

Representing a “revolution”: how the popular press has portrayed personalized medicine

Alessandro R Marcon, MA¹, Mark Bieber, BSc² and Timothy Caulfield, LLM, FRSC^{1,3}

Purpose: This study investigated the portrayal of “personalized” and “precision” medicine (PM) in North American news over the past decade. Content analysis of print and online news was conducted to determine how PM has been defined and to identify the frames used to discuss PM, including associated topics, benefits, and concerns.

Methods: A data set was built using the FACTIVA database, searching for popular North American publications with the terms “personalized (personalised) medicine” and/or “precision medicine” from 1 January 2005 to 15 March 2016. The final set of publications totaled 774.

Results: PM is almost exclusively defined as related to genetics and is often part of a story related to cancer. The PM story is overwhelmingly one of highlighting (potential) benefits and optimism, especially in

shorter publications, and ones where PM is not the main focus. This promotional PM discourse has remained fairly consistent over the past decade.

Conclusion: The numerous concerns associated with PM have received little attention over the past decade, especially in articles more likely to be encountered by a more general audience. This promotion of PM serves as an example of the science hyping that takes place in science reportage and may have implications for consumers, public expectations, and related health policy.

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INTRODUCTION

Over the past decade, the hopes, benefits, and concerns as well as the use of technological and scientific advancements in the overlapping fields of genetics, medicine, science, and health care in approaches now commonly referred to as precision or personalized medicine have attracted a significant amount of media attention. The appointment of precision-medicine proponent Francis Collins to the role of director of the National Institutes of Health, the announcement of President Obama’s Precision Medicine Initiative, and the emergence of numerous direct-to-consumer genetics-related health companies such as 23andMe, have all played a role in this rise of media discourse. Although the terms “personalized medicine” and “precision medicine” (PM) have become the most commonly used in this context, they still lack singular, concrete definitions.^{1,2} Many other terms have been used in similar contexts, including “stratified medicine,” “P4 medicine,” “genetic medicine,” and “personalized genomics.”^{2,3} The creation and ultimate popularization of the term “PM,” despite its somewhat varied use, have the fundamental roles of synthesizing under a unified title a range of genetics-related health-care practices through which information and knowledge exchanges can take place among scientists, government, industry, and the public at large. Thus, while PM, as a term, remains something of a fluid social construct, taking on diverse meanings based on the context as well as the manner in which it is used, a general, working definition of PM can be

understood as “an emerging approach for disease treatment and prevention that takes into account individual variability in environment, lifestyle, and genes for each person.”⁴

PM is typically presented as striving toward making health care more “personalized, predictive, preventive, and participatory.”² It has been portrayed as a means to optimize care^{5–7} and to empower both patients and the general public to participate more in treatment decisions as well as to take greater preventive measures.⁷ It has also been argued that PM will improve health-care efficiency and reduce system costs.^{8–10} Furthermore, it is thought not only that PM will help accelerate the development of new drugs for rare or neglected diseases¹¹ but also that drugs previously deemed ineffective might find new uses.⁷ Often, when PM is promoted to the general public, it is portrayed as representing a “revolution”¹² or part of a “breakthrough”^{13,14} in health care.

For all its potential benefits, however, PM efforts have also faced cautionary criticism. For example, commentators have questioned the clinical value of the PM approach in many contexts.^{1,15,16} In addition, evidence suggests that individuals are unlikely to change their behavior in response to genetic risk information,^{17,18} a common justification for the adoption of PM strategies.¹⁹ There is also concern that the introduction of PM might lead to increases in overdiagnosis, unnecessary testing, iatrogenic injuries,²⁰ and health-care costs.²¹ In addition, the heavily promotional language often associated with PM (such as the term “revolution”) has been criticized

¹Health Law Institute, Faculty of Law, University of Alberta, Edmonton, Alberta, Canada; ²School of Public Health, University of Alberta, Edmonton, Alberta, Canada; ³Faculty of Law and School of Public Health, University of Alberta, Edmonton, Alberta, Canada. Correspondence: Timothy Caulfield (caulfield@ualberta.ca)

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for contributing to inaccurate public representations of science²² and unrealistic public expectations,²³ as well as facilitating a market for unproven products and services.²⁴ Finally, some have suggested that an emphasis on PM may result in an inappropriate shift from public health initiatives to those focused on the individual.^{5,25} Because a large body of research has detailed issues concerning the hype²⁶ and overly optimistic portrayals of biomedical research,²⁷ a primary analytical focus of this study was to assess the degree to which PM has been portrayed as beneficial in light of the concerns also being raised.

