Medical Communications and Writing for Patients

Dear All

I'm writing this to you from lockdown. Some of us will be out of lockdown by the time you read this, and perhaps others of us will be back in! Either way, I pray that you and your families are all safe and healthy.

In this issue of *Medical Writing*, I'm delighted to present a piece from Dr Joana Fernandes, who discusses her early career as a science/medical news writer, writing articles for a non-scientific audience. Joana explains the importance of writing for this audience; the

importance of making sure that the articles are scientifically sound, accurate, and easy to follow, as a way to bring science and medicine closer to the public.

Joana is a medical writer at Scinopsis, UK. She obtained her PhD in Cellular and Molecular Biology from the University of Coimbra, Portugal, in 2014. She has over 8 years of experience in scientific research and has been working as a science/medical writer since 2016.

I hope that you enjoy Joana's insights into life as a medical news writer – perhaps it might

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inspire you to become more involved in this expanding area of medical writing.

In the meantime, stay safe and sane in lockdown, and see you in the December issue! **Bestest**,

Lisa

Sense and sensibility: Lessons from science/medical news writing

Immediately after I left the bench to pursue a medical writing career, I started working remotely for a US-based digital health news service. Its purpose was to share new scientific and pharmaceutical developments with the people who need it the most: patients and caregivers. Shortly after I started, I began appreciating the responsibility associated with that job. These readers frequently go online to find out more information about disease, for themselves or a loved one, and thus it was crucial to guarantee that my writing was clear, accurate, and honest. In this article, I discuss a few things that I learned at that job and that may hopefully help others to write for non-scientific audiences.

Switching audiences from peers to non-scientific readers

As part of that company, I wrote more than 20 articles a week, most of which covered the latest developments in research and treatment in chronic disease, including neurodegenerative,



oncologic, respiratory, muscular, metabolic, inflammatory, and autoimmune diseases. My job required that I read multiple research studies and interpret data from clinical trials, and then combine journalistic skills with my scientific knowledge to report medical news in an engaging way. I also spoke to doctors and scientists standing at the forefront of important research and, perhaps more importantly, I interviewed patients who, stricken with certain diseases, provided a true account of how they adapted to their condition, their frustrations and accomplishments, their experience of what it is like to manage their lives in the face of life-changing obstacles. For this reason, patient stories were particularly rewarding to write and publish, as they served as examples of persistence, strong will and a great desire to live, and certainly served as inspiration to everyone.

I look back at those times as a science/ medical news writer fondly, it was a marvellous experience. I was mentored by experienced journalists who taught me how to prepare interviews and write articles that would keep readers engaged until the last paragraph. It was incredibly rewarding to play the part of a "science/medical news Hermes" who delivered valuable messages and first-hand news about what was being done to advance treatment and patient management. However, as old Peter Parker's uncle once said, with great power comes great responsibility, and writing about disease and treatment for an audience that will eagerly consume such news is a big deal. Sometimes, we see journalists using flashy titles ("the cure for cancer is near") or even utterly false news ("experts warn against vaccine that leads to autism") to get their readers' attention, to the detriment of the good old deontological code for journalism. This should never be the case for a medical journalist or science writer - quite the opposite. It is important to keep in mind that patients tend to go online to find more information about their disease, so it is our duty as both writers and scientists to provide them with trustworthy, accurate information.

But this was exactly where the trickiest part of my old job lay. How does a science/medical news writer prepare a piece that is both accurate, easy to follow, and interesting to read until the end? As scientists, we are used to discussing scientific facts with our peers; our background knowledge makes it tempting to resort to scientific jargon and specific language to guarantee the accuracy of what we are writing, not to mention the constant effort to avoid generalisations and the omission of important details which otherwise might result in misleading narratives. It is especially tricky when we need to report specific terms that are hard to put in simpler terms or even uncertainties or nuances that arise from results analysis and the supporting statistics of a given study. However, the use of specialised language is discouraged when you are writing for a non-scientific audience, as these readers will likely find it difficult to understand and even boring.

Fortunately, there are several tips that we can try to follow to make our job a bit easier when it comes to adapting our language to a nonscientific audience, such as those presented and discussed by Joselita Salita in her article "Writing for lay audiences: a challenge for scientists".¹ To quote Salita, "lay communication is not just taking out jargon and replacing it with more understandable text but rather a complete 'repackaging' of the scientific message". Indeed, the zest to being a science/medical news writer is to write pieces that are simultaneously informative and compelling to read. Replacing words is not enough to achieve this, the enthusiasm of reporting must still be there.

