

A multi-step approach to develop a “storytelling” intervention to improve patient gout knowledge and improve outpatient follow-up

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ABSTRACT

Background: “Storytelling” interventions influence knowledge, attitudes and behavior to promote chronic disease management. We aimed to describe the development of a video “storytelling” intervention to increase gout knowledge and promote adherence to medications and follow-up care after an acute gout flare visit in the emergency department.

Methods: We developed a direct-to-patient storytelling intervention to mitigate modifiable barriers to gout care and promote outpatient follow-up and medication adherence. We invited adult patients with gout as storytellers. We utilized a modified Delphi process involving gout experts to identify key themes to guide development of an intervention. Using a conceptual model, we selected stories to ensure delivery of evidence-based concepts and to maintain authenticity.

Results: Our video-based storytelling intervention consisted of segments addressing modifiable barriers to gout care. Four diverse gout patients were recruited as storytellers and interviewed with questions that covered gout diagnosis and care. Eleven international gout experts from diverse geographic locations generated and ranked items they considered important messages to promote outpatient gout care follow-up and treatment adherence. Filmed videos were truncated into segments and coded thematically. Distinct segments that captured desired messages were combined to form a cohesive narrative story based on gout patient experiences that conveyed evidence-based strategies to manage gout.

Conclusions: Using the Health Belief Model, we developed a culturally appropriate narrative intervention containing “storytelling” that can be tested as an approach to improve gout outcomes. The methods we describe may be generalizable to other chronic conditions requiring outpatient follow-up and medication adherence to improve outcomes.

1. Background

“Storytelling,” a type of narrative communication, is a fundamental mode of human interaction [1,2]. This form of persuasive messaging elicits stories from individuals representing a population of focus, which can be utilized to motivate behavior change in others [3]. Stories can promote self-awareness as the viewer pictures themselves in the narrative [2]. Identification with the characters is promoted by homophily or perceived similarity between the storyteller and the patient [4]. Storytelling messages may be perceived by patients as more genuine, authentic, and notable compared to didactic communication on its own

[5–8].

The benefits of storytelling on healthcare interactions are well recognized [1,9]. Storytelling has been used in behavioral interventions to address knowledge gaps and alter attitudes and beliefs by decreasing cognitive resistance [2]. By leveraging personal stories told by peers, behavioral interventions can be tailored to under-resourced groups to address health inequities and improve outcomes [2,10]. Storytelling offers the unique mechanism to provide patient education in a culturally-appropriate context [7] and may be particularly beneficial to promote behavioral change in certain vulnerable populations [11] including those with low-health literacy [7,12,13]. Prior work from our

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group and others testing methods to improve osteoporosis care [10,14] and blood pressure control [7,12] showed stories can influence behavior change [7,10,12,14].

Eliciting appropriate and culturally-relevant stories that will be a useful component of a behavioral intervention can be challenging [11]. Stories are less effective as part of behavioral interventions if they do not address cultural relevance [11,15], which involves incorporating social and cultural community context [13,16] to ensure the stories will resonate with the intended audience. Developing an appropriate and culturally relevant story requires both careful selection of storytellers and a rigorous protocol of message selection and editing prior to inclusion in the final product. This cultural relevance must be combined with evidence-based messages that promote health or health behaviors. Moreover, eliciting stories from the storyteller in an open-ended interview format may or may not successfully link to the intervention objectives or underlying behavioral constructs [3]. To navigate such challenges, previous studies have approached this process in several broad steps: narrative collection through video-recording, narrative review by rating of the content collected, and editing of the content to develop a cohesive unit [3].

While applications utilizing narrative communication have helped address health behaviors related to hypertension [7,8], smoking cessation [3], cancer prevention [17], and osteoporosis [14], there is a paucity of data available regarding a protocolized approach to developing a storytelling intervention for gout. Gout is a chronic disease that can lead to chronic inflammatory arthritis and disproportionately affects under-resourced groups [18–20]. Despite existing treatments, gout care remains highly variable. In addition, significant disparities exist in gout care, with African Americans having a higher prevalence of gout but are less likely to receive quality gout care [21]. This is particularly relevant in our geographic region where a majority of patients with gout are African American [22]. Behavioral interventions focusing on gout self-management, including adherence to gout therapy and appropriate follow-up care, may represent the cornerstone of gout management [23]. A significant proportion of gout care occurs in the ED or urgent care centers [24–27]. A recent systematic review highlighted the potential for educational and behavioral interventions to improve outcomes among gout patients [23]. Prior work by members of our team demonstrated that use of storytelling is associated with fewer gout flares and improved health-related quality of life measures [28]. Similarly, because narrative communication through storytelling can break down cognitive resistance to promote evidence-based choices [29], we applied this approach to develop an intervention focused on outpatient follow-up customized for gout patients.

To guide the development of a gout storytelling intervention, we used the Health Belief conceptual model [30,31] that relied on stories told by community members with gout to inform and inspire healthy behavioral change. This is achieved by reducing cognitive resistance via appealing to the desire to avoid poor health outcomes through engaging in a health action to prevent or improve the illness [7,30,32]. We utilized the modified Delphi method with expert consensus to identify key barriers and facilitators to medication adherence and follow-up care, and incorporated stories told by community members which emphasized these key topics. Herein, we describe the development of a video intervention containing “storytelling” to increase gout knowledge and promote adherence to medications and follow-up care after an acute gout flare.

2. Methods

We utilized an iterative process to develop the storytelling intervention. First, we identified and recruited storytellers among patients with gout in our local rheumatology clinic. Following a review of the literature, experts in storytelling (GC) and gout (KS, MD) advised on the development of an interview guide to elicit patient stories that were used to direct the filmed interviews. These core team members had

experience in developing storytelling video interventions for gout [28] and osteoporosis [10]. Following filming, videos were truncated into distinct segments and thematically coded. Next, to identify modifiable and non-modifiable barriers and motivators they considered most important to promote two important behaviors including: 1) follow-up gout care, and 2) medication adherence, we used a modified Delphi process involving a group of international gout experts as panelists (Fig. 1 and Supplementary Material). Through an iterative process, barriers and motivators for these behaviors were prioritized by the panel resulting in a final selection of 5 key themes for each behavior. We then selected those video segments that covered those topics identified through the modified Delphi process, and the segments were combined to form a cohesive narrative story [10]. The study protocol was approved by the University of Alabama Institutional Review Board (IRB # IRB-300004983).

