

What counts as a 'successful' outcome?

SIMON CROMPTON

Every patient wants to be cured. But a culture that defines success as 'cure' condemns many patients and doctors to failure. Should the cancer community be looking to broaden the concept of success to better reflect how well care plans deliver the best possible outcome tailored to each patient's personal priorities?

What does treatment 'success' mean in cancer? Does it only mean curing the cancer? Or controlling it? Extending life? Or providing a good quality of life, even for a short time?

How we define success and failure is important because it has a profound impact on the goals that patients and their doctors set themselves and the experience of the cancer journey. Developing a shared understanding of what success means is also essen-

tial for informed public debate about the value of different interventions in different settings and how to get the best outcomes from the resources we have.

Roger Wilson, who has lived with sarcoma for 13 years, has pondered deeply on these issues. He says there is an urgent need for the cancer world to address the cultural influences that affect treatment decisions in advanced cancer: "We need to look at the patient demand for a

'right to live', the medical attitude that 'success equals cure' and the funder's view that a dying patient is just a financial burden," says Roger, who is a founder and President of Sarcoma UK.

Somewhere, amid these influences, what's right for the individual can get lost.

Perspectives from patients and family on these issues provide a rich vein of insight for professionals and policy makers. In all their variety,





they offer a central message: for a treatment to be 'successful' patients and their families must be properly engaged.

Negotiating expectations

Kathy Oliver says that when her son Colin was diagnosed with a brain tumour in 2004 at the age of 24, her only measure of success was cure. "I didn't know any better then," says Kathy, who is co-director of the International Brain Tumour Alliance.

"When the diagnosis was given to us, we were sitting in a tiny room in a London hospital, but we may as well have been sitting on a planet in outer space. We had no map, no compass, no anchor to steady us. In our naïvety, we believed at that stage that treatment success could only be measured in terms of cure: we anticipated that neurosurgery would remove nearly all the visible tumour, followed by radiation that would eliminate every last cruel cancer cell,

and then chemotherapy to guarantee a long and healthy life. Unfortunately, it didn't work out like that."

"As my son's journey progressed, and his tumour's level of malignancy did too, each successive treatment carried with it a different measure of success and expectation. With each treatment stage, the successes became more modest, but at the same time the availability of each treatment represented renewed hope."

Annemie Spaak (not her real name)

ILLUSTRATION: FRED VAN DEELEN, WWW.ORGANISART.CO.UK

from Belgium, diagnosed with multiple myeloma in 2002 at the age of 37, tells a similar story of revising expectations. Since it is a disease “that doesn’t go away”, she says, patients often have a lasting relationship with their doctor, with treatment options being constantly discussed and renegotiated.

“My idea of success has definitely changed over time,” she says. “After my diagnosis, we discussed whether I should have more aggressive treatment which would extend life, or softer treatment that would give me better quality of life. At that stage, I was ready to go for the aggressive treatment – to go as close to a cure as was possible, because I had just given birth, had two young children, and I wanted to be with my family for as long as possible. But then I realised quite quickly that a cure was not going to happen, and once you accept this, you reset your definition of success. Now success means reaching certain milestones, to get the children through adolescence, and now to bring them to graduation.

“For someone over the age of 70, the objectives might be very different,” says Annemie. “And people late on the journey sometimes say they’re fed up with treatment and just want not to suffer and to be with their families.”

Expectations, and thus definitions of success, are also heavily shaped by cultural and social influences, says Luzia Travado, head of the psycho-oncology unit at the Champalimaud Cancer Centre in Lisbon, Portugal. Patients with advanced cancer who come from lower socio-economic groups tend to be more passive recipients of care, she says. Their expectations of treatment ‘success’ may be far less ambitious than better educated patients with higher incomes, who tend to want more control, and



“I realised quite quickly that a cure was not going to happen, and once you accept this, you reset your definition of success”

push more not only for a right to live but a right to a good quality of life.

What doctors do will be partly defined by this. Those working with higher socio-economic groups are more likely to propose active treatment towards the end of life.

“There are some patients who want to control, and some who are happy that the doctor controls,” she says. “But if you want properly responsive health systems, you have to keep asking people questions, whichever group they fall in, so that they can be involved if they want to. That doesn’t always happen.”

