White Rose Research Online

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk
Universities of Leeds, Sheffield and York

Deposited via The University of Leeds.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/174942/

Version: Accepted Version

Article:
Shaffer, VA, Brodney, S, Gavaruzzi, T et al. (2021) Do Personal Stories Make Patient Decision Aids More Effective? An Update from the International Patient Decision Aids Standards. Medical Decision Making, 41 (7). pp. 897-906. ISSN: 0272-989X

https://doi.org/10.1177/0272989X211011100

© The Author(s) 2021. This is an author produced version of an article, published in / accepted for publication in Medical Decision Making (MDM). Uploaded in accordance with the publisher's self-archiving policy.

Reuse
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

UNIVERSITY OF LEEDS
University of Sheffield
UNIVERSITY of York

Shaffer V, Brodney S, Gavaruzzi T, Zisman-Ilani Y, Munro S, Smith-Lickess S, Thomas E, Valentine K, **Bekker H**. *Do Personal Stories Make Patient Decision Aids More Effective? An Update from the International Patient Decision Aids Standards [IPDAS 4 of 12]* Medical Decision Making (Accepted 19th March 2021)

Abstract

Background: This manuscript evaluates the evidence for the inclusion of patient narratives in patient decision aids (PtDAs). We define patient narratives as stories, testimonials, or anecdotes that provide illustrative examples of the experiences of others that are relevant to the decision at hand (1).

Method: To evaluate the evidence for the effectiveness of narratives in PtDAs, we conducted a narrative scoping review of the literature from January 2013 through June 2019 to identify relevant literature published since the last IPDAS update in 2013. We considered research articles that examined the impact of narratives on relevant outcomes or described relevant theoretical mechanisms.

Results: The majority of the empirical work on narratives did not measure concepts that are typically found in the PtDA literature (e.g., decisional conflict). Yet, a few themes emerged from our review that can be applied to the PtDA context including the impact of narratives on relevant outcomes (knowledge, behavior change, and psychological constructs) as well as several theoretical mechanisms about how and why narratives work that can be applied to the PtDA context.

Conclusion: Based on this evidence update, we suggest that there may be situations where narratives could enhance the effectiveness of patient decision aids. The recent theoretical work on narratives has underscored the fact that narratives are a multi-faceted construct and should no longer be considered as a binary option (include narratives or not). However, the bottom line

is that the evidence does not support a recommendation for narratives to be a necessary component of PtDAs.

Background

Definition of quality dimension

This manuscript evaluates the evidence for the inclusion of patient narratives in patient decision aids (PtDAs). PtDAs are resources that draw on evidence from the decision sciences to support people's decisions about treatment, screening, or testing options in accordance with their own values (2). PtDAs follow guidance to ensure their structure and content describes the health problem, makes explicit the decision problem, provides an accurate and balanced description of all options and their consequences using accessible language and figures, help patients evaluate these facts, and provide guidance to help make trade-offs between options (1, 3). Many PtDA developers also use patient narratives to enhance the content and delivery of the material (4-6). We define patient narratives as stories, testimonials, or anecdotes that provide illustrative examples of the experiences of others that are relevant to the decision at hand (1). Narratives can be produced in many forms (e.g., written, audio, or video). The purpose of this work is to summarize evidence for the effective use of patient narratives in PtDAs. Specifically, we will evaluate whether there is sufficient evidence to recommend that PtDA developers include patient narratives as an active ingredient of PtDAs.

Theoretical rationale

The primary theoretical rationales for the inclusion of narratives in PtDAs are to engage the audience and provide information about the patient experience. In the broader literature on narratives, there is evidence that narratives may achieve both of these goals when compared

with standard information. In a recent review, narratives have been shown to have two primary functions (7). First, narratives have been demonstrated to communicate information more effectively than didactic information because narratives: 1) tend to be more engaging (e.g., 8, 9), 2) result in better recall (e.g., 10), and 3) generate fewer counterarguments to the message (e.g., 11). Narratives also have been shown to change attitudes, judgments, and behaviors (1, 7, 12). A primary challenge for PtDAs is to include narratives to support people's reasoning, without impacting judgment (1, 13).

Theoretical and empirical work in cognitive and social psychology has demonstrated that narratives can be more persuasive than didactic information (1, 7, 12), and several studies in decision making have shown that narratives can alter preferences for medical treatment (e.g., 14, 15, 16). Further, health professionals often express concerns over the use of narratives in PtDAs because the stories themselves are not subjected to scientific scrutiny (13), and as such provide an opportunity to pass on misinformation. Some research has demonstrated that people do not adjust the weight they give to narrative information based on source credibility (i.e., narratives from an anti-vaccination website vs. narratives from a neutral news website) (17). Finally, when narratives are presented in conjunction with statistical information, narratives can overshadow the data leading people to ignore data and overweight stories in their judgments of risk (e.g., 18).

Narratives have the potential to impact the effect of patient decisions aids in both positive and negative ways. On one hand, increasing patient engagement through narratives can be viewed as a positive effect if it leads to greater knowledge about the treatment options. Yet, the fact that patient narratives can also alter decision makers' judgments and choices

provides cause for concern given the IPDAS emphasis on creating patient decision aids that are free from bias. Further, there is no current standardized best practice for the selection, inclusion, and presentation of patient narratives. Therefore, the goal of this work is to review the relevant literature since the last IPDAS update and make a recommendation about whether or not patient narratives should be a required component of patient decision aids.