2.1. Recruitment of storyteller participants

The overall goal of the interviews with patients with gout was to elicit stories that could be used to destigmatize gout, encourage other patients with gout to take actions that would prevent flares, and enhance their readiness to adhere to life-long treatments and follow up with a provider of gout care. English-speaking storytellers were identified through purposive sampling via clinic rosters and prior gout research participation and they were invited to participate based on their previous success in controlling their gout symptoms. We aimed to include a diverse group of motivated participants of various gender, race, and ethnicities who had relevant stories capturing a range of gout experiences. When recruiting our storytellers we strongly considered the demographic characteristics of the recipients of the eventual behavioral intervention. In particular, since the majority of patients with gout seen in our ED are African American [22], we sought to include compelling African American storytellers as strong motivators of behavior change via homophily.

2.2. Development of interview guide

To enhance generalizability and relevance of messaging to other gout patients, we involved a diverse group of patients with gout who presented gout information using language that was familiar to the target audience [3]. We developed an interview guide (Appendix A Supplementary Material) to direct conversations during the filmed interviews. The interview guide was used to explore detailed information about patients' perceptions of gout, and was developed by experts in qualitative research with experience in conducting in-depth interviews. The interview guide included prompts asking participants to describe themselves, their experience with gout including their initial diagnosis, and elaborate on their gout treatment strategies. We asked storytellers to identify what ultimately motivated them to treat their gout and what strategies they thought might help other patients to take their gout medications and improve their condition.

2.3. Storyteller participant interviews

We conducted six interviews with four different gout patients. Four interviews were initially conducted in-person, and two follow-up interviews were conducted over videoconferencing due to the COVID-19 pandemic. We sent interview questions in advance to interested participants to familiarize themselves with the prompts and to consider their responses. Upon arrival, we presented the participants with an overview of the process that included a detailed walkthrough of the entire filming protocol so the interviewees would be comfortable with the interview format and filming procedures. Participants were engaged in a semi-structured conversation that allowed flexibility to the interviewer to deviate from the interview guide to expand further on certain topics. We asked the participants to repeat each question before

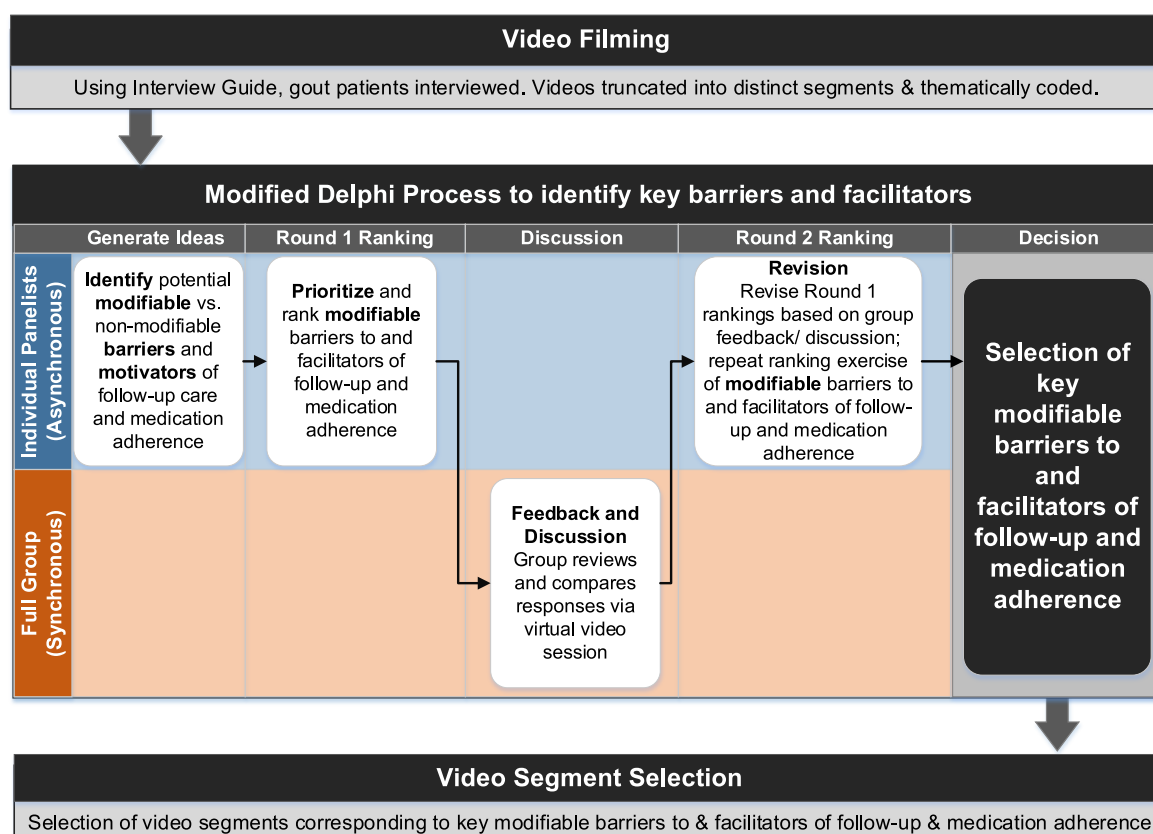


Fig. 1. Overall study design for development of a gout storytelling video intervention. Participants were interviewed, filmed videos were truncated and coded. Then, a modified Delphi process was employed. Individual members of the expert panel ($n = 11$) were asked to generate a list of potential barriers to gout treatment and follow-up. This was followed by two individual asynchronous ranking rounds and two synchronous virtual discussions by panelists to prioritize and refine key topics. This process generated a prioritized list of modifiable barriers that might be mitigated/addressed using a behavioral intervention. Distinct video segments that captured desired key topics were selected for inclusion in the final narrative story. Adapted from Khodyakov et al. [59].

answering and they were allowed to rephrase or repeat any information presented if unclear. On average, the interviews lasted ~15 min with participants discussing personal anecdotes about their gout history and different methods or therapies they found successful. All interviews were conducted in-person initially and some were repeated a second time in a virtual format due to challenges related to the COVID-19 pandemic.

