In the Words of My Mother: “I’m fighting hard for me but mostly for you”

Daniela B. Friedman

Accepted: 24 April 2022 / Published online: 30 April 2022
© The Author(s) under exclusive licence to American Association for Cancer Education 2022

Abstract
I have always been interested in health information—what it is, where people get it, how they interpret it, talk about it with others, and use it—if at all. It has been overwhelming to stay abreast of the evolving science during the COVID-19 global pandemic when it is often quite complicated in nature and when we are exposed to individuals’ and group’s spreading of misinformation and disinformation. During this pandemic, I have been reflecting a lot on my childhood during which my mother was suffering with cancer and frustrated and confused about the information she received regarding her diagnosis and treatment plan. This is not the kind of journal article I am used to writing and these are probably the most difficult few pages I have ever drafted. My observations during COVID-19 led me to want to share the aspects of my mother’s situation that motivate me and guide my work in cancer education with a focus on health literacy and communication. This piece describes my mother’s experiences with illness and medical information in her own words. It is brief and personal and reminds me clearly why I chose this field and why it is important now more than ever for cancer educators to focus our efforts on communication.

Keywords Cancer communication · Health literacy · Patient experience · Narrative

In addition to a pandemic, we have experienced “an overabundance of information, both online and offline … deliberate attempts to disseminate wrong information to undermine the public health response”—an infodemic [1]. Ninety-five percent of Americans believe that the spread of misinformation is problematic [2]. “Misinformation costs lives” [1].

Just a few months after COVID-19 became rampant, opinion pieces were published with titles like, “Covid-19: health literacy is an underestimated problem” [3] and “Health illiteracy is nothing new in America. But the pandemic magnifies how troubling it is” [4]. Years ago Meade and colleagues affirmed that health and cancer information should be written at a grade five to six level [5]. Currently, we have a double-edged sword—misinformation and complicated information. It seems to have taken a global pandemic to show us that our communication strategies may not be working.

I wanted to be a doctor. I wanted to help my family sort through complicated medical information. My mother had a master’s degree and several continuing education certificates, yet health information was confusing for her.

Between September 19, 1998 and December 4, 1999 during her final battle with metastasized breast cancer, my mother wrote a journal for me to read after she passed. She didn’t write in it every day, but she shared what she was doing, how she was feeling, and her hopes and dreams for me. She passed away on February 28, 2000, and I read the journal the very next day. I still read through it every February and a couple of other times each year. It makes me sad, scared, hopeful, and proud—all at the same time. You know that feeling when you try to talk but you can’t get the words out? That’s how I feel when I have the journal in my hands. I wish I could have done more to help her. I hope she knew that.

“I am nervous, afraid to suffer.” – Doreen Friedman (Journal entry November 16, 1998)

I was 21 when my mother died. She was first diagnosed with cancer when I was nine. I did not understand anything about cancer at nine, but over the years I knew when she was having surgeries because I was sent to sleep at my friend’s
house for a few days. When she and my father would talk about her health it sounded so complicated. They had many questions about what they heard from the specialists and about next steps. There was so much wait time between appointments and the surgery follow-ups. I remember being in the room when my mother called the Premier of Ontario and left a message with someone in his office conveying her frustration and despair. We were so fortunate to have universal health care in Canada. But the wait times during a medical crisis are frustrating for anyone anywhere.

“*I’m mostly down these days – it’s my illness and I feel lonely and confused. But I keep on trying.*” – Doreen Friedman (October 26, 1999)

I didn’t end up going the MD route. I became interested in health communication research, with a focus on aging and cancer information, and continued it throughout my BSc, MSc, and PhD programs. I studied (and still do with clinical and community collaborators) the patient-provider encounter, the difficulty level and cultural insensitivity of cancer information in various media formats with the goal of improving it, and communities’ perceptions about their access to and understanding of health and cancer information resources. I partner closely with communities to share evidence-based, plain-language, and culturally sensitive health messaging and education, social marketing initiatives, and clinic- and community-based interventions.