Method

To evaluate the evidence for the effectiveness of narratives in PtDAs, we conducted a narrative scoping review of the literature from January 2013 through June 2019 to identify relevant literature published since the last IPDAS update in 2013. We considered research articles that either examined the impact of narratives on relevant outcomes (e.g., knowledge, behavior change) or described relevant theoretical mechanisms about how and why narratives work. Several recent systematic and narrative reviews demonstrate the vast majority of research on narratives conducted since the 2013 IPDAS publication was outside the context of PtDAs (e.g., 7, 19). This scoping review methodology is more flexible than a systematic review and enables the update to be informed by a wider literature of relevance to understanding the role of narratives within PtDAs (20, 21). Accordingly, we broadened the fields of study beyond the specific context of PtDAs to include articles about the use of narratives in both health-related and non-health related contexts (e.g., Communication, Journalism). An *a priori* proposal of these methods was reviewed and approved by the IPDAS Steering Committee.

Identifying and Selecting Relevant Studies

All members of the research team, who are all co-authors on this update, participated in the process of identifying relevant studies for inclusion in the scoping review. Each member of

the research team was asked to identify important articles for inclusion across three categories: 1) Narrative research in the context of patient decisions aids or patient decision making; 2) Narrative research in the field of healthcare more broadly; and 3) Narrative research in other non-health related fields. Articles were identified through searches of relevant databases (PubMed, Google Scholar, Web of Science, PsychInfo, and PlosOne) using search terms such as "patient narratives", "personal narrative", "patient testimonials" alone and in conjunction with "decision making". The research team also mined potential studies from recent publications and through our respective networks of colleagues. We focused on articles that were published after the last IPDAS update was written. We maintained a shared research drive where the research team uploaded copies of potential articles into folders demarcating each of the three categories described above. The research team cataloged the articles into a shared database, which was coded according to these categories.

Charting the Data

We identified 170 new articles for the scoping review, with only 44 of these manuscripts loosely defined as PtDA-relevant contexts (i.e., research was done in the context of a patient decision aid or patient decision making more generally). Of the remaining 126 articles, 99 addressed issues about narratives in other health-related contexts, while 27 articles were about narratives in non-health related contexts. A recent Cochrane Review on the effectiveness of PtDAs demonstrated that these tools have been shown to increase patient knowledge, reduce decisional conflict, decrease the number of patients who are undecided about the appropriate treatment for themselves, and improve the match between patient values and their choices (2). The largest challenge in mapping the findings of the diverse body of work identified in our

review onto our objective—evaluating whether patient stories enhance the effectiveness of PtDAs—is that the majority of the empirical work on narratives did not measure concepts that are typically found in the PtDA literature (e.g., decisional conflict) or design studies to test the impact of including testimonials over-and-above information presented in a patient decision aid. However, a few themes emerged from our review that can be applied to the PtDA context including the impact of narratives on knowledge (e.g., task specific, either medical or non-medical), behavior change, and psychological constructs (e.g., emotions, perspective taking).

Collating, Summarizing, and Reporting Results

To summarize the data, each member of research team was assigned approximately 20 articles to read, create a short, written summary of the information in the article relevant to our objective, and provide key words organizing the articles topically. To collate the findings, the first author created a preliminary draft of the manuscript based on the themes identified in the review by the co-authors. The first author combined all of the summaries written by each of the co-authors and organized them by theme (e.g., knowledge, behavior change, psychological constructs). The draft was circulated to all of the co-authors for discussion, editing, and refinement. During this process, the co-authors also reviewed the integration of the research summaries they crafted into the larger thematic framework. Agreement was achieved through three cycles of manuscript drafts. The largest area of debate was concerning the extent to which we would address the modality of narrative delivery (i.e., video vs. text). Given the question was tangential to our overall objective, the research team leads opted to document the use of the different narrative modalities but not to discuss the ways in which modality may moderate the effects of the narratives. The feedback from the research team was incorporated into a revised

draft by the first author, which was sent to the team for final review before the manuscript was submitted.

Results

Knowledge

Several studies suggest narratives were an effective method of increasing knowledge in both health and non-health related contexts compared with usual communications (22-26); although a recent systematic review did not find evidence for knowledge gains with narratives in computer-based decision aids (5). Murphy and colleagues reported that narratives were more effective at increasing cervical cancer-related knowledge than non-narrative health communication interventions in a Latina population (22), and Moran and colleagues reported that the narrative health education film produced greater HPV- related knowledge gains than a non-narrative film (23). Alteren argued that narratives were useful in the development of knowledge in clinical training (24). This was consistent with the work of Kilaru and colleagues that compared the ability of an evidence-based narrative and a traditional summary to increase recall of opioid prescribing guidelines (25). Total recall was significantly greater in the narrative arm than in the summary arm. However, some themes were better recalled by the summary arm and some themes were better recalled by the narrative arm. In addition, there was a significantly greater number of extraneous or false pieces of information recalled in the summary arm than the narrative arm.