2.4. Identification of barriers to gout follow-up and treatment

The goal of our video intervention was to mitigate modifiable barriers and facilitators to gout care. Steps in the modified Delphi process occurred asynchronously and synchronously. To this end, we first generated a list of potential barriers to gout treatment and follow-up asynchronously (Fig. 1). Participating panelists were asked to individually produce a written list of 5–10 topics that they believed would motivate patients to: (1) follow up in the clinic after a visit to the ED for a recent gout attack/flare and (2) take their gout medications. This procedure generated a list of potential topics (see [Supplementary Material](#)). Two rheumatologists (LJ and MD) reviewed and grouped the topics by common themes. The next step in the modified Delphi process included asynchronous prioritization of key themes and messaging for use in the behavioral intervention [33,34]. Individual participating panelists were asked to vote on the group messages and rank their top 5 messages in order from 1 as most important to 5 as least important and send their votes via email. This resulted in a rank-order list of the top messages for each topic.

We then met synchronously through a virtual videoconferencing platform. As a group, we prioritized the barriers and facilitators using a

modified Delphi process [33,35] with 11 rheumatology panelists with expertise in gout care (Fig. 1) to refine the overall message of the storytelling intervention. Panelists included a geographically diverse group of rheumatologists from around the world. The group debated the reasons behind individual ranking order, agreement/disagreement with the group ranking, messages individuals felt were unfairly dismissed or elevated, and if an individual might be inclined to change their original order based on the results. The modified Delphi process was employed to facilitate participation and generate ideas among panelists in order to obtain consensus through iterative rounds with feedback [35]. For example, we obtained expert consensus that information and patient testimonials provided by a video could potentially address participants' concerns about long-term complications of gout but would be less successful in addressing barriers related to adherence.

Next, the round 1 rankings were revised based on the group feedback and discussion. We conducted a second round of individual asynchronous voting during which individuals voted for the top 5 key messages in each of the two main categories (i.e., encouraging the patient to follow up in clinic and encouraging patients to take their gout medications) that might be mitigated and addressed by a video-based intervention. This final consensus vote generated a list of 5 key topics within each of the two categories.

2.5. Video development and content

In this final step, we selected the video segments corresponding to the key topics identified through the modified Delphi process (Fig. 1). We followed the Health Belief Model [30,31] when determining which stories would serve as the most persuasive to induce behavioral change

in the future viewers of the material. This construct relies on the premise that health related behaviors are influenced by: 1) a desire to avoid illness and get well and, 2) that following a certain healthy behavior will result in improvement or recovery from that illness. An individual's behavior ultimately depends on their perception of the benefits and obstacles related to the behavioral change. As such, the Health Belief Model [30,31] guided content selection for the stories. Specifically, since the Health Belief Model posits that behavioral change is best achieved when messages target barriers, benefits, self-efficacy, and threat [36], we included stories that resonated with these themes and focused on preventative health behaviors [36]. In addition, risk perception theory provides a grounding theory for the proposed mechanism of how storytelling will bring about behavioral change [37,38]. Risk perceptions relate to an individual's perceived susceptibility to a threat. As part of the health decision-making process, an individual may weigh the risk of that threat with the benefits of engaging in an inconvenient but healthy behavior. Under this theory, designing interventions that change risk perceptions will be more effective in changing behavior [37,38]. Stories that are most likely to resonate with viewers and motivate them to engage in a behavioral change are those that exhibit plot and character development, build emotional response, are realistic, and successfully utilize imagery [4,17,39]. In addition, stories that repeat key messages [40] and those that describe the positive consequences of a desired behavior will be most persuasive [31].

Informed by these constructs, we considered ideal persuasive stories to be those that conveyed evidence-based strategies to manage gout while remaining true to participants' experiences. Following story filming, 2 authors (AM and GR) performed qualitative thematic analysis on each individual storyteller's full interview video and subsequently truncated sections of each interview into distinct segments [41]. This involved editing the video by splicing into discrete sections of stand-alone story units that focused on subtopics. These were coded into themes by a storytelling expert (GC). In addition, the coded story segments from each storyteller were archived under specific tags, which allows for versatility in the preparation of new gout video content depending on the theme and topic of focus. Coded sections were reviewed by team members (MD, AM, LJ), who chose the most compelling stories representing each of the highest ranked topics within each of the two areas of focus.

An experienced videographer incorporated top segments into a cohesive unit. The interviewers were edited out of the final video segments; however, a narrator (LJ) was employed to develop transition segments in the final video.

3. Results

We developed an individualized direct-to-patient, video-based intervention grounded in narrative communication ("storytelling") that consisted of video segments to address the messages ranked by international gout experts. The storytelling development process yielded 3 unique storytellers including: 1) Lorenzo, an African American man that has lived with gout for 25 years, 2) Pablo, an Hispanic man with gout for 5 years, and 3) Julie, a White woman diagnosed with gout approximately 2 years ago. A fourth storyteller was interviewed but filmed segments were ultimately not included. Compared to our other three storytellers, the topics associated with these storytelling units did not align as well with the key messages that achieved high ratings during the modified Delphi process.

3.1. Key messages derived from modified delphi process

We solicited key messages from 11 gout expert panelists including 5 at the University of Alabama at Birmingham (UAB), 2 at the Birmingham Veterans Administration Medical Center, and 1 each at Vanderbilt University Medical Center, University of Michigan, The University of Auckland, and the Veterans Administration Medical Center in San

Diego. The initial list generated by panelists consisted of 70 topics to motivate patients with gout to take their medications and to follow up in the clinic after a visit for an acute gout flare. The unique messages were then grouped into 38 common themes by LJ and MD (Supplementary Material) and ranked by the panelists via email. Following this round of voting by email and the virtual session to discuss the results of the ranking exercise, the top 5 themes in each category were selected (Table 1). The list of topics changed slightly between round 1 and round 2 voting. The goal of the round 1 asynchronous exercise was item generation, with less emphasis on the rank order of topics. The goal of the round 2 voting was to achieve a consensus on key topics following the synchronous virtual meeting. Thus, a few differences in the top 5 topics occurred between rounds 1 and 2 voting.

