



OPEN HEALTH

Navigating the nocebo effect through patient engagement is the key to setting patients up for success

By **Dr. Sumira Riaz**, psychologist and
patient engagement lead at OPEN Health and
Steve Clark, patient advocate and founder
of Strive for Five





It is no secret that patients' pre-existing beliefs and experiences can significantly affect their behaviors and outcomes.

Let's frame this discussion based on people diagnosed and living with cancer. On a populational group and individual level, their experiences may seem similar – all are living with a type of cancer, going through treatment, and adapting to life with this diagnosis. However, below surface level, there are significant individual differences, such as earlier experiences, societal influences, beliefs (cultural and environmental), perceptions, cognitive schema, relationships with their healthcare team, family, responsibilities; the list is endless.



The question is: do these additional determinants matter?

Can they really influence the clinical outcomes of a person's diagnosis? And do healthcare professionals consider the holistic attributes of the patient sitting in front of them when making clinical decisions? Do they view them only as a "patient" not as a "person"?

There is a need to trigger an important shift within healthcare communication. Although more research in the past few years has emphasised the positive benefits of shared decision-making and discussions regarding patient preferences, there is so much more left to implement.

The objective of this discussion is to encourage healthcare professionals to dive deeper and understand their patients pre-existing schema, which is likely to predict how the patient will behave once they are outside the consultation room; but why is this important?





Over the years, research has stated that those who have a positive approach to their treatment plan have lower rates of rehospitalization and better quality of life than those who may have developed an unconscious negative view of their treatment plan. The power of positive thinking and acceptance contributes to the placebo effect – the belief that a treatment will help – which can be as effective as medical intervention. Interestingly, we are learning that the opposite can also be true, coined as the **“nocebo effect”**.

Nocebo Effect

[no·ce·bo ef·fect]

The nocebo effect is described as a phenomenon “causing patients to develop side effects or unwanted symptoms, or reject treatment, due to the belief that the medical intervention will cause harm.”

In other words, an individual's pre-existing experiences and beliefs, including the environmental influences they are exposed to, can influence their outcomes.

For example, there were a huge number of media reports on the effects of COVID-19 vaccination to trigger unknown side effects, including conspiracy theories about why vaccination was being encouraged were circulating. Therefore, some people were unwilling to be vaccinated. Now, if a patient was advised to be vaccinated, the patient would unconsciously search for experiences and feedback gathered over time when making a decision. In this instance, they may decide against receiving the vaccine because they are concerned about the side effects but have not done any research personally; the decision is purely based on environmental influences.

Another example relates to a case of a patient who had been recently diagnosed with a rare cancer that require immediate surgery to remove the cancer cells. However, her reluctance to go ahead with the operation was based on environmental “noise” informing her that the surgery would trigger the cancer to spread, leaving her with a difficult dilemma. She was “rejecting” treatment because of her concerns that the treatment would do more harm – otherwise defined as the nocebo effect.

Both examples are important when understanding the nocebo effect – *rejecting treatment and advice because of significant concerns that the treatment will do harm, not good*. As stated, this can be influenced by environmental/early experiences and an individual's psychological mindset.



Clinicians can unintentionally trigger the nocebo effect during medical appointments or when obtaining informed consent, discussing potential adverse effects, outlining patient expectations, or responding to questions about the treatment or trial.

