The Use of Patient Stories as a Knowledge Translation Strategy to Facilitate the Sustainability of Evidence-Based Interventions (EBIs) in Healthcare

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This research is available in Patient Experience Journal: https://pxjournal.org/journal/vol11/iss1/7
The Use of Patient Stories as a Knowledge Translation Strategy to Facilitate the Sustainability of Evidence-Based Interventions (EBIs) in Healthcare

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ABSTRACT

Background: Patient stories are real-life experiences told from a patient’s or their family’s perspective. In the past, patient stories have served many purposes in healthcare, such as spreading knowledge, educating providers, or conveying the patient experience. Patient stories are increasingly used as a knowledge translation (KT) strategy to improve the uptake of evidence-based interventions (EBIs) into clinical healthcare practices by embodying the patient experience. However, little is known about the use of patient stories to support the sustainability of EBIs in healthcare practices. There is a need to understand how patient stories can be used for the long-term use and benefit of EBIs in practice.

Objective: Our research explored how patient stories facilitate the sustainability of EBIs in healthcare.

Methods: We conducted a secondary thematic analysis of 20 qualitative interviews from a realist evaluation previously published by Flynn et al.

Results: We found that the use of patient stories as a KT strategy for the sustainability of two EBIs created buy-in towards new research, motivated and encouraged staff to continue to engage with the intervention long-term and facilitated the spread of the EBI. Our findings demonstrate how sharing patient stories digitally or through learning collaboratives and online toolkits, can facilitate sustainability by enabling patient stories to be saved and distributed to a wide audience at any time. Despite the potential use of patient stories to support long-term research use, more research is needed to understand how effective patient stories are at supporting the long-term use of research evidence aimed to improve healthcare practice.

Keywords: Patient stories, Patient experience, Knowledge translation, Evidence-based interventions, Sustainability, Healthcare

1. Background

Within a healthcare context, the patient experience is gaining momentum as a powerful tool for acquiring knowledge, motivating both patients and providers, improving healthcare interactions, encouraging engagement, fostering communication, and driving change.1–3 The patient experience is commonly conveyed through stories, told either by the provider or the patient themselves.4 Commonly, patient stories are reflective accounts of patient experiences alongside current perspective. They offer insight into how a
Patient’s life is affected by their condition and highlight how patient perspectives and experiences can change over time. Patient stories can be gathered through a variety of methods, such as, interviews, focus groups, mirror meetings, written narratives, conversation, and multimedia platforms.4

Patient stories are increasingly used as a strategy in the field of Knowledge Translation (KT) which aims to ensure research evidence and evidence-based interventions (EBIs) are utilized in healthcare practices to improve health outcomes and health systems.5–8 EBIs are defined as practices, programs, policies, or guidelines with proven efficacy and effectiveness.9 KT strategies aim to reduce research-practice gaps, and to ensure that patients receive the most recent and beneficial EBIs, while avoiding outdated or potentially harmful treatments or practices.10 Examples of conventional KT strategies include audit and feedback, facilitation, opinion leaders and educational outreach.10

Patient stories are considered an arts-based KT strategy, with the objective of disseminating and communicating knowledge. There are broadly three groups of arts-based KT strategies: visual (photographs, drawings), literary (poetry, written narrative) and performance (eg, theatre, narrative-based arts).11,12 Arts-based KT strategies offer unique and improved ways of mobilizing knowledge to didactic KT strategies, in the way that target broad audiences, are accessible to the public, and are generally more persuasive and emotive than didactic KT strategies such as lectures, seminars, or information sessions.3,8

Stories can create vivid and engaging worlds that capture the minds of audiences.13 While patient stories have the potential to deliver a deeper level of insight to the patient experience, and thus can contribute to improving the uptake of EBIs in practice and the quality of healthcare services,4 there is little known about the use of patient stories to facilitate the long-term use and benefits of EBIs in practice, otherwise known as the sustainability of EBIs.