In other decision contexts, similar findings were observed. The National Bureau of Economic Research compared the effect of different education program formats (informational brochure, interactive visual tool, written narrative, and video narrative) on financial literacy,

measuring knowledge, confidence, and self-efficacy (26). All formats successfully increased financial knowledge, confidence, and self-efficacy relative to the control group, which did not receive any intervention. However, despite findings demonstrating narratives are an effective method of increasing knowledge in some types of intervention, a recent systematic review concluded that providing narratives in computer based PtDAs did not increase knowledge (5). A subgroup analysis from this review reported that inclusion of patient narratives (patient stories and behavior modeling) in these tools (7 studies) compared to computer based PtDAs without patient narratives (11 studies) did not have a significant effect on knowledge acquisition (5).

Attitudes, Persuasion, and Behavior Change

Several systematic reviews have addressed the ability of narrative messaging to affect behavioral intentions and behavior change. Braddock and Dillard conducted a meta-analysis of 74 studies, which included over 7,000 participants and determined that narratives can move beliefs, attitudes, intentions, and behaviors towards the viewpoints expressed in the narrative (27). A review by Shen, Sheer, and Li also indicated that narratives demonstrated a small but significant effect on attitudes, intentions, and behaviors (28). However, narratives were not equally effective on all health issues; personal stories that advocated for an increase in preventive health behaviors had a greater effect than stories focused on decreasing risky behaviors.

Of the studies reporting significant narratives effects, some of these effects described were deemed to be "positive" (i.e., results in a change in attitudes or behaviors than provides a public health benefit). For example, in their review, Perrier and colleagues reported that

narrative interventions significantly increased intentions to engage in cancer screening. It is unclear if increased uptake means a 'better' decision was made. However, there was also inconsistent evidence about whether narratives produce greater change in intentions to screen compared with statistical interventions (29). In a second systematic review, Perrier and colleagues demonstrated that narrative messages enhance health-promoting behaviors, but again evidence was mixed as to whether the effect size associated with narrative messages was larger than statistical messages in the promotion of behavior change (30). This pattern of findings is also observed in several recent studies indicating that narratives were more effective than non-narrative messaging at promoting dietary changes (31), increasing vaccination intentions (when presented in conjunction with statistical information) (32, 33), increasing intentions to be screened for colorectal cancer (34, 35), and increasing self-efficacy and self-care behavior in patients with Type II diabetes (36).

By contrast, several studies reported that narratives also had a significant negative effect on attitudes, intentions, and behaviors; in other words, the use of narratives resulted in attitudes or behaviors with potentially negative consequences for individual or public health. For example, Shaffer and colleagues assessed a narrative in a health-news story about a woman who had a severe allergic reaction to an over-the-counter medication (37). Exposure to the narrative resulted in significantly less use of the medication over the following two weeks in comparison to at baseline and intentions to use the medication in the future remained lower than baseline. Similarly, Scherer and colleagues reported that providing participants with narratives submitted to the Vaccine Adverse Events Reporting System actually decreased acceptance of the HPV vaccine despite the fact that the stories were not particularly plausible

(38). Witteman and colleagues examined the impact of polarizing social media comments on intentions and attitudes towards home births (39). Comments with one-sided opinions influenced participants' attitudes towards home birth, particularly if the comments included personal stories. Additionally, negative personal stories were particularly salient. However, when the comments reflected multiple perspectives on home birth (i.e., NOT one-sided opinions) attitudes and intentions were not affected. Finally, a manuscript by Arkes and Gaissmaier identified the power of anecdotal information in driving the backlash against the PSA screening recommendations provided by the United States Preventive Services Task Force (USPSTF) (40). They argue that the public dialogue surrounding cancer screening is replete with stories of people who believe their lives have been saved by screening and early detection despite epidemiological data to the contrary. The use of stories in response to the statistical information used by the USPSTF to justify their recommendation demonstrates the potentially persuasive power of even a single narrative over an army of statistical data.

A third group of studies report no effect of narrative messages on a wide variety of health behaviors including uptake of routine cancer screening services (41), carrier screening tests (42), online cognitive-behavioral therapy intervention for depression (43), and preferences for treatment in a hypothetical cancer scenario (44). McGregor and colleagues observed no differences in cancer screening uptake when a narrative was included in a screening invitation letter (45), and Nyhan and colleagues found that narratives (along with other informational interventions) were not effective at increasing parental intent to vaccinate a future child (46).

Psychological Constructs

Several articles examined the effect of narratives on a wide variety of psychological constructs. Bollinger and Kreuter reported more affirmative emotional responses to narrative videos than informational videos about breast cancer for African American women (47). Participants reviewing the narrative video were more likely to report feeling attentive, inspired, and proud, and less likely to feel upset. Narrative interventions were also associated with increasing empathy (48), emotional identification (22, 49, 50), and perspective taking (51, 52). Further, narratives have been associated with minimizing affective forecasting errors (53) and creating a more positive attitude towards stigmatized health behaviors (54, 55). However, Syrowatka and colleagues reported that decisional conflict increased following the use of computer-based PtDAs that included patient stories (broadly including both narratives and behavior modeling) compared with computer-based PtDAs without patient stories (5).

