Appendix 1: Reflections from the Patient Advocate

ASTRO clinical practice guidelines include a patient advocate to ensure the patient perspective is considered during the guideline process and maximize the patient-centeredness of the product. We asked the patient advocate (Warren Caldwell) for this guideline to provide his “recommendations” on how medical professionals can improve the care for individuals diagnosed with oropharyngeal squamous cell carcinoma. His thoughts are below:

1. The sound of a silent cell phone of one awaiting biopsy results is deafening. It will be a kindness of unimaginable proportion to inform patients in an expeditious manner of the results of biopsies and scans. When it is clinically possible, avoid scheduling these tests when results will be extended over a weekend.

2. There is no bad way to inform a patient of good news and no good way to inform them of such existentially bad news. Make these calls when you have time to patiently respond to a hundred questions as this is not one of life’s multi-tasking moments for your patient. They will be riveted to your every word.

3. When the call has ended, the patient’s brain will race: I am self-employed. Will I be able to work? Should I sell my nice car and get a clunker? Why didn’t I buy life insurance? Will I see my son earn his Eagle Scout? Will I be at his wedding? Will I play with grandkids?

4. How much knowledge is too much for a new patient? A new patient may self-triage with their need to know, but discuss their desire to hear details early in the conversation.

5. An important blade on the Swiss Army Knife of a patient’s resources to fight the fight is empowerment. The sudden discovery that so many things are out of one’s control places a premium on the things that are under one’s control. A shift away from the traditional paternalistic form of physician/patient relationship towards a teammate approach fosters a sense of self-control in a world that is madly spinning out of control.
6. The emerging science behind treatment options of OPSCC suggest that there are some gray areas in utilizing the tools of surgery, radiotherapy and systemic treatment. The engagement of patient preferences in determining treatment options is a preferred means of practicing medicine. Explain, Engage and Ask. Formulate a plan together.

7. Establish an understanding of a patient’s aversion to risk versus embrace of reward. Do they have a predisposition to be more aggressive with a possible loss of quality of life or less aggressive with the cancer more likely to recur?

8. If a patient elects to go less aggressively, this position should be afforded the same respect as any other. If they choose to reject some aspect of the recommended treatment, afford them the dignity and feeling of control of self-directed treatment.

9. Engage the family during the new patient discussion and enlist them as part of the team. One could successfully beat it without family but it would be immeasurably more difficult.

10. Are we getting better and better at fighting the actual disease process but not providing a great deal of formal attention to the psychosocial aspects of the ordeal? Everyone has their own unique journey and no amount of counseling or therapy will standardize it (nor should it) but the lack of the same leaves patients to their own devices and some are better equipped than others.

11. There will be quite a lot of data management that most will not be used to handling. Encourage them to buy a Spandex type file in which to keep all appointment calendars, labs, reports, documents, insurance, and written prescriptions in one place. Use pill containers to help manage medications. Consider giving them these things as part of a new patient package.

12. The prospect of the loss of one’s teeth is terrifying to comprehend. Impossibly so. It is disquieting to be a fortunate ex-patient counseling a less fortunate ex-patient who is sad that “I used to be attractive, now I
look like a different person.” Encourage patients to use their dental trays in the shower. It gives them a regular routine to use them and they are able to spit excess fluoride saliva down the drain.

13. The radiation mask is a special hurdle. The loss of control by being imprisoned by something one millionth of an inch from one’s face is near complete. If a patient exhibits complete anxiety, medicate them. But if a patient must drive themselves to appointments and cannot be medicated, encourage them to leave home early for the appointment to avoid traffic stress. Listen to comforting music on the way to the hospital. Breathe slowly and deeply. Close one’s eyes during treatment. Offer them the opportunity to listen to music of their choice during the treatment.

14. The loss of taste is much more of a loss than it would seem on the surface. It is shocking how important the sensation of taste is in driving a person’s appetite. Indeed, when one cannot taste, the act of eating is actually a tiresome ordeal in itself.

15. Have patients keep Magic Mouthwash (a lidocaine mixture) right next to their chair and bedside, not in the kitchen. Keep it super-convenient and they will use it more regularly. Recommend that patients keep moisturizer in their vehicles so that they may slather it on their necks immediately after the treatment. Make the supportive care as convenient as possible for themselves.

16. Post-surgical and radiation mucositis can make it very difficult to sleep in a normal position. Encourage patients to purchase and utilize a reclining chair to sleep in and when they transition back to a bed, have them elevate with multiple pillows. When awake and in the chair, set up a TV tray and line up all the accoutrements of healing. Water, spit cup, prescriptions, books, TV remote.

17. Encourage the patient to take mastery over their mind. Have them hang a white dry erase board or the like at their home or office. Sequentially number the amount of treatments (30, 29, 28….1, DONE). Make it a ceremony to “X” out each number as it progresses. Look forward to it. Engage family and allow them to “X” out some of the days. Write slogans of encouragement on this board.
18. Once the miraculous “tah-dah” moment of finishing treatment is reached, the “New Normal” begins. As the treatment “gift” keeps on giving in the weeks and months following radiation, a patient may feel the need for additional sleep. Encourage naps as necessary. This “lack of productivity” can result in financial strain due to reduced income but it is a matter of aligning things in their necessary hierarchy of importance.

19. The effect of radiotherapy on the skin can cause the neck to look twenty years older than the rest of the patient. Don’t discount the importance of trying to reduce the long-term visible side effects of treatment.

20. The hiring process for staff should place a special premium on the human quality of kindness. The smallest act of kindness will be something the patient will remember for life. Begin with the valet in the parking lot. They are the first face a patient will encounter and the last to see and have an opportunity to place their positive imprint on the entire visit. The same care should be extended with check-in staff, nurses and of course, physician assistants and physicians. By doing so, you will be treating patients as a human being instead of a disease, which is crucial to maintain dignity throughout the process.

21. If the patient has children, forcefully encourage (and remind) them to vaccinate their kids against HPV. Motivate them to be strong advocates for HPV vaccination for their extended family and friends.

If you have read this far, I thank you from the depths of my heart. It is because of you and people like you that I backpacked 110 miles at Philmont Scout Ranch with my son last year. Remember why you do what you do!