

Luzia Travado:

improving outcomes for patients by attending to their distress

→ Marc Beishon

At a busy hospital in the centre of Lisbon, Luzia Travado managed to transform the role of health psychology from an intervention of last resort to a place in the frontline of cancer care, by showing time and again what can be achieved when you listen to patients and help them use their own coping skills. Her determination to improve the psychosocial care offered to cancer patients has made her a familiar face at seminars and conferences across Europe and beyond.

Given that a diagnosis of cancer often has a devastating emotional impact on people it is surprising that it is only relatively recently that 'distress' has started to be seen as the sixth vital sign to check for with patients. That is no fault of the advocates of psychosocial care in oncology, who have been patiently building up an impressive armoury of evidence for the role of health psychology in cancer. But the medical model in oncology – which is still catching up with the fifth vital sign, namely pain – is a tough mindset to change (the other four signs being, of course, temperature, blood pressure, pulse and respiratory rate).

“If you assess pain properly you might also be on your way to managing distress, as pain also has a psychological component,” says Luzia Travado, head of clinical psychology at Hospital de São José in Lisbon, Portugal. “But if you don’t ask the right questions at

the right times you won’t know what the patient is also enduring from a range of sources of emotional distress, not just pain, and so you could be neglecting a very important area of intervention.

“If you don’t deal with distress – which can develop into depression, anxiety and maladjustment – patients will not have the best quality of life and clinical outcomes they might have had otherwise. They could stay in hospital longer, derive less benefit from chemotherapy, be a greater burden on their families and have a shorter overall survival.”

About 50% of cancer patients will suffer from distress that may develop into psychological conditions such as depression, she says, which indicates the scale of potential need for support.

The evidence base for the impact of psycho-oncology interventions throughout the patient cancer journey is already strong and growing fast, adds Travado. “But there is still a lot of denial about the need to cope



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with distress from both health professionals and patients, and the provision of psycho-oncologists in hospitals in countries such as Portugal is very mixed. At my hospital we have a team of seven clinical psychologists working in multidisciplinary teams in breast cancer, other cancer types and major health events such as burns and trauma. In other hospitals there may be only one part-time psychologist or psychiatrist and there is only so much they can do.”

Across Europe too, the availability of psychosocial services varies greatly, although detailed figures are hard to come by at present. “If you look at whether psycho-oncology services are included in national cancer plans, a report from 2009 showed that of the 19 countries that had plans in Europe all specified palliative care and rehabilitation, and 16 specified psychological support,” she says. “But the focus was on

palliative and end-of-life care, and few plans today have information about evaluating any type of cancer service, let alone psycho-oncology.”

She points also to a global survey of professionals working in psychosocial care that reports on where services are being offered, noting that it is by no means certain that the most cancer-oriented institutions – cancer centres and university hospitals – have regular psycho-oncology services for patients, and in other settings such as out-patient clinics and private practice they are rarely offered.

The baseline data about existing services should be boosted by a psychosocial oncology action project, part of the healthcare work package in the European Partnership for Action Against Cancer (EPAAC), which is proposing first to map the coverage of services and then develop and pilot education tools for com-



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munication skills and psychosocial care, initially in countries with low provision. Travado is leading this project, on behalf of the National Coordinating Body for Oncological Disease in Portugal, with a range of partner organisations. These include the International Psycho-Oncology Society (IPOS, for which she is currently treasurer) – a global organisation that is now promoting psychosocial services as part of standard care, which she says is being endorsed by an increasing number of cancer societies and patient groups.

The most high-profile support recently has come from the World Health Organization, which is currently involved in discussing the possibility of IPOS becoming a non-governmental organisation (NGO) partner to establish psychosocial care in cancer control programmes. In developing countries carrying out cervical cancer screening and treatment, for instance, it is hard to overestimate the importance of integrating counselling into care, as well as training professionals in communications skills – both cornerstones of psycho-oncology.

In Travado, the psycho-oncology movement has a tremendously energetic and passionate expert to help promote such support – and it must not be an optional extra for healthcare systems, she says. “All patients who need psychosocial care are entitled to it – it should be considered a human right in the same way as treatment for physical illness.” Indeed, according to a recent report she mentions from the US Institute of Medicine, ‘Cancer care for the whole patient: meeting psychosocial needs’, it is just not possible now to deliver high-quality care without integrating the approaches and tools that are already available for taking care of psychological health. Every cancer centre under the US National Cancer Institute is now required to have a psycho-oncology programme.