With these tensions in mind, the goals of this research were to examine the portrayal of PM in popular print and online North American news media over the past decade (2005–2016), to determine how PM has been defined (as a process related to “genetics” or otherwise), to identify the central topics associated with PM, and to identify which—and the extent to which—PM benefits and concerns have been discussed.

The role of the popular press

Apart from the education system, mass media stands as the primary source of health information for the general public.²⁸ In addition, studies have shown a substantial interest in novel advancements in health care and biotechnology; one reported that almost 60% of Americans said they were “very interested” in news about medical discoveries.²⁹ While the factors underlying the reporting and publication of health news are numerous and complex,³⁰ the media undeniably plays a role in how the general public learns about, and makes sense of, health-related topics. For example, studies have shown how media attention on a particular topic can affect the public’s utilization of health services.³¹ Other studies illustrate how the media plays an influential “framing” role when covering issues surrounding access to health care, at times highlighting certain aspects of debates over others³² or in some cases omitting important information concerning relevant risks and limitations.³³ The concept of “framing,” which has been taken up and expanded on by theorists and communication scholars, refers to the process of selecting, and in turn emphasizing, particular stories, topics, themes, facts, and actors over others.³⁴ As a result of framing choices, certain frames resonate more with particular audiences, gaining stronger or weaker influence depending on the context.³⁵ With regard to analyzing frames when performing content analysis, choices can be made between analyzing generic or issue-specific frames.³⁶

MATERIALS AND METHODS

Data collection

To capture the popular representation of PM in North American news media, we used the Factiva database (<https://www.dowjones.com/products/factiva/>) to collect both print and online news stories appearing in the most popular American and Canadian news sources, including newspapers, magazines, and news-related websites. Factiva is a news

source database owned by Dow Jones in which elaborate search inquiries can be performed and corresponding text—in this case, articles—can be downloaded. Details on the selection of news sources for this study can be found in the **Supplementary Material** online.

After performing a Google “news” search on the wide range of terms associated with PM (e.g., “personalized medicine,” “personalized genetics,” “precision medicine,” “individualized medicine,” “personalized treatment”) and recording the number of search results for each term, we determined that “personalized medicine” (also with the spelling “personalised”) and “precision medicine” were the terms used most frequently. While these two terms do not capture the totality of the PM discourse, they markedly substantiate the popularization of the concept. These two terms were searched in the Factiva database over the time period from 1 January 2005 to the day of collection: 15 March 2016. Because our objective was to track and analyze PM discourse over time, and because metrics such as Google Trends showed consistent use of “personalized medicine” and “precision medicine”—the latter with a sharp spike in the last 15 months—it was determined that just over a complete decade would provide an ample and sufficient data set.

A total of 1,477 articles were initially obtained. Duplicate and irrelevant articles were excluded, resulting in a final data set of 774 news articles. Articles were considered irrelevant if PM was only mentioned or briefly defined but not discussed in any detail and not connected to themes and topics represented in the story.