3.2. Storytelling video content

Although common themes emerged, each patient storyteller brought a special focus and set a different tone. We amassed 120 min of video interview footage that was truncated into short 1–2 min segments each focusing on a single topic. Two research members (MD and GC) rated segments for quality. Those segments that reflected the key topics identified from the Delphi were combined to form the final edited video that was approximately 3 min in duration. The final version consisted of 4 main segments and each discrete segment included 3–4 storytelling vignettes from gout patient storytellers interspersed with commentary by a rheumatologist (LJ) (Table 2). The first segment included an introduction by a rheumatologist (LJ) explaining why a patient with gout may be receiving the video material. The next segments included stories that matched the key themes identified from the modified Delphi with discrete sections on: working with a doctor to treat gout, managing medications, and following up with a doctor after a healthcare visit for an acute gout flare. Material from the video can be viewed online (video available upon request).

4. Discussion

We describe an innovative approach to develop a video intervention containing "storytelling" by patients to increase gout knowledge and promote adherence to medications and follow-up care after an acute gout flare in a culturally-relevant manner. In addition, we utilized a modified Delphi method with expert consensus to identify key barriers and facilitators to medication adherence and follow-up care for patients with gout to ensure that the content of the stories is evidence-based. We then incorporated stories told by community members with gout that emphasized those key topics identified through the modified Delphi method to develop a video-based behavioral intervention to inform and

Table 1
Final topics chosen to promote follow-up with a healthcare provider and adherence to gout medications after a gout flare.

Topics to motivate patients with gout to follow up with a healthcare provider after a gout flare	Topics to motivate patients with gout to take their gout medications
Outpatient follow-up visits can help prevent future ED visits	Medications can prevent gout flares
Outpatient follow-up visits focus on preventing gout flares	Because gout is due to urate build up, gout medications are needed to lower the sUA
Gout is a chronic disease that needs life-long outpatient follow-up	Gout is a chronic disease that requires life-long treatment and monitoring
Outpatient follow-up visits help prevent negative effects of gout on quality of life	Gout treatments that are safe, simple, and relatively inexpensive are available
Outpatient follow-up visits enable personalized gout care	By preventing flares, gout medications can alleviate the gout flares' negative effects on quality of life (e.g., mental health, sex life, sleep)

Table 2

Key sections of gout storytelling video intervention with stories that matched the key topics derived from the modified Delphi process.

Section and Description	Quoted Messages from Storytellers	Individual topics addressed by storyteller derived from modified Delphi process
Introduction: Rheumatologist introduces video	Narrator: "You're about to hear from some other patients just like you talking about their experience with gout. This painful joint condition is unfortunately very common, and flares or gout attacks can happen more than once. The good news is that your gout is very treatable with the right medicines and with regular follow up with your doctor."	<ul style="list-style-type: none"> •Gout is a chronic disease that needs life-long outpatient follow-up •Medications can prevent gout flares
Segment 1: Working with a doctor to treat gout	<p>Lorenzo: "When I went to the ER, they did a lot of x-rays on the toe and they couldn't find anything broken, so they did bloodwork to find out that my uric acid was really high and that's when I found out that I suffer with gout."</p> <p>Lorenzo: "What motivated me to get treatment for my gout was I got tired of just hurting, and in pain, so I just finally went to the doctor to find out what was going on. Because I tried to just, you know, take aspirin and Tylenol but none of that worked."</p> <p>Lorenzo: "I see my doctor every three months for my gout because I regularly have to get different medicines for it, you know, my medicines every three months, so I go and see him to make sure my uric acid level is low like it's supposed to be."</p> <p>Lorenzo: "See a doctor and start on a treatment plan as fast as you can."</p> <p>Pablo: "My best advice is to see a doctor. This is an illness that is not going to heal by itself. On top of that, the pain is really unbearable. So, don't do that to yourself. Go and look for help."</p> <p>Julie: "If you're newly diagnosed with it, I really recommend having that open and honest conversation with your doctor. If you know there's certain things you can't do, talk with them about it so they can offer</p>	<ul style="list-style-type: none"> •Outpatient follow-up visits help prevent negative effects of gout on quality of life •Because gout is due to urate build up, gout medications are needed to lower the sUA •Gout is a chronic disease that needs life-long outpatient follow-up •By preventing flares, gout medications can alleviate the gout flares' negative effects on quality of life (e.g., mental health, sex life, sleep) •Outpatient follow-up visits focus on preventing gout flares •Gout treatments that are safe, simple, and relatively inexpensive are available •Outpatient follow-up visits enable personalized gout care

Table 2 (continued)

Section and Description	Quoted Messages from Storytellers	Individual topics addressed by storyteller derived from modified Delphi process
Segment 2: Managing your medications	<p>other alternatives and suggestions. Don't be afraid to say it might cost too much or you're afraid of the cost of the medication. They can help you find alternatives and how to deal with it."</p> <p>Narrator: "Medications are an important part of managing gout. They can prevent gout flares, which will improve your quality of life. Gout medications are safe but need to be taken over the long-term to prevent flares."</p> <p>Lorenzo: "Yeah, it's important to take your medication every day once you find out you suffer with gout, because once you stop taking it, you'll start back having flare-ups."</p> <p>Pablo: "The illness, the gout is there. It is just waiting to jump on you. The only way to prevent that is to continue using your meds. There is no other way. Or that you are just opening the door for a flare."</p> <p>Julie: "If you're experiencing your first gout flare or your second gout flare, this is still something new for you. It was new for me. So, I think one of the things that was most helpful for me was just to stop, and listen to what the doctors, set aside my preconceived ideas about what was going on, and really just listen to what the doctors were telling me about how I can manage this and that it would improve with some simple changes."</p> <p>Julie: "If you are doing the right things, you're listening, you're making the changes that you need to make, you can get over it, manage it, live with it, and lead a wonderful life."</p> <p>Narrator: "You've just heard firsthand from patients who have had gout about how important it is to follow up with a doctor in clinic so you can get treatment that is tailored to you. After your emergency room visit, schedule an appointment with your</p>	<ul style="list-style-type: none"> •Medications can prevent gout flares •Gout treatments that are safe, simple, and relatively inexpensive are available •Medications can prevent gout flares •Gout is a chronic disease that requires life-long treatment and monitoring •Outpatient follow-up visits enable personalized gout care •Outpatient follow-up visits enable personalized gout care •Outpatient follow-up visits can help prevent future ED visits
Segment 3 and Conclusions: Rheumatologist concludes video, emphasizes importance of following up with a doctor after an emergency department visit		