Sustainability of EBIs is an identified priority for health services research.14,15 Moore et al. define sustainability as: (1) after a defined period of time, (2) a program, clinical intervention, and/or implementation strategies continue to be delivered and/or (3) individual behavior change (i.e., clinician, patient) is maintained; (4) the program and individual behavior change may evolve or adapt while (5) continuing to produce benefits for individuals/systems”.15

In order to promote long-term, quality patient care, it is crucial to promote the sustainability of effective EBIs.14 This can be supported through appropriate and effective KT strategies.14 Understanding what and how KT strategies support the sustainability of EBIs is an important area of research that needs exploration.14 Patient experiences may be a powerful way to facilitate the sustainability of EBIs in healthcare, and therefore the use of patient stories for sustainability should be explored.

2. Research aim and context

We aimed to explore how patient stories as KT strategy are used to facilitate the sustainability of EBIs in healthcare. Our study was guided by the following research question: How and why did patient stories influence the sustainability of two scaled EBIs in healthcare? We examined two interventions that had been scaled and spread across multiple clinical settings in one provincial health system in Canada, the Alberta Healthcare System.16 The two selected EBIs for our study were: A delirium intervention implemented from 2016–2019 in all 22 intensive care units (ICUs) in Alberta, and an Appropriate Use of Antipsychotics (AUA) intervention implemented in 170 long-term care sites and 140 designated supportive living sites.16

The delirium intervention multi-component intervention aimed to a) decrease the incidence and duration of ICU delirium, b) reduce ICU length of stay/hospital length of stay; c) improve quality of ICU delirium care across Alberta using evidence-informed best practices; d) collaborate & learn together as a critical care community and e) provide access to ICU delirium resources for patients, families and healthcare providers across Alberta. Overall, there were evident reduction in the incidence of delirium (10% reduction), reductions in both ICU and Hospital length of stay, increased screening of delirium risk (40% to 75%), increased standardization of evidence-based practices in every ICU across the province.17

The aim of the AUA intervention was to reduce the inappropriate use of antipsychotic medications for managing responsive behaviors associated with dementia. In designated supportive living sites, antipsychotic use in Alberta has decreased by more than 30% in the past 4.5 years. Just 17.1% of Alberta’s long term care residents (without a chronic mental health condition) are using antipsychotic medications, compared to the national average of 21.2% (2017–18).18 We purposefully selected these two EBIs based on
multiple factors such as a) implementation scale (province wide), b) evidence of improved impact and outcomes, c) diversity of context (community and acute healthcare) and d) maturity of intervention.

3. Methods

We conducted a secondary analysis of qualitative interview data from our published primary study: “Contextual factors and mechanisms that influence sustainability: A realist evaluation of two scaled, multi-component interventions.” In our primary research study, patient stories naturally emerged as an unexpected and prominently reported KT strategy that facilitated sustainability from participants perspectives. In this secondary analysis, we wanted to further explore how patient stories facilitated sustainability of the two selected EBIs.

4. Primary research study

The primary study was a realist evaluation that consisted of 30 interviews exploring participants’ perceptions of the selected interventions, implementation and sustainability processes, and factors that facilitated or hindered sustainability of the EBIs. Realist evaluation is a theory-driven approach that unpacks the ‘black box’ between complex interventions and their generated outcomes. We used a realist evaluation approach to provide a more explicit and in-depth understanding of what works, for whom and under what circumstances. While further demographic details have been published elsewhere, participants were primarily managers and frontline staff who had been involved in the implementation of the two selected EBIs. Patient stories was not initially hypothesized in our realist evaluation program theory as a KT strategy for sustainability, however it emerged from participants perspectives that sharing a patient or family story was an important strategy for sustainability.

5. Secondary analysis

For this secondary analysis, two authors (LD, EM) conducted a preliminary screening of all 30 interviews from the primary study. The two authors independently searched the primary interview dataset by reading the transcripts and then by screening for the terms “patient stories”, “storytelling”, or “stories” and included any interviews that discussed the use of patient stories for sustainability of the two selected EBIs. We managed our secondary analysis of 20 interviews with NVIVO 12. Thematic analysis was employed by two researchers (LD, EM) to identify relevant themes or patterns. The initial coding of our data began by labeling key sections of the transcripts based on their relation to patient stories and the sustainability of EBIs. Upon completing initial coding, we searched for themes by labeling and grouping the coded data. A theme was used to identify and bring together recurring experiences or perspectives which are often meaningless when viewed alone. Two research team members (LD, EM) cross-checked each other’s analysis and compared preliminary findings with a third author (RF). Final themes were identified through comparison and collation of the two research team members’ analyses.