Data analysis

Content analysis³⁷—a systematic and replicable process of analyzing text to make valid and objective inferences about a particular social context—was then performed on the articles to examine how PM was being framed in the media. This process involved building a coding frame through a sample analysis, which was then applied to all texts in the database. The coding results serve as an accurate portrayal of the PM communicative discourse. In this media study on PM, the frames chosen were issue-specific and were determined both inductively and deductively (an initial coding frame was modified through an analysis of a data sample), with the broad goal of mapping out which themes and topics become associated with PM. Analyzing the framing tensions between articles promoting PM and those raising concerns about PM sheds light on how the general public is being informed about these emerging technologies, and because the articles cover a time span of more than a decade, whether the story has changed or remained consistent over time. The final coding frame included (i) information (metadata) about publication date, headline, word count, author, and article source; (ii) identification of article type, e.g., news, commentary, news and commentary combined; (iii) the degree to which the article focuses on PM; (iv) definition of PM; (v) general topics associated with PM; (vi) mentions of specific health topics related to PM; (vii) mentions of specific drugs related to PM;

(viii) benefits attributed to PM; (ix) expected timeframe for PM benefits to come into effect; (x) Concerns associated with PM; and (xi) overall tone of the article with respect to PM. The complete coding frame can be found in the **Supplementary Material**, which provides the details of each coding category.

Assessment of the tone of the article was based on the presence and analysis of benefits versus concerns. An article detailing and stressing PM benefits but not PM concerns was coded as “positive.” An article predominantly detailing PM benefits but also mentioning and stressing some concerns was coded as “mostly positive.” The same process with the inverse values was undertaken to code articles “negative” and “mostly negative.” Articles were coded “neutral” if the benefits and concerns of PM were detailed in equal measure, or if a definitive emphasis on either side could not be determined.

Because the coding aspect of content analysis can have subjective variance, we tested just over 10% ($n = 84$) of the articles for intercoder reliability. Following a consensus-reaching session in which intercoder human error was corrected and category requirements were clarified, we achieved a mean κ score of 0.814 across all categories, demonstrating “strong” agreement based on stringent standards.³⁸ Complete κ scores for each category can be found in **Supplementary Table S1**. For category v (general topics), an agreement score ($\kappa = 0.583$) was achieved, which illustrates only “weak” agreement. Some inconsistencies in coding for this category were found, as there were ambiguities when demarcating university research, government initiatives, and biotech industries. These data have been included in the analysis because they provide a general mapping of the topics through which PM is framed but do not weigh heavily on conclusions drawn from analysis. For category ix (timeframe of PM benefits coming into effect), we obtained weak agreement ($\kappa = 0.483$) and therefore removed all data pertaining to this category from our analysis.

RESULTS

Of the 774 articles included in the final data set, 539 (69.6%) were from US news sources and 235 (30.3%) were Canadian. The numbers of articles per year and the total number of articles appearing in each US and Canadian news source are shown in **Supplementary Figures S1–3**. With respect to article type, 391 (50.5%) were “news,” 205 (26.5%) “news and commentary,” and 178 (22.9%) “commentary.” With respect to degree of PM focus, in 338 (43.7%) of the articles, PM was the “main focus” and in 436 (56.3%) it was not. Regarding definitions, PM was defined as something based solely on genetics in 675 (87.2%) articles, as something related to genetic procedures as well as other processes in 46 (5.9%) articles, and as something not related to genetics in 53 (6.8%) articles. Regarding general topics, PM was associated with university research in 40.1% of articles, with biotechnology in 32.9% and government initiatives in 22.9%. PM was discussed in the context of specific medical procedures in 13.0% of articles and was connected to direct-to-consumer companies,

products, or services in 9.9%. These data are shown in **Supplementary Figure S4**. With respect to “other” topics associated with PM, present in only 5.4% of the articles, 18 articles focused on legal proceedings, and 5 touched on topics related to fundraising, philanthropy, and competitions. The topic of ELSI (ethical, legal, and social implications) debates was raised in four articles.

More than 120 specific health topics appear in the 774 articles, but cancer had substantially the largest presence, appearing in 441 (56.9%) articles. The next most discussed health topics included diabetes, in 71 (9.2%) articles; heart disease, in 56 (7.2%) articles; cystic fibrosis, in 53 (6.8%) articles; and Alzheimer disease, in 50 (6.5%) articles. No other health topic appears in more than 6% of the total articles. For a complete list of all health topics mentioned in at least five articles, refer to **Supplementary Table S2**.

