

Chapter 12

Using Narratives to Improve Health Literacy – An Ethical and Public Health Perspective



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Abstract Most people have little interaction with the health system and tend to be unfamiliar with the prevention, diagnosis, and treatment of even common health conditions. In case of illness, the medical information delivered by health professionals can be overwhelming because of its complexity, unfamiliar terminology, and use of statistical data. Understanding such information requires specific “health literacy” skills. Health literacy empowers individuals to exercise

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their autonomy and self-determination regarding health-related matters. This chapter explores how health literacy and ethical questions are interrelated as illustrated using actual patient narratives of a woman's pregnancy experiences. The narratives were collected as part of the Swiss DIPEX (Database of individual patients' experiences) database. We demonstrate that narratives of health experiences can be used to enhance health literacy. Firstly, narratives can convey complex information in an easily understandable manner. Secondly, they allow policymakers to understand, the informational needs of users of the health care system and the communication gaps they perceive can help improve the health care system and qualitative evaluate and improve medical communication efforts. The chapter ends by raising a number of ethical questions at the individual and health system level related to the use of narratives for improving health literacy for discussion.

Keywords Health Literacy · Patient experiences · Pregnancy · Database of Individual Patients' Experiences (DIPEX) · Vulnerability · Narratives

Public Health Ethics Issue

Many of us have little interaction with the health sector and are often unfamiliar with the prevention, diagnosis and treatment of even common health conditions. When we or our close contacts fall ill, the medical information we receive can be confusing and overwhelming because of its complexity, unfamiliar terminology, and use of statistical data we do not usually encounter in our everyday lives. Understanding such information requires specific skills, which health educators' term "health literacy." Health literacy refers to "people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain and improve quality of life during the life course" (Sørensen et al. 2012, 3). According to the World Health Organization (WHO),

health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. [...] By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment. [...] Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy (WHO 1998, 10).

The efficacy of health literacy depends on peoples' understanding of the factors affecting health and their ability to control these factors by placing personal health, family health, and community health into context (WHO 2013, 10–40).

The consequences of limited health literacy include the improper use of medications; improper, under use, or non-use of health services; suboptimal management of chronic disease, and an inadequate response in emergency situations. These

consequences often lead to increasing morbidity and mortality rates, especially among vulnerable groups of people (McDonald and Shenkman 2018, 2–4, Vandenbosch et al. 2016, 1036–38). Patients with limited health literacy also often suffer from a lack of autonomy and low self-esteem regarding health-related decisions and are burdened by higher health-related costs (Zarcadoolas et al. 2006, 2). Additionally, discrimination and stigmatization of people who have a lower level of health literacy can often discourage people from improving their health.

Low health literacy tends to disproportionately impact people with poor functional literacy, a marker of socioeconomic disadvantage. This makes navigating the healthcare system even more difficult, thus further penalizing an already vulnerable population (Watson 2019, 193; Volk et al. 2008, 2–8). Moreover, poor health literacy negatively affects the quality of care vulnerable groups receive, thus exacerbating social inequalities (Sørensen et al. 2013, 72–82). Lower health literacy not only adversely affects individuals but can also negatively impact the entire health system. In Canada, for example, low health literacy accounts for 3–5% of health expenditure (WHO 2013, 8). It raises costs, for example, by increasing emergency room visits and hospitalizations, thus unnecessarily burdening the healthcare system.

Conversely, health literacy empowers individuals to exercise their autonomy and self-determination regarding health matters. Such empowerment contributes to the social goal of maximizing population health by helping to reduce health inequities. This entails increasing everyone's well-being, especially the health of disadvantaged populations (Schröder-Bäck 2007, 108–110; Schröder-Bäck et al. 2014, 3–4). Such efforts further align with the principle of social justice that demands a fair distribution of resources that does not unduly burden or benefit certain groups over others. Social justice efforts go hand in hand with empowering people with a lower levels of health literacy to participate in health promotion and maintenance programs. By contrast, insufficient health literacy thwarts not only society's obligation to maximize health but also efforts to achieve social justice and health equity.