6. Ethics

Consent for a secondary analysis was obtained for this study. The secondary analysis study was reviewed and approved by the University of Alberta Health Ethics Research Board (Pro0096202).

7. Results

We identified three overarching themes on how patient stories facilitated the sustainability of EBIs: 1) they generated buy-in regarding the intervention, 2) they motivated and encouraged staff to continue to engage with the intervention long-term, and 3) they facilitated the spread of the EBI on a provincial level (Fig. 1). These themes were underpinned by the emotive response patient stories had on participants which triggered motivation and continued engagement with the EBI, which facilitated the sustainability of the EBI. Overall, patient stories facilitated the sustainability of EBIs by maintaining continuous buy-in; participants identified this as an essential component to sustainability. Participants also described that patient stories that were positive in nature and continually shared helped to facilitate the sustainability of EBIs.

7.1. Generating buy-in for the EBI

Participants discussed how patient stories generated buy-in through an emotive connection at a personal level regarding the two EBI’s, which subsequently facilitated sustainability. To sustain the EBI, “there needs to be a connection at the personal level” so the
work of the EBI resonates with provider. Patient stories provided emotive connection by showing the positive impact the EBI had on patients and their families. This generated a willingness by participants to continue the work of the EBI long-term. As one participant stated: “The factors that have helped with making it part of the daily work [are] providing some of that why behind it [the EBI] and telling some of those processes, generating excitement, and keeping the EBI at the forefront of practice. One participant specifically conveyed the impact of patient stories on frontline staff, noting that “staff are sick of doing the same kind of work and trying to make changes without it ever really happening but when they had a previous patient share their story with the audience of pictures and feedback and talk about what it was like to be a patient within that feedback that [they] received was always very positive and that it was a patient story that really helped people to make change and continue with the work”.

Stories also motivated families and staff to use the EBI by generating excitement and enthusiasm around the practice. For example, one participant said, “who doesn’t love a good news story and knowing that the work you do has some impact on people”. If nurses see a patient story on TV, they think “hey we’re doing this work!” which in turn “sells to them a little better”, thus generating and maintaining continuous buy-in. Through demonstrating the positive impact, the two EBIs had on patient health outcomes and quality of care, patient stories motivated staff to continue with the EBIs in their day-to-day work, increasing the likelihood of sustainability. Another participant talked about how a media story of a patient improving dramatically through the AUA EBI, opened their eyes to the opportunity for long-term change in their own workplace, thus encouraging the sustainability of the EBI since it was seen as applicable. One participant noted that “once [the staff] heard the patient perspective or the effects and the outcomes of having delirium on their life once they were discharged from ICU, we had a lot more buy-in from the staff”.

Participants described that patient stories motivated them to continue to use the EBI long-term, ultimately facilitating its sustainability. For example, we heard the story: “Mrs. Jones was on anti-psychotics for a long period of time is now not. And, while she was on anti-psychotics, you know, she was kind of drowsy and not participative or communicative. And now that we’ve been able to reduce or eliminate the use of anti-psychotics, she’s up and about and... and is engaging and you know, helping with other residents. So those success stories are what the front-line staff are most interested in. And families are interested in as well. [Because] that gives them the, the energy to continue to use behavioral approaches to managing... unwanted behaviors...instead of using pharmaceutical approaches to managing difficult behaviors.” In our dataset, patient stories motivated the staff to continue to use the EBI, by sharing successes, generating excitement, and keeping the EBI relevant at the forefront of practice. One participant specifically conveyed the impact of patient stories on frontline staff, noting that “staff are sick of doing the same kind of work and trying to make changes without it ever really happening but when they had a previous patient share their story with the audience of pictures and feedback and talk about what it was like to be a patient within that feedback that [they] received was always very positive and that it was a patient story that really helped people to make change and continue with the work.”
It was evident from the qualitative interview data that the ways in which patient stories were shared (i.e., digitally, in-person learning collaboratives) also motivated staff and facilitated the sustainability of the two EBIs. For each EBI, patient stories were shared via learning collaboratives where together patients, families, and expert clinicians/faculty met to discuss ideas, share stories, and develop action plans. While both EBIs utilized learning collaboratives to disseminate patient stories, teams championing the AUA intervention also developed an intervention toolkit. This included a web page where success stories and other resources were compiled and shared digitally, making them accessible for staff to use and share with ease. The overall modality of digital stories was successful in motivating patients from various sites, who could see themselves, or their loved ones within the digital stories posted. A participant explained that they chose to use this modality so that “residents of different continuing care sites...can see themselves in those stories so it is motivating for them as well.” This positively contributed to the accessibility and dissemination of EBIs, implicating digital dissemination as another driver of sustainability, while allowing stories to be used to motivate a larger audience.