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Table 2 (continued)

Section and Description	Quoted Messages from Storytellers	Individual topics addressed by storyteller derived from modified Delphi process
	doctor to talk about your gout. These doctor visits can help you prevent future emergency room visits for gout."	

inspire healthy behavioral change [7,30,32].

Storytelling promotes social support, decreases isolation, relieves stress, and motivates behavior change in patients with chronic diseases [2,5–8]. Video-based educational materials employing stories told by patients, such as those utilized in our study, are attractive and influential in promoting behavioral change [7,8]. A recent systematic review of healthcare behavioral and education interventions designed to improve gout patient clinical outcomes highlighted the potential for educational/behavioral interventions to improve health outcomes [23].

In a United Kingdom-based randomized clinical trial of a nurse-led intervention that included patient education on gout versus routine general practitioner gout care, patients in the nurse-led intervention had higher uptake and adherence to urate lowering therapy and achieved goal serum uric acid levels after 2 years [42]. This highlights the benefits of patient education on important outcomes among people with gout [42,43]. Storytelling interventions have been developed and utilized in hypertension [7,8], osteoporosis [10,14], to improve informed consent process [44], and in this manuscript we present such an intervention for gout. Such an approach has special relevance since gout is a common but historically understudied condition and afflicted individuals interact frequently with the healthcare system since they often present to an ED or urgent care setting for gout care [24–27]. Similarly, our approach may generalize to other chronic conditions that may benefit from an intervention supporting periodic life-long outpatient care and monitoring.

In our study, the modified-Delphi process was utilized to determine key modifiable barriers and facilitators to follow-up care and medication adherence to inform selection of stories. This approach was particularly well-suited because it incorporates expert panel feedback, allows anonymity in the identification of key themes which can limit social desirability bias, and is iterative in nature with subsequent rounds refining the overall message to develop a cohesive final product. Our study was conducted in line with the internationally recognized guidelines for the Conducting and Reporting of Delphi Studies (CREDES) [45].

Storytelling promotes patient engagement through homophily. Real patients recounting their struggles with a disease fosters identification by the viewer; subsequent messaging focusing on experiences overcoming such challenges may empower viewers to engage and alter their own behavior in a similar fashion [17,31]. When a patient identifies with the storyteller, this promotes the recognition of the need to treat a health condition and more effectively confront the barriers to medication adherence, which ultimately improves health outcomes [4,7,8,46,47]. A previous randomized trial of a culturally sensitive storytelling intervention for African Americans living with hypertension demonstrated reduction in systolic and diastolic blood pressure among those with uncontrolled hypertension in intervention group participants compared to the usual care group [7]. In a comparative effectiveness study of storytelling versus informational videos on use of mammography, storytelling by African Americans was liked better, associated with improved recall and more medical discussions with family members, and was interpreted as more unique than the informational video [47]. In gout care, an optimal strategy relies on a functional understanding of gout prevention, consistent follow-up and patient empowerment for ongoing care and treatment adherence. Our intervention employed audiovisual components and could be delivered via any

mobile platform (e.g., iPad, web delivery) using various study designs aimed to improve gout outcomes. The intervention encourages outpatient follow-up and medication adherence, since proper adherence to therapy has been shown to reduce gout flares and improve quality of life [48,49]. This intervention may also serve to address and mitigate disparities in gout care, since it is specifically designed to appeal to minority patients who are at highest risk of poorer quality gout care [21].

Our intervention design has several strengths. We strived to create an intervention to influence readiness to behavior change by including a variety of storytellers by race, ethnicity, and gender in order to ensure it would be applicable to a diverse population of patients including those from minority groups. Viewers of the material may be more likely to adopt change in the setting of homophily when they see and hear stories delivered by others like themselves and that could be a catalyst for health behavior change [3,6,7,17,50–52]. In the future, we could test such an intervention in numerous venues using various study designs (e.g., clinical trials) or quality improvement activities aimed at improving gout outcomes. Moreover, our methods may be more generalizable than the stories' content, since the methods we used to develop the storytelling intervention may be employed in a similar manner to create interventions for other chronic conditions focusing on outpatient follow-up [53–55] and medication adherence [56–58] to improve outcomes. Transporting the intervention to a new cultural context might require the development of new stories by storytellers who are culturally congruent using the same methodology.

Despite its strengths, our intervention has some limitations. While the methods we used to create the storytelling intervention are generalizable, the final video is not tailored to the individual patient characteristics and the patient is not able to interact with the intervention to select themes or stories that might be most relevant to them. Future studies might address these shortcomings by allowing participants to rank barriers to gout care follow-up or treatment adherence that might be modifiable and then link those barriers to individualized messages addressing these identified barriers. In addition, due to challenges imposed by the COVID-19 pandemic we were not able to engage patients and caregivers in the process of reviewing the themes and video segments. Also related to challenges during the pandemic, we used purposive sampling to identify storytellers, which may introduce observer bias. Additional updates could include additional messages that could be obtained through future additional interviews with diverse patients. Finally, modification to the setting of the video might include allowing for asynchronous review of the storytelling intervention post-encounter.

5. Conclusions

Narrative educational programs hold promise for improving health outcomes in a variety of conditions, including gout. As an example, we describe an approach to develop a behavioral intervention employing storytelling to be delivered to gout patients. Our approach may generalize to other chronic conditions. In clinical settings, narrative communication or storytelling may help mitigate barriers to medical management and clinical research participation and may increase the effectiveness of behavioral interventions to improve outcomes.