Buying time

The question of when active treatment should cease will always be difficult to negotiate, but with health services operating under ever tighter cost constraints, many patients now feel they are being denied a worthwhile shot at achieving a valuable

added few weeks or months not because their expectations are unrealistic, but because they are considered unaffordable.

Bettina Ryll, whose husband Peter died of melanoma in February last year after treatment in Sweden and the UK, is one among many representatives of cancer patients who worry that, despite high-level debate about ‘best’ treatment towards end of life, what actually happens is often dictated by economic considerations.

She has watched with interest as academics and policy makers have grappled with the cost of new cancer drugs, and she stands alongside the many patient groups who criticised the 2011 report of the Lancet Commission on cancer costs. This claimed that giving expensive care to patients during the last weeks of life is ‘futile’ and argued that too many of the new cancer treatments only extend life by a few weeks.

“Terminally ill people are members of society too,” says Bettina, who jointly founded the Melanoma Independent Community Advisory Board – an international network and resource for people affected by melanoma – in 2011. “They have paid into their health system, have made their contribution to their health care, and as a society we have a duty to honour that. I think it’s shocking to see how, suddenly, people who are no longer in the ‘healthy club’ are considered not worthy of receiving any more from the health system.”

Bettina, who trained as a doctor herself, questions how far doctors really understand what a few extra weeks can mean to families, and she rejects the way active treatment tends to be counterposed to palliative care, arguing that treatments that extend life can also improve the quality of life.

“Peter’s melanoma was extremely aggressive,” she says. “It was diagnosed in February and by April the tumour had encased his whole arm so that he couldn’t move it and it was very painful. We didn’t expect him to see the summer.

“Then he went on a trial for a new drug and the tumour regressed – so much so, that he could even start rowing again. He died in February last year, so being on that drug bought us nearly a year. I remember thinking, before he went on the trial, ‘What’s the point of another month or so?’ But it gave us a chance to adjust, to say goodbye, to give our two daughters a chance to prepare, to get things in order. I think that year was the

most valuable year of my life.”

“As healthy individuals, I think we underestimate the value of time for the person with cancer and their family. A month can be the equivalent of a year if you have limited life expectancy.”

Something to hope for

Kathy Oliver stresses that encouraging realistic expectations must be tempered with giving patients and their families something to hope for. If there is nothing to hope for there



“A month can be the equivalent of a year if you have limited life expectancy”

Bettina Ryll

can be no hope of success.

“I wish that in the early days of my son’s diagnosis we had not faced such nihilism from some of the medical professionals we met,” she says.

“We often think of successful treatments that are either swallowed, injected, zapped or surgically per-

formed. But to be given hope is just as important a treatment, and brings benefits not just for the patient, but for the family too. I cannot stress enough how important it is to maintain hope for patients facing devastating diagnoses.

“I know that in my son’s case, when there were no more surgeries, no more chemotherapies, no more radiation to be done, he still insisted that there was a plan for him. He kept receiving experimental therapy until the day he died, and in the last days kept reminding us not to forget to give him his treatment. Was the treatment futile in terms of medical benefit? Yes, it probably was. But what was important to my son, and also to us, was that there was a plan even towards the end.”

Of course, the experience of each family will be very different. Treatment plans will be influenced by the nature of the disease, its stage, and according to the character, socioeconomic background, circumstances and wishes of the patient. With all those variables, doctors have a task on their hands when it comes to managing expectations while keeping hope alive.

Towards personalised measures of success

Roger Wilson says that a way forward is to provide doctors with “prognostic/risk assessment tools” that will give them the means to look at living with cancer in a rounded manner, not just in terms of medical treatments. This kind of personalised approach

Many patients now feel they are being denied a shot at achieving a valuable added few weeks or months

could yield a new integrated idea of treatment success for each patient.

“Such tools could be based on biological, behavioural, social and psychological markers: ‘this patient will do better if treated this way, another patient will need treating another way, and a third yet another way’ – even when clinically they are at the same stage with the same disease. Each treatment may involve lifestyle elements, would draw in expertise from non-cancer healthcare specialists, and would include practical support tuned to the needs of patients’ families.”

There have been tentative steps towards this kind of patient-centred research, he says, and it would sit very neatly with personalised cancer therapy approaches. “If we could reach the two objectives together, that would be a genuinely new definition of success.”