“Psychosocial burdens can be more threatening in many cases than the disease itself,” says Travado. “Even when a cancer is treatable someone may feel in despair and not cope. What we need to impress on policy makers and the medical community is that we are part of the frontline team and not a separate department dealing with a different part of a patient.”

Travado’s interest in therapy was sparked by a year-long stay in the US when she was just 17, as she was fortunate to gain a place on an intercultural exchange programme that had been established after World War II. “I finished my high school in America and learnt about the importance of contributing to society – in Portugal we had been used to the state providing for us. I spent time visiting people in a war veterans’ hospital and learnt how to listen to their life stories – often they had no other visitors.”

Back in Portugal, Travado decided not to do biology (“too much lab work”), and considered geology before landing in clinical psychology at Lisbon University, and was fortunate to learn from a professor who had worked with the famous psychologist Jean Piaget, and had imported cognitive behavioural therapy (CBT) from California. “I did my post-grad work on psychotherapy, focusing on what we call a constructivist approach, which we are now linking with psycho-oncology. Broadly, it’s about patient-centred care and means attending to a patient’s own preferences and decisions, and understanding what their resources are, and then helping them to explore alternatives based on what they already know, and so helping them to function.

“It’s about respecting their own equilibrium and is the opposite of a paternalistic model, in which doctors and specialists pretend they know everything and patients should learn from them. I tell my students that they must learn from their patients – about how they function and what they use to deal with difficulties, and so build their self-esteem and confidence.”

She adds that the cognitive behavioural model “arms you with brief, effective techniques and interventions for reducing patients’ symptoms of distress, anxiety, depression and pain” – and has proved to be a great foundation for clinical health psychology, as has been extensively demonstrated by international colleagues such as Maggie Watson at the Royal Marsden in the UK. But Travado was very much on her own to start with.

She was trained first in clinical psychology with people who didn’t have physical problems – that was

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to come soon – but says she “developed a passion for psychology and patient narratives”. However, there were no jobs for a health psychologist in Lisbon, and she left to try to establish a private practice in a nearby town, which was to suffer an awful event. “There was a gas explosion in a high school – two children died and thirteen had severe burns. I was asked to help those affected and their parents with the ordeal.”

Travado then met the director of Hospital São José at a community event in the town and, having heard about her work, he invited her to join the hospital as a health psychologist working with burn patients and others referred by the plastic surgery teams. “I was told, ‘Put this white coat on, write your name on it and add “psychologist” and you’ll be OK,’ but some doctors said to me that I shouldn’t be there, but at a psychiatric hospital.”

Working on short-term contracts, it wasn’t long before she was also asked to talk to head and neck cancer patients, who like trauma and burn patients had often suffered drastic physical change. “I was told that as long as I could prove myself with the number of referrals, I could have a full-time position. It was hard at first – but I was very assertive. I said, “The psychological impact of a physical illness or trauma can lead to a patient becoming silent or angry: if you have one of these, come to me and I can help them cope better.”

When asked why she was a lone psychologist in a hospital that did not even have a full-time psychiatrist, Travado would reply that clinical psychology has its own status as a science, “and I didn’t recognise anyone as superior – except a professor of psychology or the hospital director.”

The story will be familiar to others who carved out paths in psycho-oncology in the early days. “Many doctors would only call for me when they didn’t know what to do with a patient anymore. But I would see something extraordinary – I would sit with the patients, saying that the care team was concerned about them and their treatment, and I would ask what was troubling them and empathise, saying how tough it must be for them. They would then say everything

about their concerns and feel debriefed. No one had spoken to them like this before – not the doctors, nor the nurses – by sitting by their bedside to ask what was troubling them. There were even some people who had just pulled a sheet over their head such was their feeling of isolation.”

Amid all the psychotherapy theory, Travado has adopted a straightforward approach to helping patients the best, and that is simply visiting them at the bedside, or what she terms ‘proximity’ work. In the hospital, she and her team wear white coats, which at first sight seems as though that could distance themselves from people. “But we wear white coats as part of hospital regulations, as it shows we are professionals and that there is no question we are staff. And very importantly, patients know we are part of their healthcare team, which helps to lessen the stigma of what we do – they shouldn’t feel the other team members think they are a problem.”