Finally, participants mentioned that for patient stories to be motivating they should highlight a positive health outcome, or success story. This is not to imply that challenging or negative experiences should not be shared, but rather should be used to highlight a happy ending. For example, one family shared a story about their loved one who could not walk, talk, or feed herself; a negative experience to reflect on, however explained that after discontinuing her antipsychotic medications, she resumed all 3 activities of daily living. Stories such as this, with a happy ending, were described as a “really positive motivator for people continuing to do the work,” by one participant. When staff heard about the EBI yielding generally positive results, they became more inclined to practice it. Another participant noted “success stories are what the front-line staff are most interested in”. On the contrary, one participant described the demotivating effect of largely negative patient stories, where in one situation, a resident’s antipsychotics were titrated down or discontinued completely, resulting in negative behaviors. When this story was shared, “all of a sudden it [the EBI] is a problem...people are losing sight of the big picture.” As another participant explained, “it’s like you hear a hundred positive things, but you only remember the one negative”. Participants recognized the need for uplifting or affirmative stories and highlighted “the strategy of using good-news stories to encourage people and motivate them”. Successful patient stories were reported as a useful and deliberate strategy to encourage the staff to focus on and prioritize EBIs, and should be shared “often and always”, illustrating that patient stories can act as a reminder and reinforcement strategy for sustainability.

73. Facilitating spread of the EBI

Participants recognized patient stories as a useful strategy to help spread the EBI by encouraging shared learning and cross provincial engagement. Patient success stories were able to connect and engage multidisciplinary health professions across different geographical locations and multiple sites. This allowed for a unified understanding of the EBI in question, while laying the groundwork for continual implementation leading to sustainability. One participant explained that “in terms of sustainability, if you work with the variables of leadership engagement, front-line engagement, changing cultures, and sharing success stories, you can make it work in each of the environments elaborating that regardless of the facilities size or location “you still have success stories to, to share with your team, with your facility, with your peer facility.” Participants conveyed that patient stories “brought all the operators, the leaders and the SCN, the Ministry, and everybody that was working together to tell their stories to look at the data, and to say what worked and what didn’t”. Through hearing how other sites benefited from the intervention, or how they overcame hurdles, staff were better equipped and empowered to sustain the EBI. This was especially relevant to staff in the ICU who, in regards to the delirium intervention, shared that they do not usually have a chance to “hear from those patients about the impact that things did or didn’t have” as they have left the unit. Patient stories were perceived to reinforce positive outcomes more than day-to-day staff accounts of patient interactions. One participant described this discrepancy, explaining that “[being] able to bring that information and share it at a staff meeting in five or ten minutes, was not the same as hearing, you know, the patient accounts and you know, experts talk about what kind of impact this [has]”.

To facilitate long-term sustainability participants acknowledged that patient stories must be continually disseminated. One participant noted that “It is clear that “you have to kind of keep it alive at the provincial level so that people will see it’s still an important topic...if the zone leaders, provincial leaders stop talking about the importance of reducing the use of antipsychotics, it will fade from people’s cognition or from their awareness because they’re, they’re on to other things then”. Participants noted that they felt that patient stories
were crucial in keeping an EBI relevant, as a small number of stories can be disseminated on a provincial level to the different care sites with patients who can relate to the patients within the stories. The media was viewed as a powerful platform for sharing patient stories, with one participant noting the importance of “feeding the information back and telling the stories out loud publicly”. An emphasis on public sharing was made to encourage prioritization of the EBI, and in turn sustainability. For example, one participant in the AUA intervention stated “we worked deliberately to tell the stories. We told it to the Ministry of Health... That altogether helped make it work and also created sustainability”. Public sharing was an important driver of sustainability and to enable successful spread of the EBIs.

