses or family health specialist nurses, nursing technicians and community health workers. In 2013, there were no records of primary care teams providing systematic palliative care. Moreover, there are only six hospices and 24 home care services at the first level of care in Brazil, which represents less than 0.1% of primary care services delivered nationally. This is unsatisfactory, because patients live in the community most of the time and 90% of the last year of life is spent at home.^{11,12} In addition, most patients are cared for in primary care and have no need for specialist palliative care according to the model of needs.¹³

Through the network put in place by the ESF, systematic end-of-life care could potentially be offered to all patients in their last months, weeks and days of life.¹³ There are over 50,000 teams on the ground linked to the ESF¹⁴ and they have access to support from psychologists, physiotherapists or nutritionists. This structure could be used to provide palliative care in the community.

Improving training and awareness

One of the challenges is that these healthcare professionals working on the ground need to be adequately trained. Better education about death and the needs of dying people is needed in the curriculum of medical students. Currently, among more than 180 medical

■ The 'Estar ao seu lado' project in Brazil is set up in a very poor area. 'If we do palliative care here, we can do it anywhere', says Santiago Rodríguez Corrêa, one of the project's founders



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schools in Brazil, only two have formal chairs in palliative care.¹⁵ It is, therefore, not surprising that healthcare professionals are not prepared for treating patients approaching the end of life. There is a reluctance on the part of healthcare professionals to discuss death and dying, which reflects society's attitudes. In Brazil, there are low levels of awareness of how to prepare oneself for death or how to help others to die well.⁷

Improving policy and service organisation

This need to change the way we care for people at the end of life aligns with the principles of the SUS, which guarantees equity in healthcare. Furthermore, it is currently very expensive to care for patients at the end of life, and the Brazilian healthcare system is in crisis.⁷ Brazil urgently requires a new health

policy that promotes not only more effective end-of-life care, but care that is less expensive and more patient-centred.

Good end-of-life care demands time from the

healthcare teams. Delivering the right kind of care thus requires systematic organisation in order to optimise the use of time.¹¹ The Brazilian Ministry of Health has set priorities for improving the population's health and targets to be met,¹⁶ but none of these priorities or targets relate to palliative care. Palliative care will need to be incorporated into the existing structures, and a way will have to be found to integrate it into current healthcare professionals' roles.

In Brazil, there are low levels of awareness of how to prepare oneself for death

The Taskforce in Primary Palliative Care of the European Association for Palliative Care has developed a useful toolkit that can help incorporate palliative care into primary care at policy level.¹⁷ The toolkit has been endorsed by the World Organization of Family Doctors (WONCA) and its usefulness was highlighted at the World Health Assembly in May 2014.

'We are by your side'

The first systematic primary palliative care project launched in Brazil is called 'Estar ao seu lado', which roughly translates as 'We are by your side'. Its overall aim is to offer high-quality, standardised palliative care in the community.¹⁸ The project was set up to meet the needs of patients and families for holistic care, including physical, social, psychological and spiritual support. Through advance care planning, it aims to minimise avoidable crisis situations and thus reduce the demands on Brazilian hospitals. Box 1 gives more information about the project.

Conclusion

A longer life expectancy, a higher number of patients with chronic and incurable diseases¹ and an increase in the incidence of cancer (with an estimated 600,000 new cases in 2016–17)¹⁹ mean that we need a new way of providing end-of-life care. This will become increasingly urgent.¹⁷ We believe that, in Brazil, palliative care integrated into the work of primary care teams is the best solution to give everyone reliable access to palliative care.

The project 'Estar ao seu lado' ('We are by your side') was launched in June 2014 by a primary healthcare team in the state of Rio Grande do Sul, in the south of Brazil.

The team, composed of six community health workers, three nurses (including one with public health training) and one family physician, covers a healthcare area in the municipality of Rio Grande with a population of 3,000 people. It provides all the services of a Brazilian 'ESF' (Estratégia de Saúde da Família, Brazil's national family health strategy) team: prenatal care, paediatric care, acute care, care of patients with chronic diseases. Through the 'Estar ao seu lado' project, it now also offers outpatient appointments and home visits to patients and informal carers who need palliative care.

The local community is involved through the 'Comunidade cuidadora' ('Caregiving community') arm of the project. Healthcare professionals and community members meet monthly to discuss, and promote a public debate around, death, dying and the end of life. Eventually the plan is set up a 'Compassionate community' project.

For more information, you can visit the 'Estar ao seu lado' Facebook page (www.facebook.com/estaraoseuladorg?ref=hl).

Box 1. The 'Estar ao seu lado' project

Declaration of interest

The authors declare they share a vision for improving palliative care in the community internationally, but no financial interests.

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