In 210 (27.1%) articles, reference is made to specific drugs. A total of 125 different drugs are mentioned in the articles, 86 of which are mentioned only once. All drugs mentioned in at least 5 articles are listed in **Supplementary Table S3**.

With regard to the benefits of PM, 709 articles (91.6%) describe eight principal PM benefits and seven “other” benefits. Of these 709 articles, 354 (49.9%) detail only one benefit, 259 (36.5%) detail two, and 76 (10.7%) detail three. Of the 354 articles that detail only one benefit, 284 describe the efficacy of current or future PM-related treatments and 28 describe the benefit of PM-related prevention. Text examples of the efficacy of PM treatments are provided in the **Supplementary Material**. Sixty-five (8.4%) articles discuss PM without detailing any benefits. The overall presence of PM benefits is displayed in **Figure 1**. For cases where PM was seen as beneficial in terms of creating more patient autonomy or helping to assist in the prevention of diseases, we coded the rationale stated for doing so. In these cases, increased screening and monitoring (including ease of access to screening and monitoring) were mentioned in 118 (15.2%) articles. Positive changes regarding PM-based lifestyle changes were discussed in 67 (8.7%) articles. Achieving higher levels of prevention and increasing patient autonomy

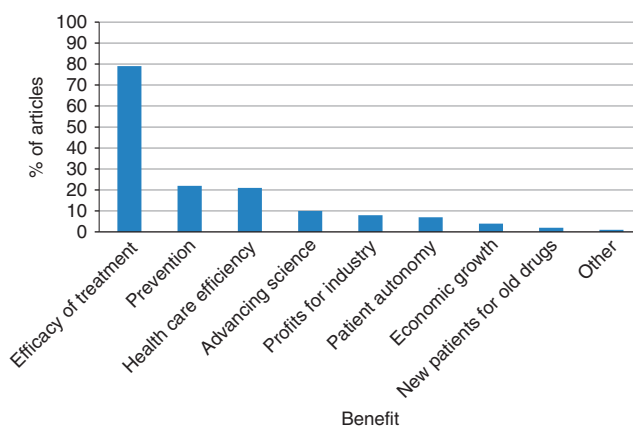


Figure 1 Mentions of personalized medicine’s benefits in publications ($N = 774$).

were equated with decreasing the burden placed on the health-care system in less than 1% of articles. PM was described as a beneficial means for “advancing science”—progressing the scientific understanding of humans and environments regardless of whether a specific practical application for that knowledge could be discerned—in 77 (9.9%) articles.

In addition to highlighting the benefits of PM, articles raised numerous PM concerns. The total number of articles raising concerns about PM, however, as displayed in **Figure 2**, was significantly lower than that of articles describing its benefits: 253 articles (32.7%) raised PM concerns while 521 (67.3%) did not.

We coded for 13 specific concerns as well as an open category labeled “other” (see Supplementary Material online for the complete list). The most common concern centered on the “limited clinical or health value of genetic information,” which was expressed in 90 (11.6%) articles. Economic cost concerns were mentioned in 79 (10.2%) articles. The other concerns present in more than 5% of articles included “other” (or miscellaneous) in 44 (5.7%) articles, the “exaggeration of benefits” in 43 (5.6%) articles, government regulations and policies (e.g., questions about how to regulate DTC products, issues over when health care systems should use and/or fund genetic tests, etc.) in 38 (4.9%) articles, and concerns surrounding access to and control of data, in 41 (5.3%) articles. Concerns not present in more than 4% of articles included concerns related to genetic literacy, too much medicine (e.g., issues related to overdiagnosing, diagnostic cascade, or iatrogenic injury), genetic discrimination, patents, managing information, doctors’ knowledge/expertise in interpreting genetic data, and ELSI topics pertaining to race, ethnicity, and ancestry, as well as the potential for increased inequality in health-care systems. For “other” (miscellaneous) topics, two topics made up 45.5% of the 44: the accuracy of genetic tests (in 11 articles) and emotional issues (anxiety, false hope, and helplessness) for PM patients (in 9 articles). In terms of PM tone, the articles were overwhelmingly positive, as shown in **Figure 3**.