Emotions and barriers experienced by people diagnosed with cancer



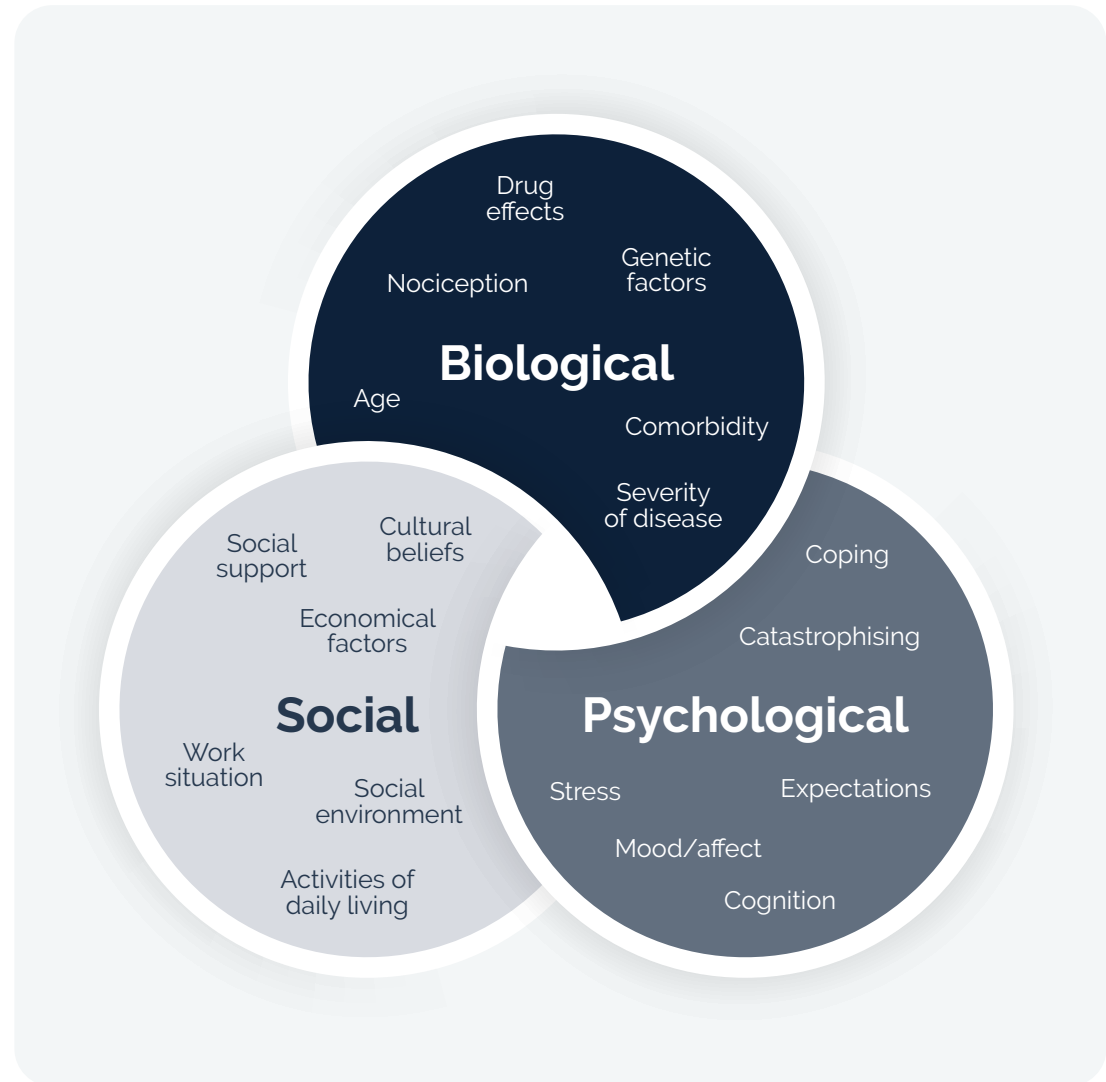
The graphic shows observational information that can be used for supporting patients with cancer. There are emotions and barriers patients commonly face as they go through their journey. In addition, they will obtain information from external sources like websites, books, and well-meaning friends and family who have scare stories and may recommend "cures". In the clinical setting, it is fair to expect that many patients may experience this sort of issue, which could become a barrier to treatment success by potentially increasing the nocebo effect. **It is vital to try to help patients to navigate around this to minimize the negative thoughts and potentially support them to a positive pathway for their treatment.**

Graphic based on observations made by Steve Clark while supporting people with advance cancer.

