Diabetes

A story of change: The influence of narrative on African-Americans with diabetes

Anna P. Goddu [a,b,c], Katie E. Raffel [d,1], Monica E. Peek [a,b,c,e,*]

[a] Department of Medicine, University of Chicago, Chicago, USA
[b] Center for Health and the Social Sciences, University of Chicago, Chicago, USA
[c] Chicago Center for Diabetes Translation Research, Chicago, USA
[d] Pritzker School of Medicine, University of Chicago, Chicago, USA
[e] Center for the Study of Race, Politics and Culture, University of Chicago, Chicago, USA

A B S T R A C T

Objective: To understand if narratives can be effective tools for diabetes empowerment, from the perspective of African-American participants in a program that improved diabetes self-efficacy and self-management.

Methods: In-depth interviews and focus groups were conducted with program graduates. Participants were asked to comment on the program's film, storytelling, and role-play, and whether those narratives had contributed to their diabetes behavior change. An iterative process of coding, analyzing, and summarizing transcripts was completed using the framework approach.

Results: African-American adults (n = 36) with diabetes reported that narratives positively influenced the diabetes behavior change they had experienced by improving their attitudes/beliefs while increasing their knowledge/skills. The social proliferation of narrative – discussing stories, rehearsing their messages with role-play, and building social support through storytelling – was reported as especially influential.

Conclusion: Utilizing narratives in group settings may facilitate health behavior change, particularly in minority communities with traditions of storytelling. Theoretical models explaining narrative's effect on behavior change should consider the social context of narratives.

Practice implications: Narratives may be promising tools to promote diabetes empowerment. Interventions using narratives may be more effective if they include group time to discuss and rehearse the stories presented, and if they foster an environment conducive to social support among participants.

© 2015 Elsevier Ireland Ltd. All rights reserved.

1. Introduction

1.1. Background

Diabetes affects 25.8 million people in the United States. Racial/ethnic minorities are disproportionately burdened by the disease: they experience higher prevalence and worse control of diabetes and its comorbid conditions (e.g. hypertension, hyperlipidemia) and higher rates of diabetes-related complications (e.g. kidney disease, blindness) [1–3]. Diabetes patient empowerment has been conceptualized as the patient confidence (i.e. self-efficacy) and skills to engage in self-care activities (e.g. healthy nutrition, physical activity, foot care) as well as shared decision-making (SDM), where patients collaborate with providers to set their diabetes priorities and treatment plans [4,5]. Diabetes self-care activities [1,2,6] and SDM [7,8] are associated with behavior change, diabetes control, and self-reported health. However, racial/ethnic minorities disproportionately face barriers to diabetes self-care and SDM, including limited access to healthy food and/or

exercise facilities, patient/provider communication barriers, and difficulty navigating the healthcare system [9,10]. Identifying effective strategies to empower patients is a national priority, particularly to improve minority health and reduce racial/ethnic diabetes disparities [11].

One effective empowerment strategy in minority populations is storytelling, or narrative [12]. Narrative facilitates processing of new information among those with lower health literacy and/or numeracy [13]. Through storytelling, people discover new self-perceptions or strengths [14], while building trust and connections with peers [15]. Storytelling helps to sustain behavior changes by creating meaning for past events and building an identity to motivate future action [16]. Narrative may be particularly effective in promoting health behavior change among racial/ethnic groups with a strong tradition of storytelling, and those with a history of medical mistrust [12,17,18]. Studies have effectively used narrative with African-Americans [19], Latinos [20,21], and Native Americans [22], to encourage behavior change in hypertension [17,23] tobacco use [24], cancer [25,26], and HIV prevention [27]. The modes of narrative studied vary and include theater performances, testimonials for a live audience, informal group storytelling, television or radio drama, films, and written stories.

Thus, narrative shows promise as a potential method to empower minority patients with diabetes, by promoting self-care and facilitating SDM. Narrative may help diabetes patients learn new information, explore and practice behavior change, build a support network of peers, and communicate effectively with their healthcare team. Indeed, narratives in the form of *novellas* have been successfully used in diabetes interventions tailored to Hispanic populations [28,29]. For African-Americans with diabetes, being able to tell one's story and "be heard" has been described as a significant component of SDM [30]. To date, the use of narrative has not been explored in urban African-Americans with diabetes, a population widely impacted by racial/ethnic diabetes disparities [1–3].

