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Consumer Beware: A Systematic Assessment of Potential Bias in the Lay Electronic Media to Examine the Portrayal of “PARP” Inhibitors for Cancer Treatment

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Abstract

This study examined how the lay electronic media covers poly-ADP-ribose polymerase, or “PARP,” inhibitors, a class of cancer agents currently under clinical investigation. Of 771 internet links, 51 targeted the lay public. Independent review by two investigators yielded the following categorizations: 36 (71%) were “overly positive”, 15 (29%) “neutral”, and none “overly negative”. “Overly positive” articles used: (1) overstated benefit, (2) included quotations from enthusiastic scientists, and (3) discussed single or small patient subsets. They used such phrases as “the holy grail of cancer research”, “the most exciting development in cancer research in a decade or more.... it could save thousands of lives”, and “we were surprised and delighted.... it's the kind of thing you don't really think will happen”. Healthcare providers should be aware of the foregoing when discussing PARP inhibitors—and perhaps other novel therapies—with cancer patients.

Keywords

Electronic media; Cancer; Novel agents

In a recent interview, Niederdeppe, an authority on health news coverage, commented, “Journalistic norms value novelty and conflict, whereas scientific norms value replication and the development of a cumulative body of evidence over time” [1]. Indeed, concerns are mounting about these divergent approaches. The lay media often omit information on the benefits, costs, and risks of medications [2]. Its current role in breast cancer treatment notwithstanding, many years ago Herceptin had received media coverage fraught with personal, patient-related anecdotes that violated “rational, criteria-based public health policy” [3]. In view of the accelerated emergence of new cancer drugs, the often lethal consequences of cancer, and the negative emotional impact of this disease on patients and their families, there is a need to analyze systematically the potential for bias within the lay press, particularly as relevant to new cancer drugs [4].

A new class of oncology drugs called PARP (poly-(ADP-ribose) polymerase) inhibitors offers a case in point [5]. The PARP enzyme repairs damaged DNA. In normal cells, this mechanism maintains cell viability, but in cancer cells, it can potentially be exploited to cause cell death. A 2009 publication in the high-profile *New England Journal of Medicine* generated multiple citations, when it reported on a single arm trial with one type of PARP inhibitor. Yet, a close reading of this report shows that among 60 patients, antitumor activity was observed in only *BRCA1* or *BRCA2* mutation carriers, overall yielding only 12 patients

(20%) who manifested a tumor response or disease stabilization. This response rate is very much in keeping with other treatments already available [6–8]. Thus far, PARP inhibitors have not demonstrated unprecedented tumor response rates, a well-established survival advantage, or a curative role in cancer treatment. An article in the *Journal of the National Cancer Institute*, “PARP Inhibitors: Will the New Class of Drugs Match the Hype?”, acknowledges that these agents are receiving much attention, but it also points out that these agents require far more in depth study prior to their routine use in the clinic [9]. In effect, the “hype” surrounding this class of drugs is derived from a paucity of clinical trials, none of which have undoubtedly demonstrated improved clinical outcomes. Indeed, at the time of this report, the United States Food and Drug Administration had yet not approved any of these drugs for any clinical indication.

Hence, the current qualitative study explored how the electronic lay media reports on such an emerging class of agents currently under clinical investigation. The internet is a major source of healthcare information, and, in fact, 80% of individuals who access it do so to acquire health-related knowledge [10]. At the same time, cancer patients represent a vulnerable group, and unrealistic news coverage of new therapies has the potential to generate false hope and, ultimately, great disappointment [11–13]. Healthcare providers must be aware of the information accessible to cancer patients in order to discuss PARP inhibitors—as well as other emerging cancer agents—in a pragmatic yet compassionate manner.

Methods

This study utilized Google®, the largest, most widely accessed search engine (<http://www.alex.com/siteinfo/google.com+yahoo.com+altavista.com>). One investigator (SC) searched the term “PARP inhibitor(s)”. All news articles which discussed PARP inhibitors as their primary focus and which were intended for the lay public were reviewed in depth.

The following categories of web sites were excluded and therefore not reviewed in depth: pharmaceutical company web sites, blogs, web sites designed for a professional medical audience, financial reports for investors, patient-focused information sources designed by non-profit groups, descriptive sources such as Wikipedia, clinical trial listings, stand-alone images specific to PARP inhibitors, articles that did not specifically discuss PARP inhibitors but mentioned them only in passing, and textbooks or advertisements for textbooks. The study team was unable to sort through and identify the uniqueness of each “hit” among the ineligible web sites and therefore did not generate frequency statistics for ineligible sites.

Articles that met the eligibility criteria were printed and reviewed independently by two investigators (SC and AJ). Both are clinicians actively involved in the treatment of cancer patients with a 20-year cumulative experience. Both had read and were knowledgeable of all recent clinical trial with PARP inhibitors within the public domain. It should also be noted that, between the two of them, these investigators had experience in prescribing PARP inhibitors and in designing clinical trials with drugs of this class. These investigators then decided whether each lay press article was “overly positive,” “neutral,” or “overly negative.” Discrepancies in categorization prompted a face-to-face discussion, and a lack of consensus was to prompt arbitration by a third colleague.

Subsequently, both investigators (SC and AJ) identified direct quotes from the “overly positive” papers to justify this categorization. These investigators then identified themes within these quotes from the “overly positive” articles.