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Lesley E. Jackson: Investigation, Data curation, Writing – original draft. **Kenneth G. Saag:** Conceptualization, Methodology, Supervision, Funding acquisition. **Germán Chiriboga:** Methodology, Investigation, Writing – review & editing. **Stephenie C. Lemon:** Writing – review &

editing. **Jeroan J. Allison:** Writing – review & editing. **Amy Mudano:** Investigation, Formal analysis, Data curation, Writing – review & editing. **Giovanna Rosas:** Formal analysis, Writing – review & editing. **Phillip J. Foster:** Resources, Writing – review & editing. **Maria I. Danila:** Conceptualization, Methodology, Writing – review & editing, Supervision, Project administration.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.conctc.2023.101149>.

References

- [1] R. Charon, Narrative and medicine, *N. Engl. J. Med.* 350 (9) (2004) 862–864, <https://doi.org/10.1056/NEJMp038249>, Feb 26.
- [2] M.D. Slater, D. Rouner, Entertainment-education and elaboration likelihood: understanding the processing of narrative persuasion, *Commun. Theor.* 12 (2) (2006) 173–191, <https://doi.org/10.1111/j.1468-2885.2002.tb00265.x>.
- [3] T.K. Houston, A. Cherrington, H.L. Coley, et al., The art and science of patient storytelling-harnessing narrative communication for behavioral interventions: the ACCE project, *J. Health Commun.* 16 (7) (2011) 686–697, <https://doi.org/10.1080/10810730.2011.551997>, Aug.
- [4] M.W. Kreuter, T.D. Buskirk, K. Holmes, et al., What makes cancer survivor stories work? An empirical study among African American women, *J. Cancer Surviv* 2 (1) (2008) 33–44, <https://doi.org/10.1007/s11764-007-0041-y>, Mar.
- [5] L.J. Hinyard, M.W. Kreuter, Using narrative communication as a tool for health behavior change: a conceptual, theoretical, and empirical overview, *Health Educ. Behav.* 34 (5) (2007) 777–792, <https://doi.org/10.1177/1090198106291963>, Oct.
- [6] G.M. Fix, T.K. Houston, A.M. Barker, et al., A novel process for integrating patient stories into patient education interventions: incorporating lessons from theater arts, *Patient Educ. Counsel.* 88 (3) (2012) 455–459, <https://doi.org/10.1016/j.pcc.2012.06.012>, Sep.
- [7] T.K. Houston, J.J. Allison, M. Sussman, et al., Culturally appropriate storytelling to improve blood pressure: a randomized trial, *Ann. Intern. Med.* 154 (2) (2011) 77–84, <https://doi.org/10.7326/0003-4819-154-2-201101180-00004>, Jan 18.
- [8] T.K. Houston, G.M. Fix, S.L. Shimada, et al., African American veterans storytelling: a multisite randomized trial to improve hypertension, *Med. Care* 55 (Suppl 9 Suppl 2) (2017) S50–S58, <https://doi.org/10.1097/MLR.0000000000000766>, Sep.
- [9] J.W. Pennebaker, Telling stories: the health benefits of narrative, *Lit Med.* Spring 19 (1) (2000) 3–18, <https://doi.org/10.1353/lm.2000.0011>.
- [10] M.I. Danila, R.C. Outman, E.J. Rahn, et al., A multi-modal intervention for Activating Patients at Risk for Osteoporosis (APROPOS): rationale, design, and uptake of online study intervention material, *Contemp. Clin. Trials Commun.* 4 (Dec 15 2016) 14–24, <https://doi.org/10.1016/j.conctc.2016.06.010>.
- [11] K.R. Myers, M.J. Green, Storytelling: a novel intervention for hypertension, *Ann Intern Med.* Jan 154 (2) (2011) 129–130, <https://doi.org/10.7326/0003-4819-154-2-201101180-00013>.
- [12] J.J. Allison, H.L. Nguyen, D.A. Ha, et al., Culturally adaptive storytelling method to improve hypertension control in Vietnam - "We talk about our hypertension": study protocol for a feasibility cluster-randomized controlled trial, *Trials* 17 (Jan 14 2016) 26, <https://doi.org/10.1186/s13063-015-1147-6>.
- [13] H.L. Nguyen, D.A. Ha, R.J. Goldberg, et al., Culturally adaptive storytelling intervention versus didactic intervention to improve hypertension control in Vietnam- 12 month follow up results: a cluster randomized controlled feasibility trial, *PLoS One* 13 (12) (2018), e0209912, <https://doi.org/10.1371/journal.pone.0209912>.
- [14] M.I. Danila, R.C. Outman, E.J. Rahn, et al., Evaluation of a multimodal, direct-to-patient educational intervention targeting barriers to osteoporosis care: a randomized clinical trial, *J. Bone Miner Res.* May 33 (5) (2018) 763–772, <https://doi.org/10.1002/jbmr.3395>.
- [15] A.J. Schulz, S. Kannan, J.T. Dvorchak, et al., Social and physical environments and disparities in risk for cardiovascular disease: the healthy environments partnership conceptual model, *Environ Health Perspect.* Dec 113 (12) (2005) 1817–1825, <https://doi.org/10.1289/ehp.7913>.
- [16] A.M. LeBron, A.J. Schulz, C. Bernal, et al., Storytelling in community intervention research: lessons learned from the walk your heart to health intervention, *Prog Community Health Partnersh.* Winter 8 (4) (2014) 477–485, <https://doi.org/10.1353/cpr.2014.0066>.
- [17] M.W. Kreuter, M.C. Green, J.N. Cappella, et al., Narrative communication in cancer prevention and control: a framework to guide research and application, *Ann. Behav. Med.* 33 (3) (Jun 2007) 221–235, <https://doi.org/10.1007/BF02879904>.
