

Determining Patient Readiness to Share Their Healthcare Stories: A Tool for Prospective Patient Storytellers to Determine Their Readiness to Discuss Their Healthcare Experiences

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Abstract

Patient stories can serve as educational tools for healthcare providers. Inherent risks to the patients sharing their medical stories do exist. Despite the positive impact that patient storytelling can have in healthcare delivery, it is important to ensure the safety of those patients who chose to share their medical experiences. A novel questionnaire was developed by a diverse group of healthcare and patient partner experts. This questionnaire would serve as a self-reflective tool that prospective storytellers would complete in order to assess their readiness to proceed with storytelling as an educational tool. This draft questionnaire was then distributed to the 10 prospective patient storytellers registered to complete our pilot workshop on preparing the patient stories where they were asked to provide feedback. Overall, feedback was positive, and minor alterations were made to the questionnaire, resulting in the novel creation of this readiness assessment tool.

Keywords

patient engagement, patient perspectives/narratives, medical education, interprofessional education, education, community engagement

Introduction

In addition to the medical knowledge that physicians require, they must possess the skills to listen to patients' illness narratives (1). Patient illness narratives, or patient stories, are different from the medical history that healthcare providers are generally used to hearing. Hearing the patient's story is not the same as the medical records (2). More specifically, "Patient stories offer valuable insights that go way beyond the statistics and the outcomes: they have the power to inspire, humanize, compel action, and challenge assumptions" (3). Many physicians report that patient stories offer them unique insights into areas they would otherwise not be aware of (3). As such, patients being asked to share their illness stories in various ways is becoming more common. Patient storytelling offers many benefits to healthcare providers such as understanding the patient's entire experience, not simply the medical experience (4). Additionally, storytelling can lead to improved collaboration between healthcare providers and patients, thus improving patient-centered care (4). It also helps to bridge the gap between

patient and healthcare providers, can offer clinicians valuable information beyond their scope of practice, and can help researchers and administrators appreciate the need for change (3). Overall, patient stories can serve as an excellent educational tool for healthcare providers (5).

The purpose of creating this novel educational tool to assess patient readiness to share their healthcare stories is to ensure that patients are ready to safely share aspects of their healthcare journey. Establishing this readiness will serve to protect prospective storytellers from unnecessary harm. However, establishing patient readiness also yields a

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more impactful and collaborative partnership between patients and healthcare providers (4).

Background Information

All the aforementioned benefits of patient storytelling are positive. However, there are some potential pitfalls to patient storytelling that can occur. For the purpose of this article, the pitfalls will focus solely on the risks to patient storytellers themselves. Patient storytellers are retelling or reliving their patient stories and, as such, run the risk of experiencing psychological trauma (3). In addition, patients who repetitively tell their stories too many times run the risk of emotional burnout (3). There can also be unpredictable emotional responses when patients are sharing their stories (5). Various resources do exist to help to mitigate these risks including a checklist of best practices from Health Quality Ontario (6).

Despite these checklists, resources/workshops are starting to be developed (4,5) to help train patient storytellers to craft and curate their stories and address these potential pitfalls. While creating such a pilot workshop at our organization, we knew it was important to ensure that patients are ready to share their stories in order to reduce the risk of harm while guiding patient storytellers to optimize the impactful experience for the healthcare audience (4). Although workshops might identify patients who aren't ready to be a storyteller, the workshops themselves can also be triggering for patients. As such, harm may already occur simply from attending the workshop. Thus, despite the positive impact patient stories can have in healthcare, it was paramount for us to reduce the risk of harm to patients as much as possible. Because of this, our group of experts (members of this expert group described in Methodology) started brainstorming on all the different aspects and areas that a patient should reflect upon before attending the workshop and especially before telling their stories in public. To initiate brainstorming, our group met with patients who were successfully telling their healthcare stories, and we asked them about what they considered when preparing their stories and what surprised them or what they wished they had known before sharing their stories. We quickly realized there were many areas to consider that most potential storytellers may not have thought about. Consequently, a literature search was done through PubMed and Google Scholar to determine whether any self-reflective tool existed for patients considering sharing their stories existed. We were surprised that no such tool existed.

Due to this lack of a self-reflective tool for patients to assess their level of readiness to engage in patient storytelling and the need for us to mitigate risks to our storytellers, we decided to create a questionnaire based on a format we came across in another area of patient engagement (7). This questionnaire would serve as a self-reflective tool that prospective storytellers would do in order to assess their readiness to proceed into our storytelling workshop (Figure 1). The goal of this questionnaire is not to have right or wrong answers that would exclude patient storyteller participation

in the workshop; rather, it serves as a starting point for reflection for storytellers to think of aspects to storytelling that they may not have otherwise thought of (ie, does their health permit them to take on this role, do they have a support system in place, etc). It allows faculty members a chance to identify prospective participants who may not be potentially ready to engage in the workshop, and a faculty member can therefore reach out privately to these participants. Additionally, it creates an opportunity for prospective participants to ask questions to designated workshop faculty privately and prior to starting the workshop. In order to allow for ample self-reflection, we plan to distribute this questionnaire 3 months prior to starting our storytelling workshop.

