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The Importance of Quality of Life in Cancer Patients

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"I never really knew what 'chemotherapy' meant, but it had the words *therapy* in it, so I expected it to be *therapeutic*" was a statement uttered to me by a patient which will always stay with me. "Little did I know my life would feel anything but healed during it," he continued. This 50-year-old stage IV, lung cancer patient, decided to end a rigorous chemotherapy treatment after 6 months under it. Andrew[1] died 2 months after this statement, but in our last meeting while lying in his bed he confirmed to me that he was "comfortable" and that he was able to spend his waking hours with his family, and not attached to tubes in a faraway hospital, or constantly being sick. He had a beautiful relationship with the ocean, so in these last few months his wife had made sure to drive him to the sea as often as possible; something he was able to do once his schedule freed up from appointments. It was clear that Andrew was looking for some quality in his life. There was a possibility that more longevity would be attained had he continued chemotherapy, but Andrew felt that quality of life (QoL) super mounted the extra days, weeks, or maybe months he would gain, if that "gained" time would have been of poorer quality.

Allow me to also introduce you to Ella,[1] a 45-year-old, stage IV pancreatic cancer patient. At every meeting, Ella would ask me, "Do you feel a lot worse before you get better?" or she would exclaim with a strength I have not often encountered in my practice, "I think I'm feeling better today, maybe this is working." Ella was visibly emaciated and while not always admitting it, under a tremendous amount of constant pain. Ella was receiving one form of treatment until her very last week. It seemed that she chose longevity of life (LoL) over QoL, even if that meant she was unable to move for 5 months, or that she lost the ability to feed herself. Ella had two teenage daughters and a doting husband. It is probable that she survived those 2 years, *because* of the treatments she received. Did her gained longevity justify the reduced quality of her life? Only she and her family can answer that question; a question the family often explored with me after her death and through their grief. What makes a patient like Andrew choose QoL over LoL? What made Ella choose the alternative? At what point do patients make this choice?

The factors that affect any patient choosing QoL are multi-faceted and dynamic: meaning it is not usually based on a single factor and similarly, it can change over time. The patient's baseline QoL plays an important role. What did

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[1] The names of the patients and the diagnoses have been altered to protect confidentiality.

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Andrew's life look like before the physical exacerbation? Societal and/or cultural relationships to death, suffering, pain, or disease can also genuinely, and sometimes unconsciously, predispose someone to certain choices. Cyprus is a small, relatively homogenous island, where I have seen that values and expectations can be similarly shared by many; and while the choice between QoL and LoL can be somewhat predictable, cultural predisposition cannot singularly account for such choices.

A family structure and the *importance* that family has on the patient plays a highly important role. A patient with little to no family members surrounding them, may be quicker to opt out of LoL, as they may feel like they have "no one to fight for." Conversely, a person with very close ties to their family, may not want them to witness their suffering and therefore reinforce as much quality into their life while trading off duration. Did Ella choose to live longer but poorer, because she wanted more time with her daughters? Very possibly. Would her decision be different if she was 20 years older and therefore by default so were her daughters? Another possibility, which brings me to the next factor. The patient's chronological age can play a huge role in not only the patient's QoL, but also the consultant's suggested course of action. The latter brings me swimmingly into my next factor which greatly affects QoL: the patient's understanding of their cancer, the treatment, and prognosis.

If you recall Andrew's statement above, he states "I never knew what chemotherapy meant…". One can argue that should he had had a better idea about his disease and its progression, he would have made different choices from the start. In my clinical practice, I have often seen a face of surprise (or is it relief?) when reminding the patient that they have a right to choose their treatment (or non-treatment) as well as the right to talk to their consultant about how cancer or its treatment is affecting their QoL. Giving the patient space and allowance to talk to their consultant about their QoL, choices and expectations may help give the patient a sense of agency, and therefore they can make a truly informed decision. In a time when a person loses control of nearly every facet in their life, be that physiological, occupational, or societal, instilling a sense of control and choice in the patient's life can, in and of itself, improve their quality of life, irrespective of their choice.

Clinicians have a large influence over a patient's final decision, so it is therefore of vital importance that the patient has a full understanding of their cancer, its treatment, and the impacts it may have on their life in its totality. Only then can a patient undergo the internal dialogue of what compromises and trade-offs they are willing to make. While clinicians undoubtedly and inherently know that quality of life plays a huge role, it is important to take note of their own and more importantly, the patient's *definition* of QoL. What did QoL mean for *Andrew*? It seemed it was one where he was still able to spend hours at the seaside any day he desired. What did quality of life mean for Ella, for Helen, or for George? This brief dialogue could easily put both parties on a pathway of open and honest communication, one which can lead to a less tumultuous road, with much better views.

How does one address the quality of life needs of a patient? As a psychologist you not only can help identify the needs of the patient, but you can also set the patient up for exploring this question in the first place. It is often the case that patients have not even had this internal dialogue, of what *really* matters to them and how it could possibly materialize. Addressing the QoL needs of a patient could be as simple as a timely referral to better pain management. In another case, it could involve being the bridge between the patient and his family members when their wishes differ on a fundamental level. Similarly, it could mean working on the family's acceptance that their loved one has reached a stage of palliation, the end of their life. Lastly but by no means least, it could involve having a discussion about their values and proposing ways where their actions can somehow be in concordance with these values. Andrew worked on the sea every day. He was a boat technician, a sailor, and as a hobby he was a scuba diver. He may not have been able to scuba dive anymore, but he was at least able to watch the sea, taste the salt, and feel its air. This was good enough for Andrew in those last few months of his life. Being able to do that with his wife gave him meaning and dignity in the end.

Addressing the QoL of a patient should be done whether they are palliative or not, whether the person is elderly or young, whether they had a “good” life before, or a “bad” one, whether they have five kids, or none. Desiring QoL can seem so obvious or implied, that it can be inadvertently neglected by not allowing the patient to define what it means to *them.* Perhaps a better term instead of the generalized QoL, could be Quality of *Their* Life, where we simply add one word to remind us as their doctors, as their family, as their therapists, that it is *their* life, and the only person that can define it is the person going through it. So, let us start a dialogue, and a frequent one at that: What does quality mean in *your* life?