While patients are in hospital, she says, it is important not to make more difficulties for them by requesting they visit a psychologist in an office. “If they are on a ward it’s because they need to be there, and we can usually talk to them privately using curtains or in the meal rooms in the wards.”

Travado did indeed prove her worth, in doing much more than stepping in with ‘problem’ patients – albeit after five years or so of ‘firefighting’, working alone and running from one patient to another. She continued with severe burns patients – a speciality she maintains today – and became increasingly involved with cancer and other conditions such as spinal-cord injury, stroke, parasuicide, morbid obesity and chronic pain. She was then able to integrate psycho-oncology much more into the multidisciplinary cancer teams that were starting to develop, especially with a breast cancer surgeon who wanted all the right people in his team, including Travado, social workers, physiotherapists, plastic surgeons and others, which was particularly crucial when mastectomy was the main option.

“But he still wanted a referral system so that patients would have to make different appointments

to see team members such as myself, and I would be at the end of the list,” she says. “I said that would just add more burden to people and instead I developed a protocol for a psychologist to be in the room when the surgeon actually gives the diagnosis. This is the time when people really feel a great impact as they receive bad news – and in many places it is often poorly managed by doctors.” This initial part of the protocol is in two steps. The first is with the surgeon or oncologist, so you can hear what is being said and see the patient’s reactions. Then afterwards the patient goes with the psychologist to a separate room for discussion about their concerns.

She explains that this model – of providing psychosocial care alongside other clinicians when and where it is needed – also applies throughout the cancer journey, including decisions about treatment, difficult treatments such as chemotherapy, when there are recurrences later on, and palliative care, and is one that has been most applied to breast cancer patients at the Lisbon hospital.

“In particular we look after patients who have recurrences here – they do not tend to get much support in many other places. When I was at an international patient group conference in Munich I heard from women with metastatic breast cancer about their needs – while they had medical care their biggest need was for psychosocial support, as a recurrence is the thing you fear the most after initial treatment. A lack of referral to psycho-oncologists for recurrences is a big gap in treatment – it is vital that we do not lose them from our services at such a dramatic time in their lives.”

As Travado adds, psychosocial care does come on-stream well in most places when people enter palliative care, but this stage she feels can happen too late in the cancer journey and she would like to see oncologists calling in such support earlier. “I have also argued in an editorial that oncologists should have quality-of-life assessment as part of their standard agenda at all stages,” she says.

By the 1990s, Travado was able to build up a team of health psychologists, and in 2000 she started

to participate in international networking at the IPOS World Congress, and was pleased to find that colleagues abroad were working on similar cognitive behaviour interventions, and that protocols such as SPIKES, for breaking bad news, were being introduced, based on research with patients. SPIKES was developed by Robert Buckman and Walter Baile (the latter heads the Interpersonal Communication and Relationship Enhancement (I*CARE) programme at MD Anderson in the US, a unit with which Travado collaborates closely).

In the last 10 years, Travado has engaged in a whirlwind of national and international activities, having been asked to advise Portugal’s National Coordinator for Oncological Diseases – the country’s cancer ‘czar’ – on national psycho-oncology coordination, and helping to organise a Europe-wide ‘roundtable’ on cancer when Portugal had the European Union presidency in 2007. “The Slovenian follow-up in the following year led to the EPAAC European partnership action plan,” she adds.

With colleague Luigi Grassi, a psycho-oncologist in Italy, she secured a chapter on psychosocial care in ‘Responding to the challenge of cancer in Europe’, the book produced under the Slovenian presidency. This is an in-depth piece on how cancer affects people at various levels – socially and spiritually, as well as psychologically – and tells the story so far on the main tools for measuring distress, the psychosocial interventions, and the training and standards now on offer for clinical settings

The chapter presented some simple tools such as the ‘distress thermometer’, developed by a panel of the US National Comprehensive Cancer Network, which helps all healthcare professionals to screen for distress, and which could help establish the ‘sixth vital sign’ in practice.

That relates to her involvement in one of her most important international research projects to date, the Southern European Psycho-Oncology Study (SEPOS), which is a collaboration between professionals in Portugal, Spain and Italy (and led by Luigi Grassi). “Southern Europe has been underserved by

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services compared with the north, and a key part of the project has been developing communication skills for healthcare professionals and also carrying out research that we could apply across the region and not reinvent the wheel in each country,” she says.