In 2004, the Institute of Medicine Committee on Health Literacy provided recommendations for improving health literacy of Americans [6]. In 2013, Rudd published a health literacy–related national call to action and developed the first population-based health literacy measure [7]. It was clear from national surveys that nearly 40% of adults have limited health literacy. The American Medical Association also developed a health literacy educational toolkit that involved a video with a patient who did not understand the consent forms she signed and did not realize she had a hysterectomy until after the procedure was over. For decades now, ours and others’ research demonstrates that consumer- and patient-focused information, including cancer information, is written at a high school or college level and incomprehensible to average readers [8, 9]. Nutbeam’s seminal work conceptualized health literacy as a “personal asset” establishing the critical role that communication plays in enhancing people’s capacity to manage their health [10]. Kreuter and colleagues advised us so accurately that “one size does not fit all” and we need to tailor accordingly for any and all health-focused messaging [11].

Plain-language communication and health literacy are national priorities. The Plain Language Act of 2010 requires federal agencies to use clear communication that the public can access, understand, and use [12]. Health literacy specifically is a focus area in recent and current iterations of Healthy People goals and objectives [13]. We consider it a social determinant of health that interacts with factors such as income, education, race, ethnicity, and discrimination. Considering social determinants in cancer education is essential as we continue to witness extreme health inequities.

“*I want to live to see it all! I’m trying to remain optimistic!*” – Doreen Friedman (September 28, 2018)

I’ve been questioning myself and my work. Has all of our work in cancer communication and health literacy been a waste of time? Why do the current COVID-19 pandemic headlines feel like Groundhog Day? How do we get the clear messages out when the anti-science and social media rhetoric seem deafening? I argue that all of the work up to this point has been needed 100%. The experience of the current pandemic reinforces an urgent call to action for all of us—regardless of discipline—to revisit how we engage with communities and patients in research, education, and practice.

So, what have I learned from my mother’s experiences that relate to the current context and our collective interest and dedication to cancer education? Knowledge really is power despite it being a cliché. Having information that is delivered with empathy by trusted sources in a timely manner is critical. If we do not have the information at hand or we are still gathering the evidence, let’s always be willing to say, “I don’t know but I am going to find out for you.”

In the clinical setting, using plain language and teach-back strategies takes time and effort. There is no reason to work alone. Similar partnerships apply and materials already exist. The Agency for Healthcare Research and Quality has published a Health Literacy Universal Precautions Toolkit [14]. As cancer educators, let’s strive to be part of health literacy–related national call to action and developed the first population-based health literacy measure [7]. It was clear from national surveys that nearly 40% of adults have limited health literacy. The American Medical Association also developed a health literacy educational toolkit that involved a video with a patient who did not understand the consent forms she signed and did not realize she had a hysterectomy until after the procedure was over. For decades now, ours and others’ research demonstrates that consumer- and patient-focused information, including cancer information, is written at a high school or college level and incomprehensible to average readers [8, 9]. Nutbeam’s seminal work conceptualized health literacy as a “personal asset” establishing the critical role that communication plays in enhancing people’s capacity to manage their health [10]. Kreuter and colleagues advised us so accurately that “one size does not fit all” and we need to tailor accordingly for any and all health-focused messaging [11].

Plain-language communication and health literacy are national priorities. The Plain Language Act of 2010 requires federal agencies to use clear communication that the public can access, understand, and use [12]. Health literacy specifically is a focus area in recent and current iterations of Healthy People goals and objectives [13]. We consider it a social determinant of health that interacts with factors such as income, education, race, ethnicity, and discrimination. Considering social determinants in cancer education is essential as we continue to witness extreme health inequities.

“I want to live to see it all! I’m trying to remain optimistic!” – Doreen Friedman (September 28, 2018)

I’ve been questioning myself and my work. Has all of our work in cancer communication and health literacy been a waste of time? Why do the current COVID-19 pandemic headlines feel like Groundhog Day? How do we get the clear messages out when the anti-science and social media rhetoric seem deafening? I argue that all of the work up to this point has been needed 100%. The experience of the current pandemic reinforces an urgent call to action for all of us—regardless of discipline—to revisit how we engage with communities and patients in research, education, and practice.

So, what have I learned from my mother’s experiences that relate to the current context and our collective interest and dedication to cancer education? Knowledge really is power despite it being a cliché. Having information that is delivered with empathy by trusted sources in a timely manner is critical. If we do not have the information at hand or we are still gathering the evidence, let’s always be willing to say, “I don’t know but I am going to find out for you.”