- [18] F. Perez-Ruiz, Treating to target: a strategy to cure gout, *Rheumatology* 48 (Suppl 2) (May 2009), <https://doi.org/10.1093/rheumatology/kep087>, ii9–ii14.
- [19] J.D. FitzGerald, N. Dalbeth, T. Mikuls, et al., American college of rheumatology guideline for the management of gout, *Arthritis Care Res.* 72 (6) (2020) 744–760, <https://doi.org/10.1002/acr.24180>, Jun 2020.
- [20] R.L. Wortmann, P.A. Macdonald, B. Hunt, R.L. Jackson, Effect of prophylaxis on gout flares after the initiation of urate-lowering therapy: analysis of data from three phase III trials, *Clin Ther.* Dec 32 (14) (2010) 2386–2397, <https://doi.org/10.1016/j.clinthera.2011.01.008>.
- [21] J.A. Singh, Racial and gender disparities among patients with gout, *Curr. Rheumatol. Rep.* Feb 15 (2) (2013) 307, <https://doi.org/10.1007/s11926-012-0307-x>.
- [22] L.E. Jackson, N. Annapureddy, M.E. Hansen, et al., Development and validation of an emergency department electronic medical record gout flare alert, *Arthritis. Care Res.* (Hoboken). Nov (2022) 21, <https://doi.org/10.1002/acr.25061>.
- [23] K. Ramsubeik, L.A. Ramrattan, G.S. Kaeley, J.A. Singh, Effectiveness of healthcare educational and behavioral interventions to improve gout outcomes: a systematic review and meta-analysis, *Ther. Adv. Musculoskelet Dis.* Dec 10 (12) (2018) 235–252, <https://doi.org/10.1177/1759720X18807117>.
- [24] R. Jackson, A. Shiozawa, E.K. Buysman, A. Altan, S. Korner, H. Choi, Flare frequency, healthcare resource utilisation and costs among patients with gout in a managed care setting: a retrospective medical claims-based analysis, *BMJ Open* 5 (6) (Jun 24 2015), e007214, <https://doi.org/10.1136/bmjopen-2014-007214>.
- [25] R. Garg, H.R. Sayles, F. Yu, et al., Gout-related health care utilization in US emergency departments, 2006 through 2008, *Arthritis Care Res.* 65 (4) (Apr 2013) 571–577, <https://doi.org/10.1002/acr.21837>.
- [26] S. Jinno, K. Hasegawa, T. Neogi, T. Goto, M. Dubreuil, Trends in emergency department visits and charges for gout in the United States between 2006 and 2012, *J. Rheumatol.* 43 (8) (Aug 2016) 1589–1592, <https://doi.org/10.1038/jrheum.151432>.
- [27] J.A. Singh, S. Yu, Time trends, predictors, and outcome of emergency department use for gout: a nationwide US study, *J. Rheumatol.* 43 (8) (Aug 2016) 1581–1588, <https://doi.org/10.3899/jrheum.151419>.
- [28] J.A. Singh, A. Joseph, J. Baker, et al., STorYtelling to Improve Disease outcomes in Gout (STRIDE-GO): a multicenter, randomized controlled trial in African American veterans with gout, *BMC Med.* Nov 9 19 (1) (2021) 265, <https://doi.org/10.1186/s12916-021-02135-w>.
- [29] M. Ofanoa, S.M. Ofanoa, M. Heather, et al., Design and implementation of a Pacific intervention to increase uptake of urate-lowering therapy for gout: a study protocol, *Int. J. Equity Health* 20 (1) (Dec 23 2021) 262, <https://doi.org/10.1186/s12939-021-01601-4>.
- [30] N.K. Janz, M.H. Becker, The health belief model: a decade later, *Health Educ Q.* Spring 11 (1) (1984) 1–47, <https://doi.org/10.1177/109019818401100101>.
- [31] N.K. Janz, V.L. Champion, V.J. Strecher, The health belief model, in: K. Glanz, F. Lewis, B. Rimer (Eds.), *Health Behavior and Health Education*, third ed., Jossey-Bass, San Francisco, 2002, pp. 45–66.
- [32] I.M. Rosenstock, Why people use health services, *Milbank Mem Fund Q.* Jul 44 (3) (1966) 94–127, Suppl.
- [33] M. Byrne, J. McSharry, O. Meade, K.L. Lavoie, S.L. Bacon, An international, Delphi consensus study to identify priorities for methodological research in behavioral trials in health research, *Trials*, Mar 21 (1) (23 2020) 292, <https://doi.org/10.1186/s13063-020-04235-z>.
- [34] K. Schloesser, Y. Eisenmann, A. Bergmann, S.T. Simon, Development of a brief cognitive and behavioral intervention for the management of episodic breathlessness-A Delphi survey with international experts, *J. Pain Symptom Manag.* 61 (5) (May 2021) 963–973 e1, <https://doi.org/10.1016/j.jpainsymman.2020.09.034>.
- [35] S.S. McMillan, M. King, M.P. Tully, How to use the nominal group and Delphi techniques, *Int J Clin Pharm.* Jun 38 (3) (2016) 655–662, <https://doi.org/10.1007/s11096-016-0257-x>.
- [36] C.L. Jones, J.D. Jensen, C.L. Scherr, N.R. Brown, K. Christy, J. Weaver, The Health Belief Model as an explanatory framework in communication research: exploring parallel, serial, and moderated mediation, *Health Commun.* 30 (6) (2015) 566–576, <https://doi.org/10.1080/10410236.2013.873363>.
- [37] R. Ferrer, W.M. Klein, Risk perceptions and health behavior, *Curr. Opin. Psychol.* 5 (Oct 1 2015) 85–89, <https://doi.org/10.1016/j.copsyc.2015.03.012>.
- [38] P. Sheeran, P.R. Harris, T. Epton, Does heightening risk appraisals change people's intentions and behavior? A meta-analysis of experimental studies, *Psychol. Bull.* Mar 140 (2) (2014) 511–543, <https://doi.org/10.1037/a0033065>.
- [39] N.D. Hicks, *Screenwriting 101: the Essential Craft of Feature Film Writing*, Michael Wiese Productions, 1999, p. 220, xi.
- [40] J.T. Cacioppo, R.E. Petty, Effects of message repetition and position on cognitive response, recall, and persuasion, *J. Personality Soc. Psychol.* 37 (1) (1979) 97–109, <https://doi.org/10.1037/0022-3514.37.1.97>.