In addition, narratives may play key roles in "finding information, feeling supported, maintaining relationships with others, affecting behavior…experiencing health services…learning to tell the story, and visualizing the disease" (56). Ziebland and Wyke also argue that 'learning to tell the story' and 'visualizing the disease' domains are important features that have been under-acknowledged so far in research (56). Narratives are also well suited to conveying emotion, explaining logic, providing relational information, and capturing naturalistic experiences (57). They may be a particularly effective tool when health communicators are trying to help patients avoid surprise and regret, recognize dominant options (e.g., smoking cessation), motivate to act or not act, and make multi-attribute tradeoff decisions. Narratives may also be helpful in communicating evidence from systematic reviews and improve stakeholder engagement (58). What is unclear is if narrative-based

communications are likely to be more effective than research-informed PtDAs communicating these more complex issues.

Narrative Theory

The IPDAS update 2013 suggested that some types of narratives may be more appropriate to include within PtDAs than others, with Shaffer and Zikmund-Fisher providing a taxonomy of narrative types: 1) Narrative Purpose (inform, engage, model behavior, persuade, and comfort); 2) Narrative Content (process narratives, experience narratives, and outcome narratives); and 3) Evaluative Valence (narratives with a positive or negative emotional tone) (7, 59). Subsequent work found that process narratives (i.e., stories that focused on *how* patients made a particular decision) increased time spent searching for information in a patient decision aid for early-stage breast cancer, and experience narratives (i.e., what it is like to have a disease or treatment) increased confidence in the hypothetical decision and a greater sense of feeling informed (60). Gavaruzzi and colleagues (61) and Graaf, Sanders, and Hoeken (62) reported that different types of emotion-laden narratives can have different effects on behavior, and Witteman and colleagues reported that negative birth stories were more influential than positive birth stories in the development of attitudes towards home birth (39). On the other hand, a relief-based narrative (i.e., describes relief from a negative test result) was more effective in promoting intentions to screen than a regret-based narrative in the context of colorectal cancer screening (61). Other work demonstrated that narratives from a positive role model who focused on healthy behaviors were more persuasive than narratives from a negative role model who focused on unhealthy behaviors (62, 63).

These typologies are important because the specific narrative content is also likely to be an important determinant of narrative impact. For example, Scherer and colleagues tested the effect of four narrative messaging conditions on interest in Prostate-Specific Antigen screening: 1) physical harm narrative, 2) emotional harm narrative, 3) overdiagnosis narrative, or 4) all three narratives together (64). The physical harm narrative was the only narrative to significantly decrease intentions to be screened for prostate cancer. Keer, van den Putte, de Wit, & Neijens reported that narratives were more effective at discouraging binge drinking in college students when they contained affective arguments, designed to address emotional consequences of decision making, than when they contained instrumental arguments, designed to address the logical consequences of decision making (65). The authors argued that the instrumental content reduced the efficacy of the narratives because they prevented the audience from being transported into the story. This represents a key theoretical development in understanding the process by which a given narrative has its impact. Narrative effects are moderated by the degree to which message recipients are *transported* by the content of the message (66). Narrative Transportation Theory (e.g. 67) describes the extent to which individuals become completely psychologically engaged in the narrative. In support of this hypothesis, Dillard and colleagues reported that increased transportation from a narrative health communication message designed to reduce skin cancer risk was associated with increased behavioral intentions (e.g., engage in skin self-exam, talk to doctor, reduce UV exposure) (66).

More recently, researchers have explored transportation as a key mechanism for the effect of narratives on people's judgements and behavior. In the Narrative Immersion Model,

Shaffer and colleagues describe the specific impact (e.g., type and magnitude of the effect) of a particular narrative by identifying narrative types and characteristics of narratives that are likely to increase their impact (7). Van Laer, De Ruyter, Visconti, and Wetzels conducted a meta-analysis on narratives to identify the antecedents and consequences of narrative transportation from a multidisciplinary literature, resulting in the development of the Extended Transportation Imagery Model (19). Narratives promoting increased transportation included: 1) characters with whom the audience can identify; 2) an imaginable plot; and 3) verisimilitude (i.e. the perception or appearance of being real). Dillard and Main also examined the moderating effects of vividness and perceived similarity in narrative messaging and reported that greater vividness (and to a lesser degree, greater identification with the narrative) was associated with increased knowledge about colorectal cancer screening and intentions to be screened for colorectal cancer (68). There also are a number of additional structural features of narratives that impact their persuasive ability (69), including format, with audio-visual narratives having greater persuasive ability than text-based narratives (30, 26, 71).

Research also has pointed to a number of audience characteristics that interact with messaging content to impact message effectiveness. For example, the meta-analyses conducted by Van Laer and colleagues concluded that message recipients who are more likely to be transported are generally: 1) familiar with the story topic; 2) pay attention to the story; 3) are transportable (i.e., high scores on this individual difference measure); 4) young; 5) educated; and 6) female (19). First person narratives are often found to be more persuasive than third person narratives (33, 63). Additionally, there are individual differences in the impact of narrative messaging. For example, Scherer and colleagues reported that the response to

didactic and narrative information was strongly related to participants' minimizing or maximizing preferences for healthcare (64), with medical maximizers (i.e., patients who tend to prefer active over passive medical treatment) being significantly less effected by the didactic and narrative health communications than were medical minimizers.

