

Primary palliative care in southern Brazil: the legacy of Cicely Saunders

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As her undergraduate medical studies drew to a close, Cicely Saunders, whose centenary is being celebrated in 2018, was moved to write her first article and to submit it for consideration to the St Thomas's Hospital Gazette. Published in 1958, it proved to be a remarkably complete statement about the issue of terminal care in Britain at that time, and a manifesto for what might be done in the future.¹

The article outlines the circumstances of four cancer patients with advanced disease. We are drawn into the worlds of two men and two women, each dying prematurely from cancer, each seeking relief from symptoms and each in need of reassurance, help for their families and strength in the face of death. Not only does it describe the prevailing issues and problems of the day, it also became a roadmap for future guidance. Condensed into its pages is the entire range of questions with which the subsequent field of palliative care would have to grapple. It was something that brought to attention the plight of terminally ill people in Britain at that time, giving voice to their suffering and serving as a stimulus for change.²

Here we pay tribute to the original Cicely Saunders article that first appeared 60 years ago. Inspired by it, we share some examples, not from London but from the city of Rio Grande in Southern Brazil. We also explore the complexity of issues and problems still occurring in the face of serious illness and impending death and how they might be approached.

But whereas the original paper focussed on the hospital as the site of main interest, our reflections relate to the primary care setting. We show how a community health service with a special programme of palliative care can respond to the

needs of local people, often over longer periods than the terminal care focus of earlier years.

Our examples here were compiled in the period January 2015 to February 2017. The patients described and their families gave us permission to share their stories with a wider audience. Each patient was cared for within the project known as *Estar ao Seu Lado – Cuidados Paliativos na Atenção Primária (We Are by Your Side – Primary Palliative Care)*.³ Each was identified using the Supportive and Palliative Care Indicators Tool (SPICT),⁴ to select people who might benefit from palliative care interventions. Once identified, each patient was offered a programme involving weekly palliative care outpatient clinics, support for carers and home visits, sometimes in emergencies. Fictitious names have been used in each case and other details changed where necessary, to preserve anonymity.

Antonio and Maria

Antonio (84 years) and Maria (83 years) were a couple living in a simple house, with good sanitary conditions. Retired with a small pension, they had five adult children, three of whom were significantly involved in their care. Their relatively good economic situation allowed them to employ outside caregivers.

Antonio had Chronic Obstructive Pulmonary Disease (COPD at level 3–4). Crises of anxiety, with bouts of crying and the worsening of his dyspnoea, were exacerbated by family conflicts in which two of his daughters refused to see him. These persisted throughout the last year of his life. One very specific challenge resulted from the pressure he came under from his paid carer who sought to impose her own religious beliefs upon him. He died at the end of 2015 after a year of

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progression of his respiratory disease, worsening frailty and a loss of independence.

His wife Maria went into rapid cognitive decline and was diagnosed with Alzheimer's disease, which was probably the cause of her under-lying psychological problems when first seen by the team in 2015. She became totally dependent on others for her care and was confined to bed. Maria had problems with her formal caregivers and her family issues carried on through 2017. Her cognitive decline did not allow a proper evaluation of her spiritual concerns. She continues to be supported by *Estar ao Seu Lado*.

Carlos

Carlos (64 years) was diagnosed with a kidney cancer in 2015. A Uruguayan, he was living with a new partner after the death of his first wife, in a comfortable home. As a foreigner however, and to his personal detriment, he encountered extended problems relating to health insurance. He had two sons and a difficult relationship with one of them.

During the first year of his illness, he underwent surgery and was subsequently prescribed moderately strong opioids. He took his medication on an irregular basis, showed a strong resistance to accept the disease and fought against his lost capacity to work and to be independent. Although he started to receive financial benefits in the final period of his illness, his other struggles continued and were present up to his death.

His problems were a complex web of family conflicts, bureaucratic and financial barriers to obtaining strong opioids and obstacles to accessing appropriate medical assessment and treatment. His increasing pain required opioid rotation, using morphine and methadone. Yet at the end of his life, he showed some acceptance of his condition and declared: 'Now I finally understand what is happening'. When Carlos had an episode of delirium, the family, despite the many meetings they had with the team and numerous attempts to plan his care in advance, asked for him to be admitted to hospital, which was where he died, in 2016.