In the clinical setting, using plain language and teach-back strategies takes time and effort. There is no reason to work alone. Similar partnerships apply and materials already exist. The Agency for Healthcare Research and Quality has published a Health Literacy Universal Precautions Toolkit [14]. As cancer educators, let’s strive to be part of health literacy–related national call to action and developed the first population-based health literacy measure [7]. It was clear from national surveys that nearly 40% of adults have limited health literacy. The American Medical Association also developed a health literacy educational toolkit that involved a video with a patient who did not understand the consent forms she signed and did not realize she had a hysterectomy until after the procedure was over. For decades now, ours and others’ research demonstrates that consumer- and patient-focused information, including cancer information, is written at a high school or college level and incomprehensible to average readers [8, 9]. Nutbeam’s seminal work conceptualized health literacy as a “personal asset” establishing the critical role that communication plays in enhancing people’s capacity to manage their health [10]. Kreuter and colleagues advised us so accurately that “one size does not fit all” and we need to tailor accordingly for any and all health-focused messaging [11].

Plain-language communication and health literacy are national priorities. The Plain Language Act of 2010 requires federal agencies to use clear communication that the public can access, understand, and use [12]. Health literacy specifically is a focus area in recent and current iterations of Healthy People goals and objectives [13]. We consider it a social determinant of health that interacts with factors such as income, education, race, ethnicity, and discrimination. Considering social determinants in cancer education is essential as we continue to witness extreme health inequities.

“I want to live to see it all! I’m trying to remain optimistic!” – Doreen Friedman (September 28, 2018)

I’ve been questioning myself and my work. Has all of our work in cancer communication and health literacy been a waste of time? Why do the current COVID-19 pandemic headlines feel like Groundhog Day? How do we get the clear messages out when the anti-science and social media rhetoric seem deafening? I argue that all of the work up to this point has been needed 100%. The experience of the current pandemic reinforces an urgent call to action for all of us—regardless of discipline—to revisit how we engage with communities and patients in research, education, and practice.

So, what have I learned from my mother’s experiences that relate to the current context and our collective interest and dedication to cancer education? Knowledge really is power despite it being a cliché. Having information that is delivered with empathy by trusted sources in a timely manner is critical. If we do not have the information at hand or we are still gathering the evidence, let’s always be willing to say, “I don’t know but I am going to find out for you.”

In the clinical setting, using plain language and teach-back strategies takes time and effort. There is no reason to work alone. Similar partnerships apply and materials already exist. The Agency for Healthcare Research and Quality has published a Health Literacy Universal Precautions Toolkit [14]. As cancer educators, let’s strive to be part of health literacy–related national call to action and developed the first population-based health literacy measure [7]. It was clear from national surveys that nearly 40% of adults have limited health literacy. The American Medical Association also developed a health literacy educational toolkit that involved a video with a patient who did not understand the consent forms she signed and did not realize she had a hysterectomy until after the procedure was over. For decades now, ours and others’ research demonstrates that consumer- and patient-focused information, including cancer information, is written at a high school or college level and incomprehensible to average readers [8, 9]. Nutbeam’s seminal work conceptualized health literacy as a “personal asset” establishing the critical role that communication plays in enhancing people’s capacity to manage their health [10]. Kreuter and colleagues advised us so accurately that “one size does not fit all” and we need to tailor accordingly for any and all health-focused messaging [11].

Plain-language communication and health literacy are national priorities. The Plain Language Act of 2010 requires federal agencies to use clear communication that the public can access, understand, and use [12]. Health literacy specifically is a focus area in recent and current iterations of Healthy People goals and objectives [13]. We consider it a social determinant of health that interacts with factors such as income, education, race, ethnicity, and discrimination. Considering social determinants in cancer education is essential as we continue to witness extreme health inequities.
science and web experts as main partners is critical to ensure the “so what’s next” actually happens once we have in-depth insights into people’s comprehension and information needs. The information must get out to those who desperately need it. Engaging interdisciplinary teams is critical as this work cannot be done any other way.

***

I will continue to read my mother’s journal a few times each year. I anticipate it will continue to have the same effect on me each time even after all these years. Her words are haunting, emotional, and also a blessing. Journaling among cancer patients demonstrates improved quality of life and treatment management and can help cancer educators and practitioners understand the patient and improve the patient-caregiver encounter [16, 17]. Exploring the effect of patient journaling on the caregiver or family member may also be important. My mother’s journal has deeply influenced my life and my career.