Results

A total of 771 internet links had PARP inhibitors as their primary focus. The vast majority of these appeared to be either those designed for a professional medical audience or patient-focused information sources designed by non-profit groups and therefore did not meet the study's eligibility criteria. However, 51 did meet the eligibility criteria. The following consensus was reached among the two investigators mentioned above without a need for further arbitration: 36 (71%) were “overly positive”, 15 (29%) “neutral”, and none “overly negative”.

Representative quotes from the “overly positive” articles are listed in Table 1 and displayed the following themes: (1) authors' use of language that suggested an overstatement of benefits, (2) direct quotations from scientists who appeared overly enthusiastic, and (3) a discussion that focused at times almost exclusively on one patient or a small patient subset who had had a highly favorable result. Most “overly positive” articles included quotes that illustrated multiple themes.

Particularly notable quotes included the following: “holy grail of cancer research”, “the most exciting development in cancer research in a decade or more.... it could save thousands of lives”, “we were surprised and delighted.... it's the kind of thing you don't really think will happen”, and “her progress after a year and a half is even surprising doctors” (Table 1).

Discussion

To our knowledge, this study is the first to examine the lay electronic media in a systematic fashion to discern how articles on PARP inhibitors are being presented and what cancer patients are learning from such sources about this class of agents. The vast majority of these articles projected these new agents in an “overly positive” manner, an observation that raises concerns that patients may be receiving unduly optimistic information on PARP inhibitors and that such information might in turn be generating false, unrealistic hope. Admittedly, patients may be reading information from other information sites, but the relative ease of reading sites that have been prepared specifically for the lay public and the fact that it is only human nature to focus on that which appears to be more positive both speak to the need to review and understand what medical information the lay press is providing to cancer patients and their families.

Should we as healthcare providers be concerned about the nature of the information on the internet? Although, to our knowledge, no previous studies have sought to evaluate the detrimental effects of such reporting, other sources suggest it might in fact be injurious to patients: “Intense and repetitive emotional campaigns may be harmful for patients not only in terms of their consequences..., but also because of their psychological sequelae” [14]. Cancer patients appear often to be in a tenuous emotional equilibrium, and overstating the benefits of treatment may have devastating consequences if such benefits are not realized. Thus, we think it important to know what information cancer patients are learning, and, subsequently, we think it important to spend time to explain to patients how best to place such information within a realistic context.

Moreover, previous studies suggest that some cancer patients come to the clinic with high expectations related to any type of experimental therapy and that these expectations may not be drug-specific. Although the chances of obtaining clinical benefit from a phase I study are <10%, Meropol and others reported that 77% of cancer patients estimated that their chance of benefit from such therapy was at least 50% [4,15]. Thus, an important role of the healthcare provider might be to temper the unrealistic expectations of patients when it comes

to a discussion of any type of experimental therapy—not just PARP inhibitors and not just the latest cancer agent that appears to be receiving a high degree of publicity.

Finally, in the last few years, there has been a growing push to “police” the internet. These efforts have centered on multiple other societal issues but appear to have achieved only modest success. To our knowledge, truth in advertising as relevant to cancer drug development has not yet fallen into the purview of such efforts. Nonetheless, a greater awareness on the part of the lay media of the consequences of such overstating of the benefits of investigational drugs might lead to a greater degree of circumspection in reporting.

In conclusion, this study found that most lay information on the internet about PARP inhibitors is “overly positive.” It is hoped that PARP inhibitors will prove to play a pivotal role in cancer therapy in the very near future, but, until then, healthcare providers should be aware of the current, “overly positive” publicity surrounding these relatively new agents—as well as perhaps the positive publicity that may be surrounding other cancer therapies currently under clinical investigation.

Acknowledgments

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Table 1
Representative quotes from “overly positive” articles

Category	Direct quotes
Authors' use of language that suggests an overstatement of benefit	<p>“... cancer patients... had their tumors shrink or vanish, often without the punishing side effects...”</p> <p>“...this may be one of the most exciting cancer treatments we have seen in a long time.”</p> <p>“...could lead to a transformational approach to understanding and treating several forms of the disease....”</p> <p>“This means that the tumor should either stop growing or get smaller.”</p> <p>“... the most exciting development in cancer research in a decade or more.... It could save thousands of lives.”</p> <p>“Blocking PARP, however, is like taking away a race car's pit crew.”</p> <p>“...offers hope to cancer patients who have exhausted all conventional treatments, offering them a second chance at life.”</p> <p>“... could revolutionize treatment for breast and other cancers....”</p> <p>“...holy grail of cancer research...”</p> <p>“PARP drugs may be a miracle cure for cancer...”</p> <p>“...breast cancer specialist calls it...one of the biggest cancer breakthroughs of her career.”</p>
Quoting scientists/investigators	<p>“We were surprised and delighted.... It's the kind of thing you don't really think will happen.”</p> <p>“Now we can... target these cells to go after their Achilles heel where they are weak and force those cells specifically to die off.”</p> <p>“Evidence so far indicates that for some women with refractory ovarian cancer it's been almost like a wonder drug.”</p> <p>“The drug is really active, and the only side effect is indigestion.”</p> <p>“It's really exciting to see drugs that have a very high chance of working in a situation where chemotherapy has a very low chance of working.”</p>
Focusing on one patient or a small subset	<p>“Her progress after a year and a half is even surprising doctors.”</p> <p>“It's a chronic disease for me now; it's something that I'm going to have to manage now for probably the rest of my hopefully long life.”</p> <p>“I'm so excited about it. I'm thrilled to be in this study.”</p> <p>“Within 3 months the tumors had virtually disappeared.”</p> <p>“This is incredible to me... I have no side effects and a completely normal standard of life.”</p> <p>“The drug has been a miracle for me.”</p>