Iracema

Iracema (54 years) lived in a house in an impoverished neighbourhood of the area covered by the team. With poor sanitary conditions, her home

and general aspect seemed carelessly organised and not always clean. It reflected Iracema's view of herself. She had four children and many family conflicts and social problems related to them; her daughters were in disagreement over how best she should be cared for and she had problems with her son, who lived with her.

Iracema had cancer of the cervix and initial assessments in early 2015 showed increasing levels of pain and the need for strong opioids. She was receiving health insurance benefit related to her disease. Radiotherapy reduced her pain. But she then developed a fistula of the bladder–vagina. Her life became one of intense suffering. Although her pain came under control, she developed urinary incontinence and recorded the highest possible score (of 10) on the Edmonton Symptom Assessment Scale.⁵ She could only obtain free diapers from government sources on an intermittent basis. Buying them herself took away valuable money which she could no longer spend on food.

Poor access to medicines and specialist appointments, and the shame occasioned by the smell of urine combined to heighten Iracema's psychological suffering and as a result, she abandoned her religious practices. During part of 2016, her condition was more stable, but by the end of the year, she presented with metastases in the abdomen, damage to her kidneys and urinary obstruction. By the end of 2017, she was awaiting surgery, but during that year she had an increase in her pain, despite higher doses of stronger opioids, and with constipation also resulting. Her multiple problems continue, perhaps with some small improvement.

Yara and João

Yara (58 years) and João (65 years) were siblings. She had a son and a daughter and lived with the son until he moved away to another city. At this point, she was under the care of the team as a result of her brother, who was also being looked after with *Estar ao Seu Lado*. Then she went to live with her daughter and was out of catchment for the team. Until that time, Yara was very careful with her approach to life and to her illness. But she had been unable to accept the move of her son and became depressed. Over time, she had financial problems in buying medications and obtaining assessment and treatment from the government healthcare system. Her problems

were made worse by her relationship with her brother and their shared difficulties in accepting his illness. Her daughter also later described many episodes of Yara calling her son in the last days of her life.

Yara had been diagnosed with lung cancer after a metastasis was identified in the mastoid region in 2015, and she was able to access health insurance benefit for some time for her treatment. Her first appointment with *Estar ao Seu Lado* was in August 2015. She had shock-like pain and paraesthesia on the right side of her face, with local tumour growth on the mastoid. As her illness progressed, she lost strength and movement on her right side due to the brain metastasis. Despite this, and with appropriate medications, her physical symptoms were generally ameliorated by the team. But her disease progressed, she was increasingly confined to bed, and in due course died at home in 2016.

Her brother João was diagnosed with rectal cancer in 2015 and experienced some improvement after treatment. But he in turn suffered episodes of mental health problems associated with his sister's illness, very complex family relationship problems and challenging behaviour from his adult children that exacerbated his episodes of pain. João had many children and his problems were often related to the attitudes of some of them. Nevertheless, he remained in employment, with no immediate financial worries.

The social and psychological problems of Yara and João were closely related and spiritual suffering played an important role in them. João never accepted his sister's religious beliefs and attributed the cause of her disease to her religion, with many negative consequences for their relationship. After his sister died, João's situation worsened socially and medically and despite many attempts to maintain contact with him, his links with the team fell away.

Commentary

Brazil has more than 208 million people, and 1.2 million deaths and 600,000 new cases of cancer per year. Palliative Care services are patchily distributed. The Family Health Strategy, made up from 43,000 primary care teams across Brazil, forms a comprehensive primary care network. The Project *Estar ao Seu Lado*-Primary Palliative Care developed by working from Community Centres in a model based on compassionate

communities,⁶ with community carers working alongside primary care teams. It identifies people who need palliative care, gives them specific care and enrolls their carers into a programme of monthly meetings called 'Comunidade Cuidadora' focussed on caring at end of life and providing skills training. The joint working of professionals and supportive networks together is recognised as being transformational. Carers themselves spread this approach by recommending it to others they know with life-limiting illness. This forms part of a compassionate community programme in the Rio Grande area. The goal is a combination of primary care working in harmony with communities, providing education, resources and training to enhance the skill of communities to care for their dying. This is a potentially realistic approach in Brazil, where resources and access to healthcare are limited.