8. Discussion

Numerous KT strategies are effective for successful implementation of EBIs in healthcare, however it is unclear to what extent they work to facilitate the sustainability of EBIs in practice. KT sustainability research and the use of patient stories is a novel field, with most efforts focused on stories as a KT strategy for the implementation of EBIs. A recurring knowledge gap is whether KT strategies that are successful for the implementation of an EBI may differ from the KT strategies required to sustain them. Our secondary analysis exemplifies patient stories as one potential KT strategy to facilitate the sustainability of EBIs in healthcare, although not without further considerations.

Our results indicated that most participants valued patient stories that were positive in nature. For example, patient stories that might showcase a success, or highlight improvements because of the EBI. Negative stories, for example, ones that depict poor outcomes, were not believed to be as impactful, especially for providing long term motivation, engagement, and reinforcement of the EBI. It is important for future research to explore the influence of the nature of the patient story (positive versus negative) on changing healthcare professional behaviors.

Furthermore, our findings found that from our participants perspectives that patients’ stories must be continually shared. This may be achieved in many ways, including the creation of digital stories, as they can be re-accessed and distributed widely with ease. For example, the AUA intervention utilized a “toolkit” (webpage pertaining to the EBI) as a means to combine and share information, digital stories, and more. In our research, digital stories were perceived as a valuable way to share patient stories to facilitate sustainability of EBIs. Similar to our findings, the use of digital stories has been highlighted in the literature to motivate staff to increase their own knowledge and attitudes, as well as evaluate any pre-existing preconceptions. This particular modality can guide healthcare providers while providing tangible evidence regarding the reasoning behind EBIs, however it is important to note that other factors such as accessibility, ongoing availability and wider exposure also contribute to success of a sustainable EBI. It has been found that narrative messages are typically better received than non-narrative ones, and the use of video or audio further enhances the persuasiveness of the narrative. Creating digital stories may also be beneficial for health professionals to reinforce their learning, in ways that typical didactic methods are not. Digital stories can illustrate the importance of interpersonal communication, connection, and that teach patient’s experience is unique, through a modality with ongoing availability, accessibility, and exposure.

Similar to Rose et al. our findings demonstrate that stories are connected to human interaction and trigger an emotive response, which can impact and change behaviors and outcomes in profound ways. They enable healthcare providers to informally learn about how patients are experiencing their care. Our findings illustrate that the emotional component of patient stories facilitated continued engagement and sustainability of the EBI. Patient stories evoke compassion, empathy, and inspiration, and, while difficult to measure and quantify in traditional ways, healthcare may learn from their successes and how to strategically use patient stories as a KT intervention to supporting EBI sustainability.

Patient stories may also be used as a collaborative approach to education, aligning with our indication of patient stories to mobilize knowledge and encourage spread and scale of EBIs. Scale-out allows the EBI to be successfully sustained in a similar setting to where it was initially implemented. Scale and spread are important components of sustainability because they expand the use of the EBI wherever feasible and appropriate, while adapting it to fit the rapidly evolving healthcare environment. Patient stories may influence this process by bringing various stakeholders from different work contexts together, ensuring the EBI is a topic of priority, and demonstrating how the EBI could impact a unit. The ability to connect across geography, site location, and job role, suggests patient stories can support broad
dissemination. To spread, scale, and subsequently sustain an EBI, stakeholders should ensure opportunity to share patient stories. Moreau et al also highlighted that the emotional response evoked by patient stories is effective to motivate healthcare providers to act on health topics in the future.²

Our secondary analysis complements the known uses for digital patient stories and is consistent with common literature conclusions that digital patient stories are an important way to convey patients' health related experiences.¹,¹⁴ Despite these documented benefits of digital stories in health, a recent systematic review demonstrated that there is limited literature on the use and effectiveness of digital stories as a KT strategy for the sustainability of EBIs, as opposed to implementation, and any research that compares the effectiveness of traditional stories versus digital stories is scarcely published.¹

9. Limitations

Our findings are based on the secondary analysis of previously data collected with a different primary question and aim. This may have limited the opportunity to yield a broader and deeper insight into this topic. Another identified limitation was keyword searching for specific text strings of “patient stories”, “storytelling”, or “stories” as opposed to a broader set of text references including “experiences” “accounts” “recollections” “reflections” “memories”, which might have returned more content.

