# THE *CANCER CONTROL* CONSULTATION

## Health and well-being: What matters and whose opinion counts?

We live longer, but do we live better? Do we value a longer life – achieving our natural life expectancy and beyond? Or the realization of a functional life – fulfilling a productive physical, mental, and social life? Or is it the enjoyment of living – relationships: personal, family, work, community, and society; satisfaction, contentment, and being remembered with respect and affection?

Although humans have been on earth for over 3 million years, it is only in the last 200+ years that life expectancy at birth has doubled – the gain of an extra life. Through the control of premature death, we live longer, create wealth, achieve a decent standard of living, value education, and promote freedom of choice through a civil society that values individual and societal well-being. In the Westernized world, we have established choice regarding our health and well-being – the resource whereby we realize aspirations, satisfy needs, cope with a changing environment, and appreciate the value of living.

However, we relinquish one-third of our gain in longevity (our lifespan) through compromise to our physical, mental, emotional, spiritual, and societal well-being (our healthspan). How do we view the balance between the things that threaten our living – our "lifespan" – and the things that threaten our days – living well, our "healthspan"?

Our genes, environment or circumstances are conferred by our parents. Irrespective of birth circumstances, the common principles underlying health and well-being: a decent standard of living; education and opportunity; a fair, just and caring society; a healthy life expectancy; freedom to make life choices; and the value systems underlying wise choices: generosity and trust; community vitality; and a safe and secure environment. We choose what we value, and choice depends upon options and the ability to pursue them. Living, dying, caring, and grieving impact us all, no matter what our circumstances. They are shaped by the socio-cultural-economic and political contexts in which we live.

If the goal is "a good life" and "a good death", as individuals, caregivers, and community/society, how do we value fully informed choice, prioritizing the person as well as disease, and social justice, social protections, and quality healthcare for all? ■

*Professor Simon Sutcliffe, Editor-in-Chief,* Cancer Control

## RESPONSES

***Bahija Gouimi,*** *President and Founder, AMAL Association, Morocco and* ***Zainab Shinkafi Bagudu,*** *CEO, Medicaid Cancer Foundation and President-Elect, Union for International Cancer Control*

In a digital age where technology, therapeutic advances, and artificial intelligence are at their peak, how do we understand care? Do we see it as cure of a disease or as healing in a more holistic sense? What about the much-touted patient-centred approach and quality of life? Are these just slogans, trends, buzzwords… or a tangible reality? Today, a person living with cancer is not merely seeking a treatment that might extend their life further into old age. They long for care that treats them with dignity – care that respects their humanity, meets their needs, soothes their fears, understands and relieves their suffering, and, above all, listens to their dream of living better, of living a "normal" life.

A healthcare system must be attuned to the real, complex, and multidimensional needs of people living with cancer. They are not just vessels for treatment, a medical file, a hospital bed, a statistic, or a cost to be reduced in a budget. They are individuals, each experiencing their own unique life situation.

And every life has value. Every person carries a unique story, voice, expectations, doubts, and personal challenges. They want personalized answers. They want to be heard, respected, supported, and involved – regardless of their illness, age, gender, location, language, origin, or beliefs.

A person living with cancer is not just "a patient" but a legitimate partner who must always be valued in the design of care pathways – not only to improve their health, but also to

enrich their quality of life.

In many low- and middle-income countries, countless people living with cancer still lack access to treatment due to distance, centralized care, or lack of resources. Entire families collapse under the mental burden, the psychological, social, and financial pressure of a cancer diagnosis. People feel alone, invisible, voiceless.

### What truly matters?

What matters is being treated with fairness, being included in the solutions, having their stories heard, their experiences respected, and health policies designed not just for them, but with them.

We cannot always emphasize the length of a person's life. What we know from people who have experienced cancer is that the quality of their life is hugely important to them and to their families.

Health is not just the absence of disease. Health is, above all, a sense of safety, support, and dignity. Unfortunately, when cancer is detected very late, where there is not access to treatment or pain relief, where there are unclear care pathways, and where people spend their life savings to secure the treatment and care they need, these principles fall by the wayside. A person in pain feels their dignity being stripped away. When a person is treated as a medical case only, they are stripped of their humanity.

The Union for International Cancer Control (UICC) is proud to launch the global World Cancer Day campaign for 2025–2027: "United by Unique", which calls for a fundamental shift in how we approach cancer care and health systems around the world. As advocates and patient representatives, we urge the cancer community to ensure that services are delivered at the right time, in the right place, and in the right way. This requires actively engaging individuals and communities in decisions about their own health – and upholding their dignity and well-being as central to every aspect of care.

