SCALP COOLING SUMMIT

ROUNDTABLE

Do Quality of Life Measurements Need to Evolve to Reflect the Impact of Hair Loss During Chemo?

Conversation led by Professor Fran Boyle with Dr Steven Isakoff, Dr Amie Jackson, Trisha Marsolini, and Isa Pupo Wiss. March 2022

KEY DISCUSSION POINTS

- There is plenty of data on the impact of hair loss as a result of chemotherapy, but studies have largely shown little difference in a patient's quality of life with scalp cooling versus those without
- Quality of life scales have historically successfully tracked patient experience, but are now not successfully measuring the details required to reflect the advances in side effect management
- Accurate quality of life measurements will be different for each patient and accounting

Many controlled trials that have examined the impact that scalp cooling can have on a patient's quality of life versus those who don't scalp cool, have found little if any difference in the patient's experience. For those who are providing supportive care to cancer patients, including scalp cooling, these findings are not representative of what is being seen in clinic. Is it time to review the scales used to examine quality of life (QoL), and acknowledge that there isn't a scale that precisely reflects the impact chemotherapy-induced alopecia (CIA) has on self-confidence, physical appearance and mental well-being?

'I'VE GOT A SNEAKING SUSPICION THAT ONCOLOGISTS AREN'T GOOD AT MEASURING THINGS THEY CAN'T FIX, AND SO WHEN HAIR LOSS WAS SOMETHING WE COULDN'T DO ANYTHING ABOUT, ONE QUESTION OUT OF 30 ON A QUALITY OF LIFE SCALE SEEMED TO BE PERFECTLY ADEQUATE' *– Professor Fran Boyle*

Understanding a patient's reasons for scalp cooling can provide a real insight into which factors will have an impact on their quality of life. Those who arrive at the oncologist's office familiar with scalp cooling, more often than not represent a patient who is looking for ways to proactively gain back control. Their motivations however can vary, from wanting to be able to continue working through treatment, to not wanting their children to be burdened with the knowledge of their diagnosis, to something as seemingly simple, but essential, as wanting to recognize the person they see in the mirror. These are the nuances that can both shape and challenge the ability to create a QoL scale which encapsulates the true impact of CIA.

Current scales cover a huge spectrum of chemotherapy experience, meaning hair loss and hair retention are often swamped by other elements. And even if these questions on hair loss and retention are covered in more detail, it should also be considered that the timing of when they are asked can be just as important as the questions themselves. For many patients scalp cooling can be challenging, particularly if they face significant hair loss, but the increased rates of hair regrowth that result from scalp cooling can mean that the real benefit won't reveal itself until several months after treatment has been completed. Therefore, the patient's perception of their quality of life may alter significantly as they start to experience this regrowth, thereby asking about the importance of scalp cooling for them during their chemotherapy treatment may not be representative of their overall experience.

So where does the physician's responsibility come in here? Managing patient expectations effectively from the beginning of the scalp cooling process - while at times challenging - can change what may have been a negative experience into a positive one. Establishing realistic expectations around hair retention, shedding being normal even with scalp cooling, and the variation in results based on regimen, are key to successful outcomes and ultimately an improved quality of life. This is also true of effective patient preparation when it comes to protocols such as hair preparation and effective cap fitting. Scalp cooling can easily render a patient disheartened or lacking in confidence if they haven't had the time to prepare and research.

'NOW THAT HAIR LOSS IS SOMETHING WE CAN DO SOMETHING ABOUT, A VERY MUCH MORE NUANCED APPROACH I THINK TO THE PATIENT EXPERIENCE IS REQUIRED' *- Professor Fran Boyle*

'WHAT SUCCESS LOOKS LIKE IS NOT YOUR HAIR LOOKING AS NICE AS IT DID ON THE DAY OF THE CONSULT, SO SOMETIMES THAT FEAR OF ON-GOING HAIR LOSS OR THAT FEELING OF "IS IT REALLY WORKING?" IS SOMETHING YOU WANT TO SET EXPECTATIONS WELL FOR AT THE START OF THE THERAPY TO MAXIMIZE BENEFIT' *– Dr Amie Jackson*

There is significant interplay between hair loss and its effect on identity, confidence, body image, and intimacy that can lead to anxiety and depression.

Maintaining a sense of self through treatment can aid a patient when dealing with the many challenges their diagnosis will throw at them. It is also important to acknowledge that experience and required support can be influenced by ethnicity and gender, let alone if they are offered scalp cooling treatment in the first place.

The subtle nuances of a patient's experience of hair loss or hair retention during chemotherapy is difficult to accurately capture or measure, which is why patient-reported outcomes are so important. Arguably, the more effective quality of life scales become at measuring the positive impact hair retention and faster hair regrowth can have, the more likely we are to see scalp cooling being offered. While current scales have led to effective implementation, more finely tuned scales which allow for more nuanced detail and understanding of patient experience will be required to make scalp cooling a universal standard of care.

FURTHER READING

Rosman S. *Cancer and stigma: experience of patients with chemotherapy-induced alopecia.* Patient Educ Couns. 2004 Mar;52(3):333-9.

Paterson C, et al. *Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review.* J Cancer Surviv. 2021 Feb;15(1):14-28.

Lemieux J, et al. *Chemotherapy-induced alopecia and effects on quality of life among women with breast cancer: a literature review.* Psychooncology. 2008 Apr;17(4):317-28.

Choi EK, et al. *Impact of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression in breast cancer patients.* Psychooncology. 2014 Oct;23(10):1103-10.

SUMMIT POLL RESULTS

We asked Summit delegates:
Do you feel that scalp cooling has a positive impact on the quality of life of your patients?

42.9% said yes, all of them.

42.9% said yes for those it is successful for.

14.2% said no, for those unsuccessful.

Scan to watch the opening discussion key points