Methodology and Results

In order to develop this questionnaire, a diverse group of experts were brought together. Clinicians, physician educators, patient-oriented researchers, a nurse, a psychologist, and most importantly, patient partners with experience in storytelling were invited to participate. This group then drafted a questionnaire to assess patient readiness in storytelling. This draft questionnaire was then distributed to the 10 prospective patient storytellers registered to complete our pilot workshop on crafting and curating the patient stories. They were asked to complete the questionnaire prior to starting the workshop in order to assess their readiness and to provide feedback anonymously after the workshop completion. The questionnaires were collected from participants and remained anonymous. The workshop participants were asked to provide feedback at the end of the questionnaires about 2 aspects. The first aspect was specifically addressing the utility of the readiness assessment questionnaires. Participants were asked to comment on whether they felt that the questionnaire assessment tool enabled them to reflect on their readiness to participate in the workshop. The vast majority of participants found the questionnaire to be extremely helpful and commented that it allowed them to reflect on things they never would have even thought of. The second area the participants were asked to comment on focused on the questions themselves within the assessment questionnaire. We wanted to know their thoughts on the question's appropriateness, wording, clarity, and any other aspects they felt were missing. Comments were minimal as participants found the questions clear, concise, and effective. Based on the participants' feedback, the readiness assessment questionnaire underwent minor alterations consisting mostly of specific words and a suggestion to include patient and family in the wording. The latter was especially helpful as it may not always be the patient telling the story; it could be family or caregivers as well. After alterations to the draft questionnaire were completed based on this patient storyteller feedback, the final version of the questionnaire was created, as seen in Figure 1.

1) I have experience public speaking and/or feel confident in my ability to do so.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2) I adapt to unforeseen circumstances.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3) I respect other opinions, even if I do not agree.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
4) I am able to receive constructive feedback and coaching related to my patient story.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
5) My health or life will not prevent my participation at this time.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6) My family and/or friends are supportive of me being a patient storyteller.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
7) My patient story is credible, reliable, and serves a purpose.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
8) I appreciate what matters to patients.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9) I have an interest in patient engagement and am motivated to use my lived experience to improve healthcare.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
10) I have thought about the vulnerability that comes with sharing personal experiences and information about myself.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11) I recognize that storytelling may cause me to experience unexpected emotional responses.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12) I have a plan for how I would cope should storytelling cause me to have a strong emotional response.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13) I am prepared to share my healthcare story with healthcare providers, researchers, other patient partners and policy makers, including those who may have been involved in my care.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
14) I have thought about how I would respond if the audience is not engaged and/or distracted during my talk (i.e.: not asking questions, checking cellphones, whispering, etc.).	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15) I have thought about privacy issues, and which parts of my healthcare story I wish to share and/or not share.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
16) I have thought about what environments would make me most comfortable when storytelling (i.e.: small vs large group, in person, webinar, recordings, etc.).	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
17) I can advocate for myself.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
18) I am aware of the ways in which I can be involved in patient engagement, and storytelling is a good fit for me.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19) Were there any questions that took you by surprise? Which questions made you reflect on your role as a storyteller?	_____				
20) Do you have any additional comments, questions, etc.?	_____				

Figure 1. Patient storytelling: Readiness Assessment Questionnaire.

Conclusion

Feedback from the initial use of this readiness tool from patient storytellers was encouraging. Due to the fact that this questionnaire was only distributed to the 10 participants of our inaugural workshop, it is too early to comment on whether the purpose of this tool was achieved, that is, whether this tool will allow patients to assess their readiness to safely share their stories with a healthcare audience. The distribution of this questionnaire to subsequent prospective workshop participants will allow us to better assess its utility. Although in its early stages, this novel educational tool was received positively by prospective patient storytellers. We feel this readiness assessment questionnaire is innovative, helpful, and valuable. Further use of this educational tool and more in-depth research studies are needed in the future.

Authors' Note

Tacit consent was obtained by experts' involvement in the project to create the questionnaire.

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Author Biographies

Lynn C Ashdown was near completion of her residency in Family Medicine when she began a complex journey as a full-time patient. She gained a unique insight into the system from lived experience as both a provider and receiver of healthcare. She serves as a senior patient partner to the Patient and Family Engagement program at The Ottawa Hospital, gives various presentations, participates in research and education, and advocates for the patient voice to be included in all levels of healthcare.

Jerry M Maniate is the vice president of Education for The Ottawa Hospital and is also an associate professor in both the Department of Medicine and the Department of Innovation in Medical Education (DIME) at the University of Ottawa. As an education researcher, Dr Maniate is currently working on creating and evaluating novel models of education that supports and engages all learners, including trainees, staff, physicians, as well as patients, families and caregivers.