Background Information

Problems with health literacy are not confined to developing countries. It is estimated that almost half of the adult population in America may have difficulties acting on health information (IOM 2004, 65, Sørensen et al. 2012, 2). The European Health Literacy Survey showed a worrisome 47% of respondents with either inadequate or problematic health literacy. Limited health literacy is therefore not just a problem confined to conventionally vulnerable populations but affects a significant majority of the European population (Sørensen et al. 2015, 1057).

In the early 1970's the concept of health literacy was first framed as a matter of social policy (Simonds 1974, 1–5). The current conceptional understanding of health literacy from the WHO Ottawa Charter has changed to, “the process of enabling people to increase control over, and to improve, their health” (WHO 1986). In order to reach a state of complete physical, mental and social well-being, an

individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment (WHO 1986). This recognizes health as a resource for daily living, and points to the need for political commitment to address health and equity (WHO 1986).

Health literacy continues to be identified by world leaders and global health experts as a key priority to promote health and eradicate poverty in order to achieve the ‘Sustainable Development Goals’ (Shanghai Declaration on Health Promotion, WHO 2016b, 2). Health literacy also remains the current focus of the most recent “Global Action Plan on Physical Activity, 2018–2030”, which aims to utilize health literacy to achieve a healthier world (WHO 2018a, 7).

One-way people try to understand medical information is to look to the experiences of others (Ziebland and Herxheimer 2008, 434; WHO 2016a, 33). Today’s digitally networked societies have great potential to strengthen health literacy. People make their experience more accessible by routinely sharing them and participating in discussions on digital platforms (Ziebland and Herxheimer 2008, 434; Hurwitz et al. 2008, 122).

The potential harm from accessing unverified and unregulated ‘health stories’ via digital formats can be overcome by adapting the wealth of science-based qualitative research into a format that is accessible and understandable to the lay person (Schlesinger et al. 2015, 678). An example of this is the Database of Individual Patient Experiences (DIPEx), which serves as an open access tool for health communication by systematically collecting narratives about health experiences and making them accessible via an online platform. The platform presents a collection of personal stories about health and illness experiences collected through rigorous qualitative inquiry methods, and presented in written, video and/or audio formats (depending on the consent of those sharing their stories). Short segments of these stories are arranged into relevant categories to contextualize information for other patients in similar situations. The site is run by a research team, which ensures the information is reliable. (Law et al. 2018; Ziebland and Wyke 2012, 220; Ziebland and Herxheimer 2008, 434). As an open-access platform, it is accessible to the public without the need for personal accounts or subscriptions, and can be used both on personal electronic devices or on public computers (for example those available at national libraries). The platform can also be used by healthcare staff during clinical interaction, which is also useful for those with restricted access to internet services. The sharing of these stories complements traditional forms of epidemiologic evidence and facilitates health communication, which is the cornerstone of effective public health strategies (Bernhardt 2004, 2051–52).

Including qualitative research methods based on narratives into health service research allows for a critical understanding of lived experiences, e.g. regarding information gaps and specific needs in different populations. Such methods may verify measurable aspects of quality management systems or highlight discrepancies between presumed practice and actual experiences. At the level of the individual, narratives can be shared in formats that overcome barriers of health literacy. Additionally, relatability to narratives has been shown to transcend functional literacy levels and culture (WHO 2018b, 105; WHO 2015, 13). A narrative that is

relatable is one that an individual is able to identify with. A relatable narrative provides a means of contextualizing health-related information to an individual's personal situation, thus allowing a tailored and critical reflection on health-related interventions.

Recognizing the importance of narrative methods, DIPEX has grown into a global movement that aims to reliably document narratives of patient experiences using rigorous qualitative research methods to collect health experiences. Contributors to the database are sampled across a multitude of factors to obtain what is known in qualitative research as a maximum variation sample (Glaser and Strauss 1967, 61). The intent behind this sampling is to represent as broad and comprehensive a range of experiences as possible. Broad sampling from a variety of perspectives helps contextualize information for various health-related uses that can then complement quantitative evidence-based information for public health issues (Entwistle et al. 2011, 297). The ultimate goal of DIPEX is to listen to the voices of participants and to use this information to create meaningful improvements in healthcare.