Discussion

The objective of this review was to evaluate whether there is sufficient evidence to recommend that PtDA developers include patient narratives as an active ingredient of PtDAs. As few studies systematically evaluated narratives and PtDA effectiveness since the last review (1), we used a scoping method to capture research investigating narratives and their impact on health-related decisions more broadly. The pattern of results observed in this update was similar to the findings reported in the 2013 IPDAS update. In some studies, narratives increased people's adherence or uptake behaviors (i.e., were persuasive) and enhanced knowledge (e.g., 25). Other studies demonstrated psychological benefits including the potential to improve affective forecasting judgments (e.g., 53) and increase empathy (e.g., 48). However, other studies report that narratives had no effect on attitudes, behaviors, or other psychological constructs (e.g., 27, 28). Some researchers are beginning to systematically investigate the specific characteristics of the narrative, intervention type, and recipient to better understand the impact of narratives on health and illness decisions. However, most studies in our review were not designed to explicitly examine narratives and their function in enhancing the effectiveness of PtDAs to facilitate people's informed, value-based decisions. Null findings may be attributable to the fact that studies were missing important narrative attributes (e.g., authenticity), inadequately measuring the "true" narrative effects, or were being compared with a well-

designed patient decision aid where the complexity of the health problem, decision problem and trade-offs for the decision maker were clearly represented. However, systematic reviews have shown consistently over the last 15 years that narratives are an effective tool for persuasion, although their superiority to statistical messaging has not been sufficiently established (e.g., 28, 29).

This review is the third iteration of the IPDAS personal stories evidence synthesis and the same pattern of results is observed: a) patient narratives can be powerful ways of communicating information that can persuade as well as engage others and b) research exploring people's narratives around illness and healthcare decisions provide evidence that can be integrated within patient resources to enhance their health literacy. However, there are several narratives, in addition to patient stories, that may enhance resources and support patient's navigation of healthcare to make a decision that best suits their lives, such as those from family and caregivers, health professionals reasoning about evidence-based care, multi-disciplinary team patient management plans, and health policy rationale guiding service availability. It may be useful for researchers to broaden their focus from patient stories to a set of stories enabling people to make connections with decision maker perspectives along the healthcare pathway (i.e., a narrative thread). The research undertaken when developing patient decision aid intervention should seek to capture the complexity of the decision within the healthcare system through investigation of health professional and delivery of care narratives (73-75). The findings do not need to be represented as a story or anecdote but can be threaded through patient decision aids using components such as engagement prompts, value clarification tasks, decision guidance statements or facts about the health and decision context.

For example, researchers have recently designed *decision maps* from their development research to provide a visual representation or overview of the decision problem in the context of managing health and illness for use in patient decision aids (73-75).

Recommendation

Our research team had varying opinions about the value of narratives and the role narrative research should play in PtDA development. However, our final recommendation was reached with consensus. The goal of this review was to make a recommendation about whether patient stories should be a required component of PtDAs by reviewing the current evidence regarding their effectiveness, and we have concluded that the literature does not support such a recommendation. Our conclusion is based on two points identified in this review. First, although there may be situations where narratives could enhance the effectiveness of patient decision aids, we continued to find evidence of situations in which narratives produce responses, such as bias and persuasion, that run counter to the intended purpose of PtDAs. Because of these findings, we concluded that we cannot provide a blanket recommendation for the inclusion of all types of patient stories. Recent theoretical work on narratives has underscored the fact that narratives are a multi-faceted construct and should no longer be evaluated in a unidimensional framework. Moving forward, a more appropriate question is whether there are types of patient narratives that might be more appropriate for some PtDAs than others (13). For example, outcome narratives designed to be persuasive may not be appropriate for a patient decision aid designed to support decisions in the context of clinical

equipoise, whereas process and experience narratives designed to engage, inform, and comfort could contribute to the stated goals of a PtDA (7).

A second consideration in the development of our recommendation was the fact that we identified a number of practical challenges to developing narratives for inclusion within PtDAs. The development of compelling stories requires a rigorous elicitation process, and a number of important editorial choices must be made along the way, including which stakeholder voices to include and whether or not quotes are used verbatim or are edited (75, 76). PtDA developers must also address several issues including: a) which component of the IPDAS checklist the story is enhancing, b) how stories should be systematically and ethically elicited, edited and compiled, and c) which points of view, conflict, resolution, and structure should be chosen (76). With the growing prevalence of mHealth, computerized, app and internet-based decision aids, developers of PtDAs should also consider the preferred format for inclusion of narratives as well as the type of patients and/or potential end-users (e.g., 71). Developers looking to include narratives in healthcare communications and PtDAs need to be mindful of the process used to elicit narratives to ensure they achieve the developers' goal with no unintended consequences on judgments and behaviors. PtDA developers should rely on qualitative methods to identify all the needs of stakeholders and to capture a full description of the health problem, decision problem and consequences on daily life as well as illness for all options. In sum, we concluded that the literature does not support a recommendation for narratives to be a required element of PtDAs.

References

1. Bekker HL, Winterbottom A, Butow P, Dillard A, Feldman-Stewart D, Jibaja-Weiss M, et al. Using personal stories. BMC Med Inform Decis Mak. 2013;13(S2):S9.

2. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2017(4).

3. Sepucha KR, Fowler Jr FJ, Mulley Jr AG. Policy Support For Patient-Centered Care: The Need For Measurable Improvements In Decision Quality: Documenting gaps in patients' knowledge could stimulate rapid change, moving decisions and care closer to a patient-centered ideal. Health Aff (Millwood). 2004;23(Suppl2):VAR-54-VAR-62.

4. Khangura S, Bennett C, Stacey D, O'Connor AM. Personal stories in publicly available patient decision aids. Patient Educ Couns. 2008;73:456-64.

5. Syrowatka A, Kroemker D, Meguerditchian AN, Tamblyn R. Features of computer-based decision aids: systematic review, thematic synthesis, and meta-analyses. J Med Internet Res. 2016;18(1):e20.

6. Volk RJ, Jibaja-Weiss ML, Hawley ST, Kneuper S, Spann SJ, Miles BJ, et al. Entertainment education for prostate cancer screening: a randomized trial among primary care patients with low health literacy. Patient Educ Couns. 2008;73(3):482-9.

7. Shaffer VA, Focella ES, Hathaway A, Scherer LD, Zikmund-Fisher BJ. On the usefulness of narratives: an interdisciplinary review and theoretical model. Ann Behav Med. 2018;52(5):429-42.

8. Kreuter MW, Green MC, Cappella JN, Slater MD, Wise ME, Storey D, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. Ann Behav Med. 2007;33(3):221-35.

9. Leshner G, Bolls P, Gardner E, Moore J, Kreuter M. Breast cancer survivor testimonies: Effects of narrative and emotional valence on affect and cognition. Cogent Social Sciences. 2018;4(1):1426281.

10. Graesser AC, Olde B, Klettke B. How does the mind construct and represent stories? In: Green MC, Strange JJ, Brock TC, editors. Narrative Impact: Social and Cognitive Foundations. Mahwah, NJ: Lawerence Erlbaum Associates, Inc. ; 2002.

11. Green MC. Narratives and Cancer Communication. J Commun. 2006;56(Suppl 1):S163-S83.

12. Winterbottom A, Bekker HL, Conner M, Mooney A. Does narrative information bias individual's decision making? A systematic review. Soc Sci Med. 2008;67(12):2079-88.

13. Shaffer VA, Zikmund-Fisher BJ. Narratives in decision aids: A controversy. In: Lucius-Hoene G, Holmberg C, Meyer T, editors. Illness narratives in practice: Potentials and challenges of using narratives in health-related contexts. Oxford, UK: Oxford University Press; 2018.

14. Ubel PA, Jepson C, Baron J. The inclusion of patient testimonials in decision aids: effects on treatment choices. Med Decis Making. 2001;21(1):60-8.

15. Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y, et al. Video decision support tool for advance care planning in dementia: Randomised controlled trial. BMJ. 2009;338:b2159.

16. Winterbottom A, Bekker HL, Conner M, Mooney A. Patient stories about their dialysis experience bias others' choices regardless of doctor's advice: An experimental study. Nephrology Dialysis Transplantation. 2012;27:325-31.

17. Haase N, Betsch C, Renkewitz F. Source credibility and the biasing effect of narrative information on the perception of vaccination risks. J Health Commun. 2015;20(8):920-9.

18. Betsch C, Ulshofer C, Renkewitz F, Betsch T. The Influence of Narrative v. Statistical Information on Perceiving Vaccination Risks. Med Decis Making. 2011;31(5):742-53.

19. Van Laer T, De Ruyter K, Visconti LM, Wetzels M. The extended transportation-imagery model: A meta-analysis of the antecedents and consequences of consumers' narrative transportation. Journal of Consumer Research. 2014;40(5):797-817.

20. Arksey H, O'Malley L. Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.

21. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci. 2010;5(1):69.

22. Murphy ST, Frank LB, Chatterjee JS, Baezconde-Garbanati L. Narrative versus nonnarrative: The role of identification, transportation, and emotion in reducing health disparities. J Commun. 2013;63(1):116-37.

23. Moran MB, Frank LB, Chatterjee JS, Murphy ST, Baezconde-Garbanati L. A pilot test of the acceptability and efficacy of narrative and non-narrative health education materials in a low health literacy population. Journal of communication in healthcare. 2016;9(1):40-8.

24. Alteren J. Narratives in student nurses' knowledge development: A hermeneutical research study. Nurse Educ Today. 2019;76:51-5.

25. Kilaru AS, Perrone J, Auriemma CL, Shofer FS, Barg FK, Meisel ZF. Evidence-based Narratives to Improve Recall of Opioid Prescribing Guidelines: A Randomized Experiment. Acad Emerg Med. 2014;21(3):244-9.

26. Lusardi A, Samek A, Kapteyn A, Glinert L, Hung A, Heinberg A. Visual tools and narratives: New ways to improve financial literacy. Journal of Pension Economics & Finance. 2017;16(3):297-323.

27. Braddock K, Dillard JP. Meta-analytic evidence for the persuasive effect of narratives on beliefs, attitudes, intentions, and behaviors. Communication Monographs. 2016;83(4):446-67.