Given that many hospitals do not have a full psycho-oncology service, it is often up to oncologists and nurses to provide the main support roles, and SEPOS has found that the vast majority of cancer doctors in the three countries had received no or very little communication skills training during their medical education. Although they felt proficient in talking with patients, says Travado, “learning how to communicate with empathy is a difficult technique for many – but once they practice asking about a patient’s concerns and feelings in role-play training sessions, the outcomes can

be different, such as helping patients to come to terms with difficult treatments they may have first refused. You have to understand concerns, letting patients talk without interruption and allowing them to bring their own agenda to the discussion. A small difference in a doctor’s communication approach can make a big difference in outcomes.”

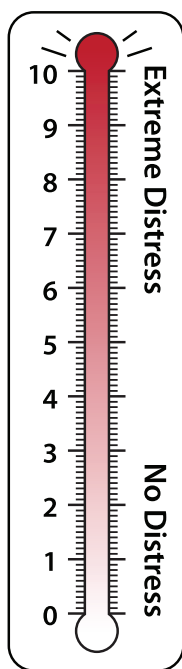
The SEPOS group, she adds, has developed training modules for cancer doctors, and in Portugal Travado has been instrumental in launching a national communication skills training programme in 2009, although she has been running local training for much longer. A hundred cancer professionals – more than expected – turned up at the national launch event in Lisbon to hear invited speakers such as SPIKES protocol developer Walter Baile, and Lesley Fallowfield from the UK – the latter has carried out considerable research into communications skills in cancer.

“We then ran workshops in main cities, targeting cancer physicians, oncologists and others, but surgeons were the ones who needed the most support for this skill, and I worked with my husband, Joaquim Reis – also a health psychologist – to produce a two-set DVD that includes communication techniques and an introduction to the SPIKES breaking bad news protocol, as an educational tool to support this training.

“But as in many other countries, communication skills training is not mandatory and is still scarce in medical education. I of course would like it to be much more widespread.” Travado adds that when other healthcare professionals are properly trained, they can pick up distress in a ‘tiered’ system, as patients move around clinics. “For example, we are working with oncology nurses at the hospital’s chemotherapy outpatient day clinic in Lisbon to assess distress levels before chemotherapy treatment, where they can refer those who are suffering more to my team.” Communication skills can also help prevent physician ‘burnout’, she adds.

Although she is critical of the ‘medical model’ and prescribing drugs as a first choice for dealing with the symptoms of distress, she is keen to point out that there

MEASURING THE SIXTH VITAL SIGN



The concept of a distress thermometer emphasises that distress level is a vital sign, just like temperature and blood pressure, that can and should be measured on a regular basis.

Patients are asked to circle their distress level over the past week on a scale of 0 to 10, and to check ‘yes’ or ‘no’ to a list of specific stressors that are listed under five main headings:

Practical problems (e.g. childcare, housing, treatment decisions)

Family problems (e.g. dealing with children or partner, ability to have children)

Emotional problems (e.g. depression, fear, sadness, loss of interest in usual activities)

Spiritual/religious concerns

Physical problems (e.g. appearance, diarrhoea, fatigue, memory/concentration, mouth sores, sexual)

The distress thermometer screening tool was developed by the US National Cancer Center Network, and can be accessed under their guidelines for supportive care at www.nccn.org



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is no great dividing line between the professions of psychology and psychiatry in the field, at least among those who support the aims of IPOS. Close international colleagues such as Grassi and Baile, and also William Breitbart in the US and Sylvie Dolbeault in France, are psychiatrists. It is still common, though, for antidepressants and tranquillisers to be prescribed, including by medical oncologists.

People in southern Europe can have different psychosocial needs to other populations, she adds. Many cancer patients in Portugal are older people with little formal education, and they often adopt a more fatalistic and spiritual approach to their condition, in line with the 'fado' mournful music tradition in the country. "That does not mean people necessarily feel hopeless – in other countries fatalism can be seen as negative, but not here," says Travado, who has also explored the role of spirituality in a SEPOS study, finding it is a protective factor against depression, which is important in countries with a strong religious background.