At the same time, it is important to recognize that there is a certain tension between the ambition of providing high-quality, scientifically valid content and the intention to capture individuals' voices and to allow for a free expression of what matters to people. By setting standards on how participants are chosen, on suitable content or on how interviews are staged, DIPEX establishes a normative frame. The inherent value judgements on what is fitting, proper and important, even though mitigated by qualitative research standards such as negotiating codes and themes in a team rather than having an individual researcher determine them, in avoidably affect the presentation of patients' voices. This may lead to a perceived standard of evidence that excludes voices and perspectives that do not seem to fit – possibly even by self-censorship of interview partners. This tension can be mitigated by considering DIPEX not as an exclusive source but as part of a larger ecosystem that comprises different ways of how patients share their stories, including, for example, self-reports on social media. These freestyle self-reports can inspire additional DIPEX research. Another strategy for dealing with the issue consists of understanding DIPEX itself as a participatory research endeavor by inviting citizen feedback on DIPEX interview guides, processes, and results. This way, the bottom-up component of building health literacy can be maintained without forgoing scientific standards.

Approach to the Narrative

The following narrative about pregnancy experiences is based on an entry in the Swiss DIPEX database. It illustrates how health experiences can promote health literacy at two levels. Firstly, shared narratives can be a way of conveying information that is hard to communicate in a more abstract form (e.g. about the lived experience of a health condition). Secondly, at the level of policymaking, understanding the information needs of users of the health care system and the communication

gaps they perceive can help improve the health care system, which will in turn positively affect health literacy.

The narrative describes Kate, a 28-year-old Belgian woman who lived with her partner in Bern, Switzerland. Kate had been living in Switzerland for 2 years before she conceived. She works for a biotechnology firm, while her partner is a laboratory technician at a hospital. Kate sees herself as career-oriented but has also always wanted a child. Her pregnancy, though much-desired, coincided with a new career opportunity, so she organized her prenatal check-ups to minimize job disruption. Unfortunately, her pregnancy was not an easy one. She shared the following story with us.

Narrative

I found out I was pregnant maybe 4 weeks into my pregnancy. I am new to Switzerland, having worked very hard less than a year ago to get a job here. My gynecologist was someone I was seeing for routine gynecological care before I was pregnant, but he was not at all the person I would have chosen if I had a range of options. I chose him for convenience; he was close enough so that I could see him before work, or in between/during lunch, without disruption. He would usually ask me how I was doing, and let me speak a little, which made sense because then he would know what was on my mind, although he never really commented on what I relayed. He would just say, "Okay, let's check on the embryo." I noticed that he would always call it an embryo, not a baby, and I thought that was smart just in case someone was considering an abortion. I guess that's training, I guess doctors are trained to communicate that way.

The checkups were very standardized. I noticed him ticking things off in his mind, checking this, checking that, and in the end, he would say, "Everything's okay, get dressed." There was not much else. If I had my 'dream' gynecologist, I might have expected a little more empathy and emotional reaction, but then again, he was the one I had chosen to manage my career ambitions during my pregnancy.

I suspected I had prenatal depression and brought it up with him. I expected to be referred to a psychiatrist, but instead, he said, "Well, just chat with the midwives." I was confused, since I didn't have a midwife then, and wondered if one would indeed be able to help me with a psychological issue. I never managed to get the help I needed. If I had one piece of advice to doctors, it would be to think of the woman's emotional frame of mind. I really think a woman's emotional frame of mind is probably more important than her physical condition, and I don't think that that's recognized enough, or that doctors are equipped to handle that. It would be nice for the average doctor to broach that subject and let us know what might be going on emotionally or mentally during the pregnancy.

I had basic insurance, so I just did the prenatal tests that my doctor said were standard and normal. I did what the health insurance paid for, and I wasn't expecting a bad result. I went in that day not because it was a scheduled prenatal screen, but

because I was feeling so sick. My doctor was always very thorough, though, and did an ultrasound anyway. It was the only appointment I went to without my husband, and he has never missed one since. My doctor went, “Oh,” and then he went quiet, and he’s never quiet like this. He kept looking and I realized something was wrong. That’s when I found out what nuchal translucency means, and that her neck was too thick. I was told the risk of Down’s syndrome was one in 16.