28. Shen F, Sheer VC, Li R. Impact of Narratives on Persuasion in Health Communication: A Meta-Analysis. Journal of Advertising. 2015;44(2):105-13.

29. Perrier M-J, Martin Ginis KA. Narrative interventions for health screening behaviours: A systematic review. Journal of health psychology. 2017;22(3):375-93.

30. Perrier M-J, Martin Ginis KA. Changing health-promoting behaviours through narrative interventions: a systematic review. Journal of health psychology. 2018;23(11):1499-517.

31. Niederdeppe J, Connelly NA, Lauber TB, Knuth BA. Effects of a personal narrative in messages designed to promote healthy fish consumption among women of childbearing age. Health Commun. 2019;34(8):825-37.

32. Okuhara T, Ishikawa H, Okada M, Kato M, Kiuchi T. Persuasiveness of statistics and patients' and mothers' narratives in human papillomavirus vaccine recommendation messages: A randomized controlled study in Japan. Frontiers in public health. 2018;6:105.

33. Nan X, Dahlstrom MF, Richards A, Rangarajan S. Influence of evidence type and narrative type on HPV risk perception and intention to obtain the HPV vaccine. Health Commun. 2015;30(3):301-8.

34. Jensen JD, King AJ, Carcioppolo N, Krakow M, Samadder NJ, Morgan S. Comparing tailored and narrative worksite interventions at increasing colonoscopy adherence in adults 50–75: A randomized controlled trial. Soc Sci Med. 2014;104:31-40.

35. McGregor LM, von Wagner C, Vart G, Yuen WC, Raine R, Wardle J, et al. The impact of supplementary narrative-based information on colorectal cancer screening beliefs and intention. BMC Cancer. 2015;15(1):162.

36. Campbell T, Dunt D, Fitzgerald J, Gordon I. The impact of patient narratives on self-efficacy and self-care in Australians with type 2 diabetes: Stage 1 results of a randomized trial. Health Promotion International. 2015;30(3):438-48.

37. Shaffer VA, Scherer LD, Focella ES, Hinnant A, Len-Ríos ME, Zikmund-Fisher BJ. What Is the story with narratives? How using narratives in journalism changes health behavior. Health Commun. 2018;33(9):1151-7.

38. Scherer LD, Shaffer VA, Patel N, Zikmund-Fisher BJ. Can the vaccine adverse event reporting system be used to increase vaccine acceptance and trust? Vaccine. 2016;34(21):2424-9.

39. Witteman HO, Fagerlin A, Exe N, Trottier M-E, Zikmund-Fisher BJ. One-sided social media comments influenced opinions and intentions about home birth: an experimental study. Health Aff (Millwood). 2016;35(4):726-33.

40. Arkes HR, Gaissmaier W. Psychological research and the prostate-cancer screening controversy. Psychol Sci. 2012;23(6):547-53.

41. Sheridan SL, Sutkowi-Hemstreet A, Barclay C, Brewer NT, Dolor RJ, Gizlice Z, et al. A comparative effectiveness trial of alternate formats for presenting benefits and harms information for low-value screening services: a randomized clinical trial. JAMA internal medicine. 2016;176(1):31-41.

42. Voorwinden JS, Buitenhuis AH, Birnie E, Lucassen AM, Verkerk MA, Van Langen IM, et al. Expanded carrier screening: What determines intended participation and can this be influenced by message framing and narrative information? Eur J Hum Genet. 2017;25(7):793-800.

43. Healey BJ, Griffiths KM, Bennett K. The effect of programme testimonials on registrations for an online cognitive behaviour therapy intervention: A randomised trial. Digital health. 2017;3:2055207617729937.

44. Shaffer VA, Tomek S, Hulsey L. The effect of narrative information in a publicly available patient decision aid for early-stage breast cancer. Health Commun. 2014:1-10.

45. McGregor LM, von Wagner C, Atkin W, Kralj-Hans I, Halloran SP, Handley G, et al. Reducing the social gradient in uptake of the NHS colorectal cancer screening programme using a narrative-based information leaflet: a cluster-randomised trial. Gastroenterology research and practice. 2016;2016.

46. Nyhan B, Reifler J, Richey S, Freed GL. Effective messages in vaccine promotion: A randomized trial. Pediatrics. 2014;133(4):e835-e42.

47. Bollinger S, Kreuter MW. Real-time moment-to-moment emotional responses to narrative and informational breast cancer videos in African American women. Health Educ Res. 2012;27(3):537-43.

48. Oh J, Lim HS, Copple JG, Chadraba EK. Harnessing the persuasive potential of data: The combinatory effects of data visualization and interactive narratives on obesity perceptions and policy attitudes. Telematics and Informatics. 2018;35(6):1755-69.

49. Christy KR. I, You, or He: Examining the impact of point of view on narrative persuasion. Media Psychology. 2018;21(4):700-18.

50. Igartua JJ, Fiuza D. Persuading with narratives against gender violence. Effect of similarity with the protagonist on identification and risk-perception. Palabra Clave. 2018;21(2):499-523.

51. Kaufman GF, Libby LK. Changing beliefs and behavior through experience-taking. J Pers Soc Psychol. 2012;103(1):1.

52. Johnson DR, Jasper DM, Griffin S, Huffman BL. Reading narrative fiction reduces Arab-Muslim prejudice and offers a safe haven from intergroup anxiety. Social Cognition. 2013;31(5):578-98.