We investigated how narrative may influence diabetes empowerment in urban African-Americans with type 2 diabetes. Our team leads The Diabetes Empowerment Program (DEP), a culturally-tailored patient empowerment intervention associated with improved self-efficacy, diabetes self-management (e.g. healthy eating) and health outcomes (e.g. diabetes and lipid control) [4]. In addition, the DEP has had excellent retention rates: 78% of participants came to 70% of classes, and 38% attended 100% of classes [31]. Anecdotally, patients noted that the narrative components of DEP contributed to their success in making diabetes-related behavior changes. Therefore, we conducted a qualitative study to better understand how former DEP participants perceived the role of narrative in promoting patient empowerment (i.e. self-efficacy, self-care and SDM) [4].

In this paper, we briefly summarize theoretical models explaining narrative's effect, and, as background, illustrate how DEP incorporated narrative into the empowerment intervention. We then describe our qualitative study, the focus of this paper, which aimed to understand how DEP participants perceived the role of narrative in potential behavior change and empowerment. Finally, we return to the theory surrounding narrative's influence and outline the impact our results have on existing models.

1.2. How narrative promotes behavior change

Kreuter defines narrative as "a representation of *connected events and characters* that has an identifiable structure, is bounded in space and time, and contains *implicit or explicit messages* about the topic being addressed." Nonnarrative, in contrast, "includes *expository and didactic styles* of communication that present propositions in the form of *reasons and evidence* supporting a claim" [13] (emphasis added).

Predominant models of narrative's influence have historically focused on how individuals personally interact with a narrative [32–35]. In contrast, a recent model proposed by Larkey and Hecht moves beyond the personal level at which one interacts with narrative to also consider the sociocultural level [36]. This approach suggests that health narratives shared by members of a group may help to create more culturally representative health programs [36]. Because culturally-tailored interventions are essential to reducing disparities among minority patients [37], we utilized this model to explore how narrative worked among African-Americans with diabetes.

At the individual level, the Larkey and Hecht model states that when recipients are *engaged* in a narrative, they are less likely to resist its messages, and the story can impact their attitudes and beliefs [35]. At the sociocultural level, the model adds *cultural embeddedness* as another persuasive characteristic of narrative. Cultural embeddedness is the extent to which characters, events, and language are similar to participants' experiences, thereby evoking empathy and liking of the characters and events.

According to Larkey and Hecht, engagement and cultural embeddedness impact behavior change via three mediators: (1) *transportation*; (2) *identification*; and (3) *social proliferation*. *Transportation* is when a recipient is "swept away," immersed in the story, and it makes recipients more likely to agree with the story's messages [38]. *Identification* is when recipients are involved with characters, e.g. they may see themselves in the characters, like them, or imagine relationships with them [13,39], and it makes recipients more ready to learn and adopt behaviors modeled by those characters [12].

The addition of *social proliferation*, Larkey and Hecht's third mediator, reflects the sociocultural level at which they propose narrative influences behavior. Social proliferation is the discussion of stories, the reinforcement of their messages, and the reciprocal support that emerges from sharing them. When recipients share stories, they diffuse the information to new people, "rehearse" the messages by modeling the promoted behavior for each other, and nurture social support for the behavior that encourages its implementation.

It is unclear whether some of these mediators (transportation, identification, and social proliferation) are more influential in different populations. Understanding the different roles these mediators play, and how they vary by patient population, is an important question for designing and implementing narrative interventions that can empower patients and reduce health disparities.

1.3. Narrative in the Diabetes Empowerment Program

Our team, a multi-disciplinary group (with expertise in diabetes, health services research, health disparities, behavioral change, implementation science, diabetes education and social psychology) at the University of Chicago, in partnership with six clinics, leads a multifaceted intervention to improve diabetes on the South Side of Chicago [40], a largely working class, African-American community with significant diabetes disparities. One component of the intervention, the Diabetes Empowerment Program (DEP), is a series of weekly small group classes at participating clinics, which lasts for 10 weeks and is followed by monthly support group meetings. The DEP has been described in detail elsewhere [4]; it combines culturally-tailored diabetes education with training in shared decision-making (SDM). The DEP emphasizes that patients can become empowered to manage their diabetes [41], as they have expertise in their life with diabetes, are problem solvers and caregivers, and can make informed choices.