We have a school for disabled children near our home, so we could see some children living with Down’s who were really happy. At the same time, I did think, if there was anything where the baby might not survive, or the quality of life would be really poor, it would have been an obvious decision for us to terminate the pregnancy, because I wouldn’t have wanted to just wait for it to happen. Honestly, to this day, I don’t know what we would have actually done. I wish I had the courage to accept a child with a disability, but I have so much fear. I worry about how a disabled child would survive in today’s world. I’m not thinking of how she would thrive, but how would she even survive? The world is bigger than our family, and there are so few opportunities for the disabled. I’ve read that having a mental disability makes people vulnerable to sexual assault, yet at the same time, they aren’t believed when they report a crime. Even something as basic as wheelchair access is so lacking for people with mobility impairments. Financially, it would be a huge burden. I know there is support, but I’ve heard so many stories about difficulties accessing whatever support there is. You really have to jump through hoops, find the right doctors who can diagnose the right things, and then hope it’s covered under existing plans. Even if we could afford the kind of care that is needed now, what would happen after we die? If I’m honest, I also worry about how it would reflect on me – whether people would judge me or fault me for the child I have, whether I would still be welcomed among my own friends, whether mothers would shun us from their playgroups, and whether I would still be valued at work.

I ended up in the hospital because I just couldn’t keep any water down. I expected vomiting as part of the pregnancy, I was told it was a sign of a healthy pregnancy. But I hadn’t realized how different my pregnancy was from other women. I wish I had known, and I would have sought help sooner. Once you throw up for more than 24 h and you don’t urinate, you end up being admitted and get medications and IV fluids. Later, my doctor said my vomiting wasn’t simply morning sickness, but a more serious condition called hyperemesis. When I got the poor prenatal test results, a part of me was thinking, “You know what, this means the nightmare is over.” It’s something I can only say in hindsight, I wouldn’t have dared tell anyone this then. As much as I wanted that baby, a part of me was like, “Oh, I might actually be able to be myself again.”

Someone recommended us a CVS (*chorionic villus sampling – a biopsy of the placenta*) to confirm the results. At his private practice, my doctor had given us a leaflet with all the details – what it covers, what it doesn’t. It was written at a level that I thought was almost too high for the average person. We were referred to the university hospital for the CVS. At the university hospital, I didn’t find that they were helpful in explaining the information, so that was a missing piece for me – to identify someone to follow up with afterwards. We had consent forms, but I don’t

think anyone sat down to talk us through what that really was about. Our doctor had said that they were looking for all the ‘top-line’ mutations, and if we wanted someone to go through all the results, he would send us to a geneticist. My understanding was that they would only refer us if any of the results were off, so we never got to see a genetic counselor. Not knowing beforehand what we were going through, for me was like the floor suddenly collapsing. I was young and didn’t expect to be so sick with hyperemesis. And I almost certainly didn’t expect this test result.

In hindsight, I wish there were someone besides the doctors who talks you through and explains what it is. I can only imagine someone without scientific training going through what I did, and how much more unsettling it might be for them. I tried explaining to my mother what it meant in terms of risks, and if you don’t necessarily have that scientific background and confidence dealing with numbers, it’s really hard. I found a Facebook group of moms in the same situation, and read through the different things they did, and then I found a research advisory group that also offered free advice to mothers who called in. In the end, I received the support I needed through this voluntary group. Something had stuck in my mind, “one in 16, one in 16,” – I was haunted by the number. The first thing one of the volunteers said was, “Flip it around, that’s a 95% chance that everything’s okay. I get that it’s very scary, but there’s only a 5% chance of something being wrong. So, if you were a betting woman, or this were an exam result, it would be very good. It says there’s a 95% chance, this is what it means. Do you want me to explain what your options are afterwards?” And I realized I didn’t know what the options were afterwards. I like planning, and I liked to have a mental plan. Now, whenever I have friends that go through it, when I see that, I always try and get people to turn it into a percentage, because a 95% chance, I think, is pretty good. It turned out that my child did not have Down’s syndrome after all.