Please join me in continuing to make clear communication and dispelling of misinformation and disinformation a priority. I owe it to my mother to ensure that these journal publications are not our only final products.

“I haven’t written in a while – my pen ran out of ink – not a very good excuse. Nothing out of the ordinary is happening but being alive one more day is extraordinary.” – Doreen Friedman, educator, mother, wife, & inspiring role model (October 5, 1998).

Acknowledgements Quotations included in this paper are taken verbatim from a journal written by Doreen Friedman (1948–2000) for her daughter Daniela.

Declarations

Conflict of interest The author declares no competing interests.

References

1. World Health Organization. Managing the COVID-19 infodemic: promoting healthy behaviours and mitigating the harm from misinformation and disinformation (Joint statement by WHO, UN, UNICEF, UNDP, UNESCO, UNAIDS, ITU, UN Global Pulse, and IFRC). http://www.who.int/news/item/23-09-2020-managing-the-covid-19-infodemic-promoting-health-behaviours-and-mitigating-the-harm-from-misinformation-and-disinformation. Accessed October 10, 2021.

2. Pearson Institute for the Study and Resolution of Global Conflicts at the University of Chicago and The Associated Press-NORC Center for Public Affairs Research, The American public views the spread of misinformation as a major problem. https://apnorc.org/wp-content/uploads/2021/10/misinformation_Formatted_v2-002.pdf. Accessed October 21, 2021.

3. Paakkari L, Okan O (2020) COVID-19: health literacy is an underestimated problem. Lancet Public Health 5:e249–e250

4. Glicksman E. Health illiteracy is nothing new in America. But the pandemic magnifies how troubling it is. The Washington Post. https://www.washingtonpost.com/health/health-illiteracy-is-nothing-new-in-america-but-the-pandemic-magnifies-how-troubling-it-is/2020/07/31/091c8a18-d053-11ea-9038-a089b63ac21_story.html2020, August 2. Accessed October 21, 2021.

5. Meade CD, McKinney WP, Barnas GP (1994) Educating patients with limited literacy skills: the effectiveness of printed and videotaped materials about colon cancer. Am J Public Health 84:119–121

6. Institute of Medicine (US) Committee on Health Literacy; Nielsen-Bohlman L; Panzer AM; Kindig DA; editors. Health literacy: a prescription to end confusion. Washington, DC: National Academies Press, 2004.

7. Rudd RE (2013) Needed action in health literacy. J Health Psychol 18:1004–1010

8. Choi SK, Seel JS, Yelton B et al (2018) Prostate cancer information available in health-care provider offices: an analysis of content, readability, and cultural sensitivity. Am J Mens Health 12:1160–1167

9. Friedman DB, Kim SH, Tanner A et al (2014) How are we communicating about clinical trials?: an assessment of the content and readability of recruitment resources. Contemp Clin Trials 38:275–283

10. Nutbeam D (2008) The evolving concept of health literacy. Soc Sci Med 67:2072–2078

11. Kreuter MW, Streecher VJ, Glassman B (1999) One size does not fit all: the case for tailoring print materials. Ann Behav Med 21:276–283

12. Public Law 111 - 274 - Plain Writing Act of 2010, https://www.govinfo.gov/app/details/PLAW-111publ274 (2010, October 13). Accessed October 21, 2021.

13. Health Literacy in Healthy People 2030. https://health.gov/our-work/healthy-people/healthy-people-2030/health-literacy-healthy-people-2030. Accessed June 1, 2021.

14. Agency for Healthcare Research and Quality. Health Literacy Universal Precautions Toolkit, 2nd Edition. https://www.ahrq.gov/heath-literacy/improve/precautions/index.html. Accessed October 10, 2021.

15. The U.S. Surgeon General’s Advisory on Building a Healthy Information Environment. Confronting Health Misinformation. https://www.hhs.gov/sites/default/files/surgeon-general-misinformation-advisory.pdf. Accessed October 10, 2021.

16. Ragan SL, Kanter E (2017) Learning the patient’s story. Semin Oncol Nurs 33(5):467–474

17. Speece NJ, Menglin X, Tinoco G, Liebner DA, Chen JL (2022) Randomized prospective trial exploring the impact of structured journaling in patients with sarcoma on the management of treatment-related adverse events. JCO Oncol Pract 18(2):e250–e260

Publisher’s Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.