53. Shaffer VA, Focella ES, Scherer LD, Zikmund-Fisher BJ. Debiasing affective forecasting errors with targeted, but not representative, experience narratives. Patient Educ Couns. 2016.

54. Ma Z, Nan X. Role of narratives in promoting mental illnesses acceptance. Atlantic Journal of Communication. 2018;26(3):196-209.

55. Shaffer VA, Bohanek J, Focella ES, Horstman H, Saffran L. Encouraging perspective taking: Using narrative writing to induce empathy for others engaging in negative health behaviors. PLoS ONE. 2019;14(10).

56. Ziebland S, Wyke S. Health and illness in a connected world: how might sharing experiences on the internet affect people's health? Milbank Q. 2012;90(2):219-49.

57. Finucane ML, Martino SC, Parker AM, Schlesinger M, Grob R, Cerully JL, et al. A framework for conceptualizing how narratives from health-care consumers might improve or impede the use of information about provider quality. Patient Experience Journal. 2018;5(1):15-26.

58. Sundin A, Andersson K, Watt R. Rethinking communication: integrating storytelling for increased stakeholder engagement in environmental evidence synthesis. Environmental Evidence. 2018;7(1):6.

59. Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: A purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. Med Decis Making. 2013;33:4-13.

60. Shaffer VA, Hulsey L, Zikmund-Fisher BJ. The effects of process-focused versus experience-focused narratives in a breast cancer treatment decision task. Patient Educ Couns. 2013;93(2):255-64.

61. Gavaruzzi T, Sarlo M, Giandomenico F, Rumiati R, Polato F, De Lazzari F, et al. Assessing emotions conveyed and elicited by patient narratives and their impact on intention to participate in colorectal cancer screening: A psychophysiological investigation. PLoS ONE. 2018;13(6).

62. Graaf Ad, Sanders J, Hoeken H. Characteristics of narrative interventions and health effects: A review of the content, form, and context of narratives in health-related narrative persuasion research. Review of Communication Research. 2016;4:88-131.

63. Chen M, Bell RA, Taylor LD. Narrator point of view and persuasion in health narratives: The role of protagonist–reader similarity, identification, and self-referencing. J Health Commun. 2016;21(8):908-18.

64. Scherer LD, Kullgren JT, Caverly T, Scherer AM, Shaffer VA, Fagerlin A, et al. Medical Maximizing-Minimizing Preferences Predict Responses to Information about Prostate-Specific Antigen Screening. Med Decis Making. 2018;38(6):708-18.

65. Keer M, van den Putte B, de Wit J, Neijens P. The effects of integrating instrumental and affective arguments in rhetorical and testimonial health messages. J Health Commun. 2013;18(9):1148-61.

66. Dillard AJ, Ferrer RA, Welch JD. Associations between narrative transportation, risk perception and behaviour intentions following narrative messages about skin cancer. Psychology & health. 2018;33(5):573-93.

67. Green MC, Brock TC. The role of transportation in the persuasiveness of public narratives. J Pers Soc Psychol. 2000;79(5):701-21.

68. Dillard AJ, Main JL. Using a health message with a testimonial to motivate colon cancer screening: Associations with perceived identification and vividness. Health Educ Behav. 2013;40(6):673-82.

69. Sanders-Jackson A. Rated Measures of Narrative Structure for Written Smoking-Cessation Texts. Health Commun. 2014;29(10):1009-19.

70. Dahodwala M, Geransar R, Babion J, de Grood J, Sargious P. The impact of the use of video-based educational interventions on patient outcomes in hospital settings: A scoping review. Patient Educ Couns. 2018;101(12):2116-24.

71. Zisman-Ilani Y, Gorbenko KO, Shern D, Elwyn G. Comparing digital vs paper decision aids about the use of antipsychotic medication: Client, clinician, caregiver and administrator perspectives. International Journal of Person Centered Medicine. 2017;7(1):21-30.

72. Winterbottom AE, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Finderup J, Bekker HL. Kidney Disease Pathways, Options and Decisions (KD-POD): An Environmental Scan of International Patient Decision Aids (PtDA). Nephrol Dial Transplant .2020. 1–11. 10.1093/ndt/gfaa102.

73. Winterbottom AE, Mooney A, Russon L, Hipkiss V, Ziegler L, Williams R, Bekker HL. Critical review of leaflets about conservative management used in UK renal services. Journal of Renal Care. 2020. 10.1111/jorc.12327

74. Mahmoodi N, Bekker HL, King NV, Hughes J, and Jones GL on behalf of the Cancer, Fertility and Me research team. Are publicly available internet resources enabling women to make informed fertility preservation decisions before starting cancer treatment: an environmental scan? BMC Medical Informatics and Decision Making. 2018; 18:104

75. Schlesinger M, Grob R, Shaller D, Martino SC, Parker AM, Finucane ML, et al. Taking Patients' Narratives about Clinicians from Anecdote to Science. The New England journal of medicine. 2015;373(7):675.

76. Thompson T, Kreuter MW. Peer reviewed: Using written narratives in public health practice: A creative writing perspective. Prev Chronic Dis. 2014;11.