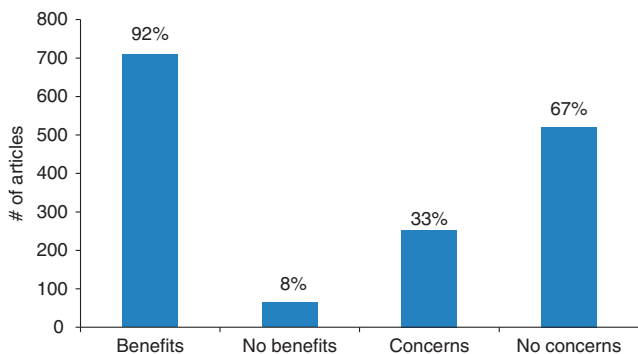


Figure 2 Mentions of personalized medicine’s benefits versus concerns.

ORIGINAL RESEARCH ARTICLE

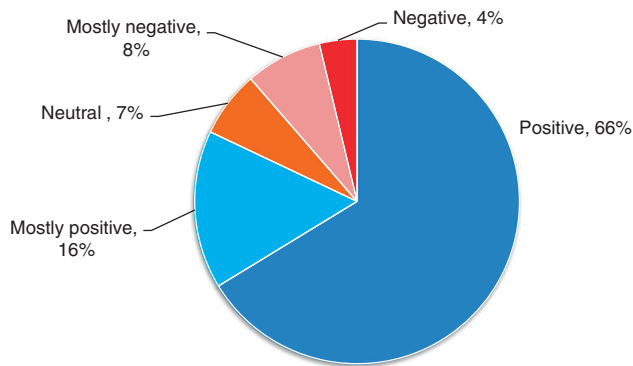


Figure 3 Overall tone of the articles with respect to personalized medicine.

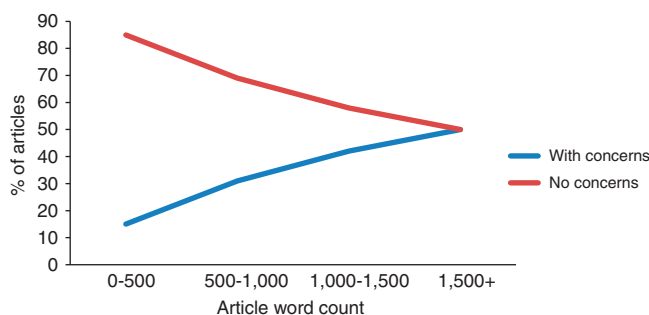


Figure 4 The percentage of articles mentioning concerns in relation to word count.

PM values, the presence of concerns, and the story over time

Concerns and PM focus

In calculating the presence of concerns when PM is the main focus versus when it is not (i.e., PM is referred to but is not the principal topic of the news story), the data reveal that more concerns are present when PM is the main focus. Of the articles in which PM is the main focus (43.7% of all the articles), concerns are mentioned in 39.1%. In contrast, of the articles in which PM is not the main focus (56.3% of all the articles), an even smaller proportion mention concerns: 27.1% of the articles. **Supplementary Figures S5 and S6** present this information.

Concerns and word count

The data show a relationship between length of article and presence of concerns. The average length of articles was approximately 1,000 words. Analysis by category—articles with fewer than 500 words, 500–1,000 words, 1,000–1,500 words, and more than 1,500 words—showed an increasing presence of concerns with increasing word count, as shown in **Figure 4**.