Sorting the wheat from the chaff: Not all details matter

Back in those days, most of my weekly work was reading freshly published scientific research

papers and write a small article with the readers' perspective in mind. After all, patients and caregivers are not interested in knowing the very same details that will excite a scientist. But this was not so obvious to a scientist freshly out of the lab. Indeed, a scientific article and a news article could not be more distinct, and this is reflected in the order in which the information is presented. While scientific articles follow the traditional pyramid structure that starts with background information, followed by discussion and conclusion, a science/medical news article follows the opposite order: it starts with the conclusion (the "lede", as journalists call it, the main message), which is then followed by background information (context) and some details from the discussion, which can be interesting to the reader (depending on the story). The conclusion/lede is what captures the readers' attention at the very first paragraph: it tells the readers what is new, why the article was written, what important message we wanted to share. We start with the why: why is this study important? Because something relevant was found and may even help scientists develop new therapeutic strategies, for example.

It is important to note that the title of the scientific paper will not necessarily make a good lede. Consider, for example, the scientific study titled "Loss of Frataxin Activates the Iron/ Sphingolipid/ PDK1/Mef2 Pathway in Mammals". A lede that uses these words to introduce what our news article is about will certainly scare the readers away: it is too specific and too scientific. It is far more likely that readers will want to read our article if we start by saying that "a new study in mice identified the mechanism through which loss of frataxin, the protein missing in Friedreich's ataxia, leads to the death of neurons", and that this finding could be helpful in developing potential future treatments for this disease.

As we work our way from conclusion to background information, we leave out several details that may not be relevant for a non-scientific reader. In contrast to scientists, these readers will not care about whether a given study was published in *Nature* or *Science* or whether the authors used the latest state-of-theart microscope technique or the correct statistical tests. While our experience as scientists makes it tempting to explain everything in

detail and leave little room for misleading conclusions, when writing for a non-scientific audience we need to select what is truly important for the reader: Are these results trustworthy? Does this add anything to the research done in this disease? Will these results lead to the development of a new treatment, and if so, when? Can these results potentially help patients in any way? In this context, sorting the wheat from the chaff consists of addressing these specific questions while preparing our articles and leaving out anything superfluous that may be distracting or confusing.

Source material with a pinch of salt

As Jo Whelan once said, true journalism involves doing background research into the context surrounding the finding being reported, seeking comments from independent experts, and highlighting the negative as well as the positive aspects.²

Another important aspect about writing for a non-scientific audience is to analyse the source materials in a critical manner and avoid taking them at face value. When I was a science/medical news writer, I received all sorts of material to base my articles on, often newly published research studies. Naturally, these studies presented different levels of quality.

Well-designed studies were easy to follow from a scientific perspective, so my job was to ensure that the message was delivered with clarity and accuracy, without exaggerating or even forcing the impact of the results just because they



were scientifically sound or were published in a high-ranked journal. For example, a significant drug-induced reduction in tumour burden in mice may be good news, but we cannot extrapolate that to humans and say that a new cancer treatment has been found. As we know, there is a substantial amount of work to be done before we can say something like that, and writers need to make that very clear.

I also came across research studies whose quality or impact were a lot less strong and that I would have preferred to leave out, but the company I worked for had a daily need to cover any new material, so sometimes I had to write about these studies as well. These studies were sometimes published in non-peer-reviewed journals, or had no control group, or were case reports about a single patient. A well-trained scientist will read these studies with a pinch of salt (or several) and know that their design and results make it hard to draw strong scientific conclusions, let alone medical conclusions. Again, this must be part of the message in news articles. It is crucial to make it very clear to the reader that those results were obtained in studies with certain limitations and that results must be interpreted with caution. I believe it is the writers' job to highlight the context in which results were obtained and, more importantly, what is their true contribution and value to the research done in a given disease.

When reporting on new scientific/medical advances for a non-scientific audience, writers

should guarantee that certain tips are followed to ensure that the final piece is sound and clear. In her article *Medical journalism – a career move?*,³ Jo Whelan recommended several useful guiding tips:

- We should never take press releases, corporate publications, or newspaper/magazine articles at face value – we must always use our scientific skills to critically analyse the source material. If we are writing about a topic outside of our main expertise, it may be helpful to look up other reading sources as well or speak to an expert;
- It is crucial to get the background on our story (background reading will definitely help understand the impact/importance of the material we have to cover for our article);
- Whenever possible, we should interview someone (for example, the authors of the study) for our article, ask searching questions or get an independent expert to comment;
- We must be aware of people's motivations, agendas, conflicting interests, and potential prejudices;
- We should never report statements as facts and should always use qualifying phrases like "according to Kuritech", or "says Dr X" (I also used "the authors wrote in their study" when quoting directly from a research paper).

Conclusion

Writing for non-scientific audiences is a very interesting job that teaches writers to adapt their

language and choose carefully what details are relevant to share. Patients and caregivers increasingly rely on digital material to find out more about disease, thus writers must consider the impact their writing has. It is not enough to write a compelling read, they must also be accurate and clear about the science they are reporting and use their skills to help readers understand what is true and relevant, and what is not.

Disclaimer

The views expressed in the submitted article are the author's own and not an official position of Scinopsis Ltd or EMWA.

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