Considerations for the Telephone Disclosure of Genetic Test Results to Patients With Cancer

I would like to thank Cantril, Moore, and Yan (2019) for their informative article on patient preferences for the disclosure of a breast cancer diagnosis in the December issue of the Clinical Journal of Oncology Nursing. The findings of Cantril et al.’s (2019) study suggest that patients prefer in-person disclosure. Additional patient priorities included knowing the results of tests quickly, having those results disclosed by an expert with a sensitive touch, and having a clear understanding of the next steps in the treatment plan.

In genomic care, disclosure is also a challenge. Genetic testing is often a component of the breast cancer diagnostic process, and some women are confronted with a second diagnosis—the distressing news of their hereditary susceptibility to developing cancer.

There is no clear answer to the best approach. Telephone disclosure of test results has been increasingly used to reduce time and travel burdens on patients and to improve access to care (Beri et al., 2019). In a randomized trial on the disclosure preferences of 1,178 patients, Bradbury et al. (2018) found that telephone disclosure is an acceptable alternative to in-person disclosure. Following in-person pretest counseling, in Bradbury et al.’s (2018) study, telephone disclosure was not associated with greater anxiety or distress when compared to in-person disclosure.

Although they promote accessibility, smartphones also increase the possibility of disclosing information at an inappropriate time. When I disclosed results 15 years ago, it was usually to patients in their homes, sitting at the kitchen table on a landline telephone. With today’s technology, patients can be anywhere and with anyone. If they are driving while operating a smartphone, it can be dangerous to others, as well.

In my practice, the preference is always in-person disclosure. I am very clear about this with patients. Once a decision is made during an in-person pretest counseling session to pursue genetic testing, the disclosure process is explored. I have patients for which positive test results will directly influence surgical decisions (e.g., having bilateral risk-reducing mastectomies). Often, genetic test results are the last piece of data needed to make an informed decision. Depending on insurance issues and laboratory volumes, it can take 10–21 days or more to receive test results, making it difficult to know when to schedule a disclosure appointment with the patient. Patients and surgeons want to receive the results as soon as possible. In addition, I have many patients who travel two hours or more for counseling. Traveling long distances to receive test results is an additional burden.

My practice for patients who prefer telephone disclosure is to specifically tell them that I will call them, and the first thing that I will say is that their results are available. I clearly inform them that the next thing I will ask is if it is a good time to discuss their results. I emphasize that this does not mean that there is a positive test result; I am simply asking if it is an appropriate time. During disclosure, if the patient says that it is a good time to discuss results, I ask what they are doing and where they are. If it seems like the timing is less than optimal (e.g., driving, background noise, vague responses from the patient, no available support system), I encourage the patient to pick a better time for disclosure.

I cannot change the patient’s test results, but I can try to deliver them in a way that keeps the patient informed and supported. Anyone with positive test results is encouraged to return for additional in-person counseling, ideally with other family members who are at risk. Telephone disclosure may not be optimal, but it can be a necessity. If it is, every effort needs to be made to inform the patient how the test results are going to be disclosed. It is also important to have the disclosure delivered by a knowledgeable individual with whom there is rapport and at a time when the patient can focus and, ideally, has a supportive individual with him or her. Because telephone disclosure is often unavoidable, future research should identify strategies to optimize outcomes.

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REFERENCES

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