10. Future research implications

Further research is needed to determine the effectiveness of patient stories as a KT strategy for sustainability. Some key questions remain for future research on patient stories as a KT strategy for sustainability such as:

- What mechanisms of change do patient stories trigger for EBI sustainability?
- How do patient stories align with and complement other KT strategies for EBI sustainability?
- What are the core characteristics of patient stories as a knowledge translation strategy to facilitate the sustainability of evidence-based interventions (EBIs) in healthcare?

Such evidence will help inform future use of patient stories for long-term healthcare change. The need for further research in this area is also indicated by concerns that media-based digital storytelling may feature information that is not necessarily filtered through experts or clinicians. This potentially enables media and patients to share information that is not consistent with a scientific understanding, thus literature suggests the need to further collaborate with patients to create resources and disseminate health information.¹ Beyond researchers, patient stories are also valuable for patients as they provide an opportunity for them to contribute and engage in health research.¹,²⁷ It is worth further investigation to determine how best to do this. More specifically, there is a need to further explore the value of positive versus negative patient stories, as well as other factors including language, accessibility, equity, diversity and inclusion considerations in the development and use of patient stories as a KT strategy to facilitate the sustainability of evidence-based interventions (EBIs) in healthcare. Finally, as suggested by other publications, further evaluation research of the impact of patient stories on patient, provider and system outcomes will provide stronger evidence on the use and effectiveness of patient stories as a KT strategy for the sustainability of EBIs in healthcare.¹

11. Conclusion

While the use of patient stories as a KT strategy for sustainability is a novel idea, patient stories in our study provided the why behind the EBI thus creating buy-in, motivating individuals, and facilitating sustainability of the EBI, and encouraging spread of the EBI. In the context of this study, patient stories were shared digitally, in person through learning collaboratives and through online toolkits, allowing them to be continually distributed. Patient stories encouraged staff to engrain the EBI into their daily practice by clearly conveying the intervention’s importance. Through hearing positive patient accounts from their own perspective, staff were motivated and encouraged to continue practicing the EBI. Negative stories were noted to lack the same motivating effect as positive stories, which can be considered proof regarding the intervention’s impact, and were also found to be perceived as more meaningful than quantitative data. By enabling staff to hear about the EBI, as well as adapt it to their needs, patient stories also may impact sustainability by helping with the spread and scale. Further research is needed to evaluate the effectiveness of different story modalities, as well as the impact of patient stories on EBI outcomes.
List of abbreviations

KT: Knowledge translation

EBI: Evidence-based intervention

AHS: Alberta Health Services

AUA: Appropriate Use of Antipsychotics

Declarations

Ethics

Ethics approval for this secondary analysis was given by the University of Alberta Health Ethics Research Board (Pro0096202).

Consent for publication

Informed consent was obtained from participants, for the publication of quotes in this manuscript. Consent regarding the patient stories posted online in the AUA toolkit would have been obtained by the Strategic Clinical Network, Alberta Health Services.

Availability of data and material

The qualitative data supporting this study is not available as participants did not consent to having their data publicly available but anonymized quotations are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This work was funded by a grant ($23,587.30) provided by the Strategic Clinical Networks™ and AHS awarded to R Flynn and S Scott. SDS is supported by a Canada Research Chair and a Distinguished Researcher Award from the Stollery Science Lab.

Authors contributions

RF, SDS, EM, LD contributed to the conception of this paper. LD and EM led the secondary analysis of the interview data. LD, EM and RF led the development and writing of this paper. SDS, TW, KM and RF provided content and methodological expertise for this and the original study. AC led the data collection and analysis of the primary dataset. All authors read and approved the final manuscript.

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