But in Portugal, as in other parts of southern Europe especially, it has taken time for doctors to fully

disclose a cancer diagnosis with the majority of patients. "You can't adjust to something you don't understand, and a psychologist then cannot help them. I used to find patients who were angry because they thought they were being given inferior treatment, but they hadn't been told the truth." Following a survey in Portugal that showed that 85% of people wanted to know about a cancer diagnosis, the situation has begun to improve, she says.

At Lisbon, Travado's team has several of the major cancers – especially breast cancer and head and neck – firmly integrated into psycho-oncology, but by no means all. A few surgical teams have been less receptive. Personally, she focuses primarily on breast cancer and palliative care, and has established teamworking protocols and hospital education programmes in both, as well as also supervising health psychology students. Ongoing research includes women's subjective meanings about breast cancer and how they affect the type and intensity of their emotional reactions and coping.

An initiative that she is especially proud of is helping to set up a Portuguese patient group for breast can-

A roomful of experience. Insight, support and advice from fellow patients and survivors can be immensely important, so at the São José Hospital, Viva Mulher Viva is considered part of the care team

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cer patients within her hospital. Viva Mulher Viva started in 2003 “to bring professionals and patients together,” and is not a typical advocacy group. “Though we were providing the best care as professionals, patients were not seeing how others were going through the experience of having cancer – if they could see that, we could show them that a good quality of life is possible. And we wanted patients to feel welcome in the hospital, and that it is their institution – it doesn’t belong to healthcare professionals – and that we could collaborate together in making patients’ experiences less traumatic and more hopeful.

“It was my vision that women survivors of breast cancer should be part of the team, bringing their expertise in to help others going through the treatment process and complement the professionals’ role, and we have taken to heart the tagline of the European Cancer Patient Coalition [ECPC], ‘Nothing about us without us’, and we have joined ECPC as a member.”

The emphasis is on the patient’s experience and quality of life, with awareness events, calendars, DVDs (addressing topics such as intimate relations and sexual matters), and communication training for volunteers, who wear pink T-shirts in the hospital and visit breast cancer patients in treatment, in close collaboration with the psycho-oncology team. “We encourage women to be more assertive about their healthcare and to make informed decisions – there is a tendency here for people to be passive in front of authority figures and to ‘victimise’ themselves after traumatic events. We want to help them participate in their healthcare and wellbeing, and gain more control for making better choices to maximise treatment and improve their quality of life.”

The partnership between psycho-oncologists and patient advocacy groups such as ECPC is critical to improving multidisciplinary care, she adds, and both are prime movers in EPAAC’s psychosocial oncology action initiative.

As treasurer of IPOS, Travado is earmarked for possible promotion to the presidency, but this is not in her sights at present. The society has annual conferences,

which are well attended, and which are now receiving hundreds of abstracts, and has recently developed a federation of psycho-oncology societies for national and regional groups, but there is no pressing need yet to establish a European branch.

“What we are doing at a high level is pressing for the IPOS statement on psychosocial care to be taken up as widely as possible.” One great quality of the statement, as she points out, is its simplicity:

1. Quality cancer care must integrate the psychosocial domain into routine care.
2. Distress should be measured as the sixth vital sign after temperature, blood pressure, pulse, respiratory rate and pain.

“We did want a third point, for psycho-oncology to be included in national cancer plans, but we left it out because too many countries still don’t have plans,” she says. The IPOS core curriculum, developed recently with ESO, is also an important step forward, she adds (see also *Cancer World* March–April 2007).

Travado’s husband, Joaquim, is now working in social health marketing, a field that interests her as it’s about the use of marketing principles to influence human behaviour, such as smoking, to improve health or benefit society. She has two children and is a fitness and dance activist, which no doubt helps fuel her energy levels at work.

International colleagues could hardly speak more highly of Travado, describing her as the leading Portuguese authority on psycho-oncology and an important organiser and voice now in cancer control policy in Europe, as well as a pioneer of integrated psychosocial care in breast cancer and palliative care.

“I’ll be happy when psycho-oncology is recognised in all national cancer plans and distress is routinely assessed and managed throughout the cancer journey,” she says. As one policy maker said, after he had heard Travado speak at the European Cancer Conference in Ljubljana in 2008, “Now I finally understand what this is all about,” so there is a good chance these aims will be realised sooner rather than later.