For Annemie Spaak a good relationship with their doctor remains the key for patients to perceive their treatment as successful. “It’s about partnership. I didn’t feel on the same wavelength with my first doctor and felt very unhappy, but when I changed I could accept my situation much better.”

However, a study published recently in the *New England Journal of Medicine* warns against jumping to the conclusion that a ‘good relationship’ necessarily improves the chances of patients achieving an outcome they perceive as ‘successful’. Quite the reverse in fact.

“To be given hope is just as important a treatment, and brings benefits not just for the patient, but for the family”

Kathy Oliver



JOHN FLOWERDEW WWW.STUDIOJ.CO.UK

69% of patients with lung cancer and 81% of those with colorectal cancer did not understand that chemotherapy was unlikely to cure their cancer. Surprisingly, perhaps, the risk of reporting inaccurate beliefs about the chemotherapy was higher among patients who rated their communication with their physician very favourably.

The implication is that the cost of a good relationship between doctors and their patients is an inability to face up to difficult facts – or at least a tacit agreement to collude in unrealistic expectations. The consequences of this may only come home to roost when patients and doctors are both faced with a sense of failure late in the cancer journey.

A planned and transparent transition

Bettina Ryll believes that altering the emphasis at medical school would go a long way. “At medical school you still have a rose-tinted view of how medicine saves lives, and maybe more could be done to demonstrate how

palliative care is an important part of medicine too, and about the palliative ability of advanced treatments.”

Luzia Travado agrees that both patients and doctors find it difficult to acknowledge when cure is no longer possible. But it is up to the doctor to regulate expectations, right from the point of diagnosis. “It’s difficult,” she says. “Patients cling to any hope, and doctors want to avoid their patients getting too emotional. I’ve seen some

The surprise findings show that misunderstandings about treatments and their objectives are more common, not less, when doctors and patients have a good relationship.

The study, published in October last year, examined the expectations of 1193 patients receiving chemotherapy for metastatic lung or colorectal cancer. This can prolong life by weeks or months, or relieve symptoms, but does not cure. However,

“So it all depends on establishing a proper partnership, and negotiating where you are heading at different stages”

patients who want to continue with their chemotherapy whatever the circumstances, because their coping mechanism is to not even consider the possibility of death.

“So it all depends on establishing a proper partnership and negotiating where you are heading at different stages. That’s why it’s so important that doctors are given the communication skills, and understand, for example, the SPIKES six-step protocol for delivering bad news.

“Patients need to be helped to understand that the doctor can do something for them at all stages, even if they can’t cure. Here, we have abolished the phrase ‘There’s nothing more I can do for you.’ If there isn’t open communication from the start, patients and their families can easily feel frightened and isolated when the language doctors use changes, and doctors stop talking about ‘active’ treatment.”

Roger Wilson agrees with that prescription. But given the cultural influences that make it so difficult for doctors and their patients to look forward and discuss dying, he believes we have to look further than training time-strapped doctors. Healthcare systems need to plan for greater involvement from palliative care experts with psychological training from early on in the cancer journey.

“The truth is that we do not do communication well, but is unfair to look at it solely as a clinical problem best resolved by training cancer doctors better than we currently do,” he says. “Our healthcare systems have

a general lack of will to support cancer patients with professionals who have had psychological training first and have then learned about cancer.

“A treatment approach which starts as curative but which recognises the ‘point of no return’ in a positive way would go a long way to challenging the current cultural influences on doctors and patients. The transition to palliative treatment should be planned and transparent. Expert palliative support should be seen as constructive and introduced to the patient long before there is the recognition that curative treatments are no longer feasible. Those

who die will not die as ‘failures’, while those who are ‘cured’ will have had a better experience.”

Such planning could redefine everyone’s ideas of treatment success, he says. And it might mean that people with cancer and their families are helped to make decisions that are better suited to them as life reaches its end.

“It might mean that a few more patients die a few days earlier than they might otherwise have done, but the whole family experience and remembrance of dying would be more positive,” says Roger Wilson. “That would also be a benefit to society.” ■



“Those who die will not die as ‘failures’, while those who are ‘cured’ will have had a better experience”

Roger Wilson

ULI DECK