PM over time

Figure 5 displays the tone of the articles over the decade (January 2005 to March 2016). As shown, the tone—essentially

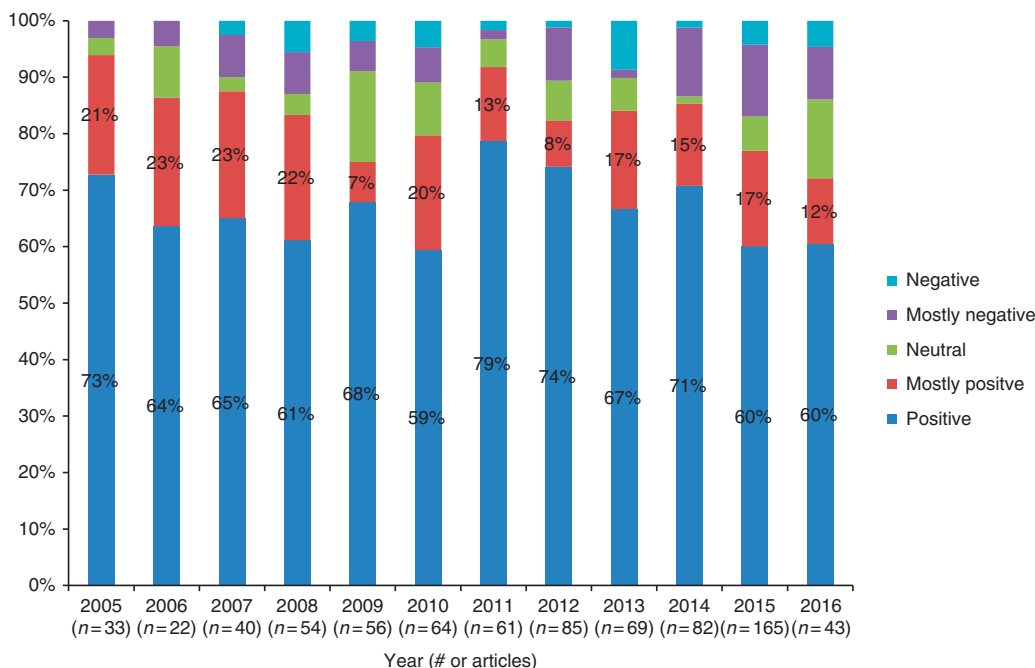


Figure 5 The overall tone of articles across the decade (up to 15 March 2016).

a portrayal of PM benefits and concerns—shows a fairly consistent pattern with no obvious directional trends.

DISCUSSION

Analyzing the PM news stories appearing over the past 10 years reveals key aspects of how PM has been framed and demonstrates that PM is largely portrayed in a promotional or positive light. Regarding PM health topics, PM is most typically presented in a story related to cancer. Other health topics, such as diabetes, heart disease, cystic fibrosis, and Alzheimer disease, receive some PM-related attention but considerably less, and PM in connection with topics such as cardiovascular disease, multiple sclerosis, autism, Crohn disease and Parkinson disease are seldom discussed in the popular press. General readers of PM-related news are therefore more likely to associate PM with cancer and are probably exposed to considerably fewer PM-related developments and issues pertaining to a wide range of health topics. Furthermore, there generally seems to be consensus in the popular press regarding the definition of PM. It is used, rightly or not, almost exclusively to define procedures, topics, or themes related to genetics. For those who believe that PM is really a broader concept—one that encompasses a variety of factors relevant to a patient, including relationships, socio-economics, and lifestyle—this finding will undoubtedly be frustrating. However, it also speaks to how successful those invested in branding the concept of PM have been, especially since our research has observed a fairly consistent framing over the study period. In the popular sphere, PM is primarily about genetics. This raises interesting questions, worth further investigation, about whether this popular culture emphasis

may facilitate an inappropriate de-emphasis of important, nongenetic, factors relevant to population health.

Another major theme is optimism. PM is almost always framed as positive or mostly positive (in 82% of the articles). Only a small percentage of the articles present PM in a negative light. Furthermore, nearly all articles (approximately 92%) detail specific PM benefits, such as the effectiveness of current or prospective PM treatments. In contrast, the exaggeration of PM benefits, which is commonly raised by critics concerned about the lack of data surrounding PM,¹⁵ is mentioned in only 6% of articles. This conclusion aligns with past research that has mapped the phenomenon of science hype,³⁹ showing genetic research to be portrayed in a predominantly positive manner and as part of a near-future “revolution.”¹⁴ Future research should (continue to) explore whether the positivity surrounding the portrayal of PM is translating into an increased demand by the public for genetics-related testing. This would be especially worthwhile seeing as this study highlights increased screening and monitoring as a core PM benefit.