How can we prevent the nocebo effect and support patients?

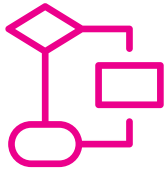
Simple – by enabling the patient to openly communicate their beliefs and concerns with their doctor, and importantly, by doctors asking their patients what is important to them in a given moment. This would then help direct healthcare professionals to make more personalized and informed decisions about how they are going to interact and engage with their patients; flexibility is important. It would also give healthcare professionals the knowledge to signpost patients to the right information sources to help their specific needs. **Understanding in practical terms how to set the patient up for greater success by minimizing the potential nocebo effect is key.**

Biopsychosocial model of health

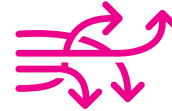


Engel, G.L. (1978) "The Biopsychosocial Model and the Education of Health Professionals' Annals of the New York Academy of Sciences 310:169–187

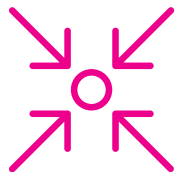
Other areas of consideration are outlined below:



Healthcare professionals can use a framework to support and guide their discussions with patients. For example, the biopsychosocial model emphasizes the three types of factors that impact disease management: biological, psychological, and social. Using this framework to lead discussions can support healthcare professionals in determining what is key for the patient and what support could help minimize the nocebo effect.



Removing the rigidity and developing a flexible, personalized approach with patients is imperative. For example, some patients might start out wanting information about the biological aspects of the disease to better understand how the disease process is impacting their bodies. However, as treatment progresses, their focus might shift to the other aspects of navigating acute or chronic illnesses.



Healthcare professionals would benefit from considering patients' external experiences that influence healthcare decisions. By allowing individuals to navigate these discussions, healthcare professionals can offer information that is relevant for the individual and their priorities; this shift in mindset could have a profound impact on doctor-patient communication and relationships.



Talking to patients about their knowledge and previous experience with a disease or treatment and their preconceptions and beliefs about how it will affect them can help reduce the nocebo effect. Using a positive framework to share information, focusing on alleviating symptoms, the chances of improvement, and survival rates (as opposed to making potential side effects the focus), can also have an impact on patient retention strategies.



The onus is on healthcare professionals to help their patients approach their disease and treatment on as positive a footing as possible.

Healthcare professionals would benefit greatly from communication training to ensure they understand their individual patients better as people, and so they can improve their interactions and set their patients up for success. Communication should be an integral part of continuing medical education.

The pharmaceutical industry can have a critical role in helping set patients up for success by supporting healthcare professionals. The industry can help improve how healthcare professionals communicate with their patients to try to minimize a potential “nocebo spiral”, produce tailored tools and programs for healthcare professionals and patients, and help with signposting to robust and reliable information sources and supportive forums.

About the authors



Dr. Sumira Riaz

Sumira is a clinical health psychologist and leads the Patient Engagement division at OPEN Health. Sumira specializes in behavior modeling, assessing, and formulating clinical and health experiences to support the development of robust and strategic interventions. Sumira still works in the NHS where she is involved in pain management, mental health care, and psychological support for people living with chronic health disorders.

OPEN Health specializes in patient engagement strategies that improve health outcomes and patient well-being. Contact us to connect with specialist experts and unlock possibilities for omnichannel strategies that minimize the nocebo effect.



Steve Clark

Steve was diagnosed with stage 4 colorectal cancer in 2013 and has become an active patient advocate. He is a regular speaker for audiences of patients, healthcare professionals, researchers, and industry representatives as well as being a Campaigns Ambassador for Cancer Research UK.

He set up [StriveForFive.org](https://www.striveforfive.org), a not-for-profit organization with the mission to give hope to fellow patients with stage 4 cancer and to advocate for improved care for those with advanced cancer.

He is a business and marketing consultant for the pharmaceutical industry with Redwood Brand Curators.

Steve was awarded Healthcare Communications Advocate by Communiqué.





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