The patients and families described here are good illustrations of those who can benefit from primary palliative care in Brazil. They received the best care possible within existing resources, benefitting from the structure of the *Estar ao Seu Lado* programme, the knowledge and attitudes of the team, and use of medications matched to their needs and conditions. However, they struggled to overcome obstacles exposed by the lack of a public health approach to end-of-life care within the National Health System.

For many others, the situation is much worse. Difficult access to opioids, the absence of palliative care specialists to consult when necessary, delays in getting appointments with other specialists and for clinical examinations, the lack of a network of electronic communication to record and share information about the clinical history of patients – all of these factors conspire to prevent receiving the best possible care. The scale is daunting. In Brazil, it is estimated that 180,000 people each year could benefit from palliative care but this may be a low figure given the realities of healthcare in the country and the need for palliative care among people with chronic and long-term conditions.

To address and overcome these issues and to try to improve access to best palliative care within existing resources, 'Estar ao Seu Lado – Cuidados Paliativos na Atenção Primária' is working with the Municipal Health Secretary and the Coordinator of the Family Health Strategy programme.⁷ As a result, a public health agenda

for palliative care has been incorporated into the Municipal Health Plan for 2018–2021. This will enhance skills to primary care professionals as the main objective and address how barriers to medications, clinical tests and services can be overcome.

These activities should improve access to primary and community palliative care for the local population and the example of Rio Grande could become one from which others can learn in other parts of Brazil. The importance of this cannot be ignored. Brazil is a country where 25% of the population lives in poverty, the National Health System is in crisis, and there is very poor access to palliative care. The Family Health Strategy includes teams distributed across the country, including rural areas covering more than 60% of the Brazilian population, meaning 138 million people.

The framework of integrating people/communities/health system/governance echoes the spirit of the recent Declaration of Astana.⁸ The Declaration renews the goals of Alma-Ata with a final objective to achieve Universal Health Coverage for all in the context of the Sustainable Development Goals. It also addresses the new challenges of chronic conditions and includes the provision of palliative care, accessible to all, on a continuum of health promotion, curative treatment and rehabilitation.

Primary care is key to improving access to palliative care and should be recognised by National Health Systems as a way to increase the coverage of people who need palliative care, whose needs are identified, whose quality of life is improved and whose dignity is respected across their disease trajectory. Here we see the frameworks of primary care and public health working together to serve the people and improve their health and well-being, even in the context of advanced disease. Primary care is defined as ‘the first-contact, continuous, comprehensive, and coordinated care provided to populations undifferentiated by gender, disease, or organ system’.⁹ Public health is defined as the ‘art and science of preventing disease, prolonging life and promoting health through the efforts of society’, something related to well-being and health, and not just to the eradication of particular diseases. Primary care and public health are therefore closely related – and palliative care draws on the inspiration of

both.¹⁰ Could the Rio Grande example be replicated and scaled up to achieve maximal coverage thereby reaching the objectives of the Declaration of Astana, promoting health and well-being for the people who need palliative care within a primary care context?

Conclusion

Sixty years after publication of her first article and 100 years after she was born, the legacy of Cicely Saunders still resonates. In the cases presented here, we see many echoes of the ‘total pain’ she first described in 1964.¹¹

As we try to show, the context of suffering is also highly relevant to its understanding and amelioration. Poverty, a lack of resources, barriers to accessing medication, difficulties in obtaining specialist appointments and diagnostic examinations, these all frame a set of experiences that require greater priority from public policies. Combined with personal and psychological problems, spiritual concerns and challenging family circumstances, they create a form of ‘structural violence’ that is inflicted on whole communities and which exacerbates the experience of illness and loss.¹²

Estar ao Seu Lado is one of the few primary palliative care projects in Brazil and advocates for greater palliative care awareness and the need to build compassionate communities. It is here, in local communities, that palliative care has much to offer, alongside and within the provision of primary care services. It is here that early identification of people who can benefit from palliative care interventions can take place. It is here that a person can be followed through the trajectory of illness and where family members can be supported, including in bereavement.

As Cicely Saunders recognised, a pro-active attitude, specific skills and competencies and attention to the essence of care can have powerful effects. She once observed ‘we are caring *for* persons and *as* persons’.¹³ To this, we can add persons *in community*. We need to better understand how palliative care can operate in community contexts of many types as well as how and if ‘compassionate communities’ can be fostered and sustained. The stories we present here, echoing Cicely Saunders’ approach, indicate there is much important and necessary work to be done.

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