Another strongly promoted benefit of PM is its potential ability to encourage preventative health measures and increase patient autonomy. Specifically, several articles present PM as a way to assist individuals in adopting beneficial lifestyle changes, including screening behavior, diet, and exercise. Given that existing research suggests that the provision of genetic-risk information has little impact on behavior change,^{16,17} these media representations seem out of step with the existing research. Indeed, the inaccurate representations of the empowerment message stand as a good example of how the media portrayals of PM may mislead both the public and policy makers about the value of

some PM technologies. Given that previous research has highlighted the potential impact of media representations on utilization patterns, policies, and public expectations,^{31,33} these results may be cause for concern. In addition, these media portrayals may facilitate the marketing of unproven direct-to-consumer genetic testing services²³ by making unsubstantiated marketing promises—which often include messages of empowerment—seem more plausible.

Given the dominance of the enthusiastic portrayals, it is somewhat ironic that the most common concerns found in the popular press focus on the limited value of genetic information and the problems of exaggerated claims of benefit (e.g., questioning the ability of PM to enable preventative measures). In other words, when concerns are found in the popular press, they often touch on the problems of overly enthusiastic portrayals of benefit. But critiques of this kind are only seldom presented in popular PM news stories.

Another interesting theme that emerged from our data was that longer and more PM-focused articles were, in general, more balanced (that is, mentioned both benefits and concerns). For example, articles focusing specifically on PM were more likely to highlight concerns (39%), compared with articles mentioning PM as part of a broader news story (27%). Broader news stories, therefore, including those pertaining to, for example, business/finance, government initiatives, or technological developments, generally describe PM in a more optimistic or promotional tone than do articles that focus on PM specifically. This serves as an example of “implicit hype,” a phenomenon that has been noted with other emerging health technologies,⁴⁰ whereby the news media simply takes benefits for granted. Audiences encountering the topic of PM through news stories that are more general in scope are even more likely to be exposed to a positive portrayal of PM than audiences reading specifically about PM. This trend is also evident in analyzing article length. As shown in **Figure 4**, the longer an article is, the more likely it is to highlight concerns surrounding PM. As such, readers more on the periphery of PM-related news stories, encountering only shorter articles that describe PM using fewer words and less detail, are probably exposed to more favorable or optimistic representations of PM than those reading longer, more detailed analyses. Again, this plays into the hyping associated with PM,²⁶ which, as a result, has the potential to create not only unrealistic expectations¹⁴ but could lead to an erosion of trust and/or enthusiasm surrounding science more generally.²⁷

The primary limitation of our study was in our choice of search terms. There is an abundance of terms associated with personalized or precision medicine. While terms such as “individualized medicine,” “genetic medicine,” and “personalized genomics” appeared in Google news searches with substantially less frequency than “personalized medicine” or “precision medicine,” it is possible that including a wider range of search terms in our query would have resulted in a data set of articles highlighting different PM-related benefits, topics, and concerns. Further research could take this approach, exploring whether there are similar or dissimilar discourses between various PM-related terms.

Ultimately, this study captured the popularization and framing of what is now commonly known and referred to as personalized or precision medicine. It shows that in popular discourse, PM has been framed in a consistent manner: as a positive health-care trend associated with few concerns. Given the power of the media to shape public discourse, including patient expectations, this could have implications for the implementation of PM technologies. To date, the concerns associated with PM have received little attention. This is unfortunate. The public discourse would benefit from a more balanced and nuanced framing.

SUPPLEMENTARY MATERIAL

Supplementary material is linked to the online version of the paper at <http://www.nature.com/gim>

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DISCLOSURE

The authors declare no conflict of interest.

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