In my 12th week, a blood screening test showed that my blood pressure was high (which I later learnt was part of pre-eclampsia), and I was put on daily aspirin. I had to check my blood pressure regularly and had to test my urine every 2 weeks. I was quite hesitant to take the aspirin – my father has high blood pressure and he manages by cutting down his salt and taking some blood pressure medicines. I thought aspirin was quite extreme, something that is given to people with heart attacks or strokes. I was worried about the effect it might have had on the baby. I only took it if I felt unwell, like if I had a headache. I was supposed to deliver at 36 weeks, but I ended up having an emergency Caesarean section much earlier when there were issues with the placenta. Given everything else that I was going through, I didn’t realize how serious my blood pressure issue could have been to my health and my baby, until after I delivered.

Even though the worst of the hyperemesis was over by about 17 weeks, I never really enjoyed the experience of being pregnant with my daughter. Just to be clear, I don’t think my doctor was unprofessional. I just don’t think that support resources were available. Although it would have been nice for my doctor to be more empathetic and to have more time for me, he did do his duty of making sure my pregnancy went as smoothly as possible and preventing any complications from happening to myself and my baby. He was medically competent, and objective. I do

think, however, that other resources need to be routinely available to pregnant women, like access to genetic counselling services so we can understand fully our prenatal tests and their results, or psychological support since pregnancy is such a transformative experience.

Ever since the pregnancy, I've been seeing a counsellor, to work through the things I experienced. I think it is good, because the experience can be quite traumatic. I don't think I ever switched off from that, in spite of the good outcome I eventually had with the birth of a healthy child. A part of me is jealous of some friends of mine who had fantastic pregnancies, even though I am happy for them.

Questions for Discussion

Had Kate had access to other women's experiences in a narrative format, it may have helped her in dealing with her own situation. Narratives about pre-eclampsia may even have had a preventive effect in alerting Kate to her condition. Health policymakers and communicators could benefit considerably from relations such as Kate's by better understanding current communication gaps that need to be addressed to improve health literacy and also patient satisfaction with the healthcare encounter (Britten 2011, 385; Jack 2006, 279).

Still, this narrative raises several ethical questions both at the individual and health system level relating to the use of narrative as a method for improving health literacy. The following questions are proposed to start a discussion about the topic of health narratives related to health literacy:

1. How does discrimination and stigmatization against people who have low health literacy impact health outcomes and effect efforts to address health inequities and achieve social justice?
2. Narratives have been advocated as a means of improving health literacy in vulnerable populations. What is the best way to share narratives to ensure that vulnerable populations have access to information? Are there particular formats (e.g. videos or audio clips) that are best suited for overcoming functional literacy and addressing health disparities? In what situations or with whom do you think the narrative in this chapter would be useful to share?
3. Whose responsibility is it to provide narrative information, and at what point along the health care management process, which includes health promotion, prevention and health treatment or maintenance, would the use of narratives have the biggest impact?
4. How can we ensure that vulnerable populations or minorities are represented in the collection of narratives? How can we show the spectrum of health-related situations, when diversity may not be represented by a small number of narratives? How can we avoid suppressing voices that do not fit the standards or expectations of academic research?

5. The narrator of the story believes that a woman's emotional frame of mind during pregnancy is possibly more important than her physical condition. How might a women's frame of mind affect her pregnancy, and could it also have an impact on physical outcomes?
6. The narrator of the story believes that her doctor fulfilled his professional responsibilities in spite of her unmet psychological health needs. Did her doctor adequately fulfil his professional duties towards her, if he was unable to provide care in an area she perceived as essential to her health and well-being? What barriers did he face in providing/facilitating psychological support during her pregnancy?
7. When using narratives, how would you assess the relative importance of the reliability of the information provided versus its relatability?
8. How do we ensure the emotional pull of stories does not influence patients or users to make decisions contrary to their values?
9. What is the balance between epidemiological and narrative data when presented as evidence for decision-making?
10. Even when narratives are anonymized, personal stories may have unique elements that render them identifiable to personal contacts. How can the personal identity of narrator be protected while keeping the essence of their story?

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