- [41] QSR International Pty Ltd, NVivo, 2018, Version 12. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
- [42] M. Doherty, W. Jenkins, H. Richardson, et al., Efficacy and cost-effectiveness of nurse-led care involving education and engagement of patients and a treat-to-target urate-lowering strategy versus usual care for gout: a randomised controlled trial, *Lancet* 392 (10156) (Oct 20 2018) 1403–1412, [https://doi.org/10.1016/S0140-6736\(18\)32158-5](https://doi.org/10.1016/S0140-6736(18)32158-5).
- [43] F. Rees, W. Jenkins, M. Doherty, Patients with gout adhere to curative treatment if informed appropriately: proof-of-concept observational study, *Ann Rheum Dis*. Jun 72 (6) (2013) 826–830, <https://doi.org/10.1136/annrheumdis-2012-201676>.
- [44] M.I. Danila, J.J. Allison, K.V. Goins, et al., Development of a multi-component intervention to promote participation of Black and Latinx individuals in biomedical research, *J. Clin. Transl. Sci.* 5 (1) (2021) e134, <https://doi.org/10.1017/cts.2021.797>.
- [45] S. Junger, S.A. Payne, J. Brine, L. Radbruch, S.G. Brearley, Guidance on Conducting and Reporting DELphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review, *Palliat. Med.* Sep 31 (8) (2017) 684–706, <https://doi.org/10.1177/0269216317690685>.
- [46] B.A. Gaudiano, C.H. Davis, I.W. Miller, L.A. Uebelacker, Development of a storytelling video self-help intervention based on acceptance and commitment therapy for major depression: open trial results, *Behav. Modif.* Jan 43 (1) (2019) 56–81, <https://doi.org/10.1177/0145445517738932>.
- [47] M.W. Kreuter, K. Holmes, K. Alcaraz, et al., Comparing narrative and informational videos to increase mammography in low-income African American women, *Patient Educ. Counsel.* 81 (Suppl) (Dec 2010) S6–S14, <https://doi.org/10.1016/j.pec.2010.09.008>.
- [48] J.S. Sundry, H.S. Baraf, R.A. Yood, et al., Efficacy and tolerability of pegloticase for the treatment of chronic gout in patients refractory to conventional treatment: two randomized controlled trials, *JAMA* 306 (7) (Aug 17 2011) 711–720, <https://doi.org/10.1001/jama.2011.1169>.
- [49] V. Strand, D. Khanna, J.A. Singh, A. Forsythe, N.L. Edwards, Improved health-related quality of life and physical function in patients with refractory chronic gout following treatment with pegloticase: evidence from phase III randomized controlled trials, *J. Rheumatol.* Jul 39 (7) (2012) 1450–1457, <https://doi.org/10.3899/jrheum.111375>.
- [50] A. McQueen, M.W. Kreuter, Women's cognitive and affective reactions to breast cancer survivor stories: a structural equation analysis, *Patient Educ. Counsel.* 81 (Suppl) (Dec 2010) S15–S21, <https://doi.org/10.1016/j.pec.2010.08.015>.
- [51] A. Cherrington, J.H. Williams, P.P. Foster, et al., Narratives to enhance smoking cessation interventions among African-American smokers, the ACCE project, *BMC Res. Notes* 8 (Oct 14 2015) 567, <https://doi.org/10.1186/s13104-015-1513-1>.
- [52] C.M. Ashton, T.K. Houston, J.H. Williams, et al., A stories-based interactive DVD intended to help people with hypertension achieve blood pressure control through improved communication with their doctors, *Patient Educ. Counsel.* 79 (2) (May 2010) 245–250, <https://doi.org/10.1016/j.pec.2009.09.021>.
- [53] C.H. Feldman, C. Xu, J. Williams, J.E. Collins, K.H. Costenbader, Patterns and predictors of recurrent acute care use among Medicaid beneficiaries with systemic lupus erythematosus, *Semin. Arthritis. Rheum.* Dec 50 (6) (2020) 1428–1436, <https://doi.org/10.1016/j.semarthrit.2020.02.012>.
- [54] J.N. Williams, K. Taber, W. Huang, et al., The impact of an integrated care management program on acute care use and outpatient appointment attendance among high-risk patients with lupus, *ACR Open Rheumatol.* Apr 4 (4) (2022) 338–344, <https://doi.org/10.1002/acr2.11391>.
- [55] F.A. McAlister, E. Youngson, P. Kaul, J.A. Ezekowitz, Early follow-up after a heart failure exacerbation: the importance of continuity, *Circ. Heart Fail.* 9 (9) (Sep 2016), <https://doi.org/10.1161/CIRCHEARTFAILURE.116.003194>.
- [56] C.C. Kao, H.M. Hsieh, D.Y. Lee, K.P. Hsieh, S.J. Sheu, Importance of medication adherence in treatment needed diabetic retinopathy, *Sci. Rep.* 11 (1) (Sep 27 2021), 19100, <https://doi.org/10.1038/s41598-021-98488-6>.
- [57] C. Asche, J. LaFleur, C. Conner, A review of diabetes treatment adherence and the association with clinical and economic outcomes, *Clin Ther.* Jan 33 (1) (2011) 74–109, <https://doi.org/10.1016/j.clinthera.2011.01.019>.
- [58] T.M. Ruppert, P.S. Cooper, D.R. Mehr, J.M. Delgado, J.M. Dunbar-Jacob, Medication adherence interventions improve heart failure mortality and readmission rates: systematic review and meta-analysis of controlled trials, *J. Am. Heart Assoc.* 5 (6) (Jun 17 2016), <https://doi.org/10.1161/JAHA.115.002606>.
- [59] Khodyakov D, Grant S, Denger B, Kinnett K, Martin A, Peay H, Coulter I. Practical Considerations in Using Online Modified-Delphi Approaches to Engage Patients and Other Stakeholders in Clinical Practice Guideline Development. *Patient.* 2020 Feb;13(1):11–21. doi: 10.1007/s40271-019-00389-4. PMID: 31544219; PMCID: PMC6957573.