If a life is marked by delayed diagnoses, lack of information, insufficient support, treatment disruptions, inequality, stigma, indifference to my suffering, long waits, and unclear care pathways… then that's not LIFE – it's mere SURVIVAL.

## RESPONSES

***Annie Young,*** *Professor Emerita, Warwick Medical School, University of Warwick, and Co-Founder, Global Power of Oncology Nursing*

Well-being is intrinsically linked to the basic human rights of mental and physical health, and a decent standard of living, as Simon Sutcliffe points out.

We now have robust evidence on how to improve healthspan; we have the measurements (for example, the new WHO Well-Being Index: WHO-5) nonetheless, we now need to get a GRIP (getting research into practice) to help us close the gap between lifespan and healthspan. Genes aside, if we only perform what we already know, including striving for an active social life, keeping mentally engaged, eating well, exercising, and sleeping well, we may succeed.

In countries of mid to high human development, a diagnosis of cancer or other serious condition is sometimes a trigger to make a fresh start – to work towards a productive as possible physical, mental, and social life, enjoy spending more time with family and colleagues; and give something back to the community towards a more compassionate society. These are not mutually exclusive.

As cancer healthcare professionals, we learn to listen and value the opinion of a person with a cancer diagnosis in front of us and, if their relationship is good, listen to the caregivers. They tell us what life is really like. We not only listen but hear their words and concerns, act on what is within our sphere of influence and strive to keep in touch.

Now is the time to move outside our comfort zones – to lobby for interventions known to improve the subjective well-being of people – to be added to the list of public health measures crucial to personal, community, and socioeconomic development. Nevertheless, putting the list into practice is all down to first-rate personalized care and also setting an example ourselves. In addition, as global healthcare professionals, we will not be shy to speak out about people who are denied these basic human rights; for example, people who live in areas of conflict and have no choice over their healthspan, not to mention their lifespan. We will shout loud for some form of basic healthcare, social justice, and social protection, including publishing the facts.

Currently, we live longer and do not live better. We can change this for the collective good. What matters is acting on the voice of the individual wherever they may live; their opinion counts.

## RESPONSES

***Jane Ross*** *has worked for many international and Canadian organizations supporting the physical, mental, and emotional support of people with disabilities and challenges. She is now retired.*

Scientific research, emergent technologies and therapeutics, and evidence-based medicine have dramatically expanded detection and treatment of cancer. Survival has improved, lifespan is longer. However, research is costly, slowly translated, and of limited reach to all who could benefit.

Cardiotoxicity (heart damage from treatment) impacting the health of cancer survivors is the second leading cause of death following diagnosis. Thirty percent of those surviving cancer struggle with cardiotoxicity and its long-term effects. Yet, worldwide, cardio-oncology services are non-existent or of limited availability despite telemedicine, machine learning, and integrative technologies to embed AI (as Augmented Technology) into clinical practice.

The study of survivorship, whilst not new, grows as the number of survivors grows, as does the suffering and the side effects – cardiotoxicity, post-surgical, radiation late effects, hormonal changes, and physical, mental, emotional, social, and spiritual distress.

Once strong community life has "taken a back-seat" in the quest for individual cures. Human and cultural factors are ignored – human hearts cry out for attention and loving kindness. Despite the appeal of compelling medical science and technology, has the value of efficacious local practices, places, and healing sights, sounds and smells once familiar and collectively shared within thriving social communities been eroded? My wise teacher, UK-educated Dr Thomas Kargbo of Sierra Leone, said "no Western doctor has ever cured an African. While my people may seek Western medicine for symptom relief and treatment, there can be no cure without the engagement of indigenous healers tending to the socio-cultural and spiritual reasons for illness and misfortune". In the global context, this lack of appreciation for the sacred and familiar is not unusual, nor is it conducive to improving the human condition *(1)*.

The special needs of children with cancer are reflected on by David Morley (Founder, Institute for Child Health, UK), who states, "When we diagnose a medical problem and perform a procedure to correct it, we do not just resolve a problem experienced by a patient – we impact his life, his family, his community, and the world. This patient will go on to make the world a better place" *(2)*.

This Consultation explores personal and collective questions of vital importance. The realities and threats of climate change – that "rapidly growing risks outpace corrective actions" - invites citizen engagement, knowledge integration, comprehensive collaboration, and practical application of research to communities worldwide. Local and global change means we must act differently; we need to think big and small, embrace innovative changemakers, and encourage fresh strategies in rural and urban communities alike. As the anthropologist Margaret Mead instructed, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has".

1. McGilchrest, Iain. *The matter with things. Perspectiva Press.* 2021.
2. Krive, Marianna. *Personal communication.* 2025